TOKYO ALBINISM CONFERENCE and Beyond

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Supported by:
United Nations Independent Expert on the enjoyment of human rights by persons with albinism
Africa Japan Forum
Center for Human Rights Education and Training
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Preface

It was November 2015 when I first had an opportunity to learn firsthand about the astonishing violations of human rights taking place in Sub-Saharan Africa against persons with albinism. It was at the 1st Pan-African Albinism Conference held in Dar es Salaam, Tanzania. The Nippon Foundation's Chairman Mr. Yohei Sasakawa, had become aware of these violations through a field visit to Africa as WHO Goodwill Ambassador for Leprosy Elimination, and he wanted to know more. This is how I came to attend the conference.

I met Ms. Vicky Ntetema, a former reporter for the BBC, and learned how she had visited a number of crime scenes and documented them as Executive Director of Under The Same Sun (UTSS) in Tanzania. Every participant that I talked to at the Pan-African Conference was sincerely worried for Vicky's life. Horrendous crimes of this nature tend to go underground and people tend to keep their mouth shut. Going to a crime scene right after the crime has been committed, interviewing people and encouraging the victim to report the crime, was extremely dangerous. I once asked her why she chose this job. "I don't see it as a job, but as a calling," she told me.

Mr. Peter Ash, who has a background in the church ministry and was for a long time successful businessman, used his finances to establish UTSS in 2008. A Canadian citizen and a person with albinism himself, he has been supporting children with albinism in Tanzania. Over a decade, he has placed more than 400 students with albinism in proper schools. These efforts have begun to bear fruit. Some of them are even holding important positions in the soceity. However, it seems that many witchdoctors continue to be involved in horrific crimes against persons with albinism. Only recently, I read a story by the BBC that described how the Tanzanian police had arrested 65 witchdoctors who were suspected of the ritual killings of children with albinism. Freedom of the press is vital in overcoming this situation.

The Tokyo Albinism Conference was the first international conference on human rights issues concerning persons with albinism to be held in Japan. The participants in this historic conference came from various Sub-Saharan African countries, such as Tanzania, Malawi, Mozambique, Nigeria, South Africa and Kenya. Of course, Japanese persons with albinism also participated, and the Japanese Albinism Network (JAN) provided valuable support that helped to make the event possible.

The dreadful violations of human rights that have taken place in Sub-Saharan Africa should not be regarded as some minor events in some faraway place somewhere in Africa. Human rights violations are in fact on a spectrum, as pointed out by Ms. Ikponwosa Ero, the United Nations Independent Expert on albinism. The key issue here is intolerance against persons who are different from the mass population, a problem that is found in all societies, including here in Japan.

In compiling this report, we have applied minimal editing to retain as much as possible the flavor of the occasion. Since the conference took place, some of the participants have updated their presentations and added information as necessary, as they had only ten minutes each to speak on the day.

Finally, we would like to offer our special thanks to the UN Independent Expert on albinism Ms. Ikponwosa Ero for offering us so much of her time to help organize this conference, and for her invaluable and pertinent advice. Our thanks go also to Mr. Masashi Yokota and Mr. Ryoichiro Saito of The Africa Japan Forum and Dr. Yasuo Yabuki of Rikkyo University for their continued and heartfelt support. We would also like to express our appreciation to Ms. Connie Chiu, who not only contributed greatly as a speaker but also gave a delightful lunchtime jazz concert on the conference day, and to Ms. Patricia Willocq, who so generously permitted the use of her strikingly beautiful and expressive photos for the Tokyo Albinism Conference and in this report.

—Kyoko Itoh, Senior Officer, The Nippon Foundation

About Albinism

Albinism is a rare, non-contagious, genetically inherited condition that occurs worldwide. In North America and Europe, 1 in 17,000 people are said to have the condition, while the prevalence in Sub-Saharan Africa is much higher. In Tanzania, for example, 1 in 1,400 people are estimated to have albinism.

Myths and superstitions expose persons with albinism to varying degrees of discrimination, prejudice and stigmatization, ranging from teasing and bullying to being physically threatened, mutilated and killed for their body parts. The problems people with the condition face are especially severe in Sub-Saharan Africa.

Now, Let the Conference Begin

Message from the Organizer

Chairman, The Nippon Foundation

Yohei Sasakawa

Ladies and gentlemen,
I would like to extend my warmest welcome to Ms. Ikponwosa Ero, Independent Expert on the enjoyment of human rights of persons with albinism and to all the participants who have come from afar to attend the Tokyo Albinism Conference.

I myself have been actively involved in eliminating leprosy from the world for over forty years, and this work often takes me to Africa. Over this long period of time, I have learned many sad incidences of persecution of persons with albinism, notably in Sub-Saharan Africa.

On this occasion, I am also reminded of the terrorist bomb attack in the capital of Somalia in 2015 that took the life of a great human rights advocate, Ambassador Yusuf Mohamed Ismail 'Bari Bari,' the Permanent Representative of the Federal Republic of Somalia to the United Nations in Geneva, a few months after the establishment of June 13th as International Albinism Awareness Day. The world has lost a widely admired and respected leader with a commitment to global human rights.

Although leprosy and albinism cannot be regarded in the same light, they have a common core issue in that they both deprive the affected persons of their human rights and human dignity due to social stigma and discrimination. Living in Japan, a country of relative stability and peace, we must remember that our country, as a member of the globalized world, has an obligation to fulfill its responsibilities to the rest of the world.

I believe that it is of utmost importance that the Japanese public have an understanding of the serious issues confronting persons with albinism, and gives serious thought to the contribution it can make. This is the objective of this conference today. I would like to take this opportunity to express my gratitude to all those present who have taken an interest in the issue of albinism.

An exhibition of photographs by Ms. Patricia Willocq is being held on the first floor of this building, and Ms. Connie Chiu, a jazz singer with albinism, is going to sing for us during the lunch break.

I would like to invite all of you to take today as an opportunity to know more about the real situation under which persons with albinism are suffering. Should you have any insights during this conference of possible future directions for assisting persons with albinism, all of us at The Nippon Foundation would very much like to hear from you.

Once again, a warm welcome to you all.

PROFILE As chairman of The Nippon Foundation, Asia's largest philanthropic foundation established in 1962, Mr. Sasakawa is known for bringing an entrepreneurial spirit to his work with entities from the political, governmental, academic, and private sectors in addressing issues in such diverse areas as health, education, social welfare, and food security in Africa.
Serving as WHO's Goodwill Ambassador for Leprosy Elimination since 2001, his global fight against leprosy and its accompanying stigma and social discrimination is an issue to which he has remained highly committed for more than 40 years.

Session 1

Realities: Our Experiences

© Patricia Willocq

Overview: Human Rights Issues of Albinism

PROFILE Ms. Ikponwosa Ero was designated in June 2015 as the first UN Independent Expert on the enjoyment of human rights by persons with albinism. The vision is driven by the principle of the UN Sustainable development goals: “Leaving No One Behind, Starting with the Furthest Behind First.” In addition to working in the Department of Justice in Canada, she has had over a decade of experience in research, policy development, and practice of human rights concerning persons with albinism, and has advised organizations and governments around the world. She is also a Legal Officer for Under The Same Sun. As the UN Expert, Ms. Ero has authored numerous papers and articles, particularly with regards to the applicable legal frameworks as well as the development and implementation of specific measures through action plans to facilitate the enjoyment of human rights by persons with albinism. In 2015, Ms. Ero was chosen for UNESCO's List of 70 Who-is-Who of Women Speakers across the world to celebrate UNESCO's 70th anniversary. She was also recently named in New African Magazine’s list of 100 most influential persons of 2017.

UN Independent Expert on the enjoyment of human rights by persons with albinism

Ikponwosa(I.K.) Ero

Good morning. My name is Ikponwosa Ero, and I am from Nigeria. My mother and father are black; as black as most black Africans. I have albinism.

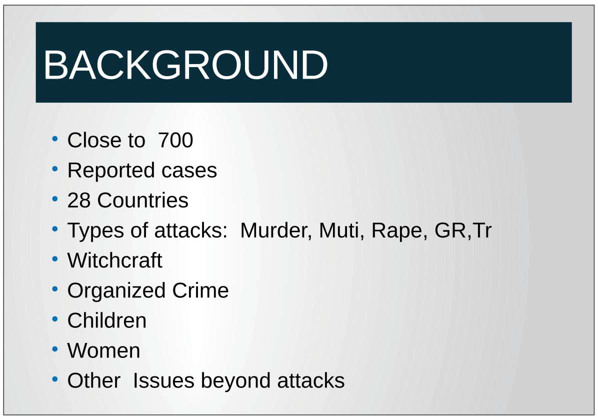
I started this job as the UN Independent Expert on albinism, at United Nations in 2015 after I was appointed by the United Nations Human Rights Council to address the situation of human rights concerning people with albinism around the world. Therefore, I am very happy to hear – as we just did - the perspective of persons with albinism in Japan. (※*See page* 80.) Even though there are different levels of discrimination in each region, there is also some degree of sameness in our experiences such as rejection and social exclusion in many areas of life.

My presentation today will give an overview of what albinism is and some of the global problems. This is to give you a general background before my colleagues begin to give you details.

700 cases: A Tip of the Iceberg

As I sit here with you today, there has been about 700 cases of attacks against persons with albinism. These cases include murder, mutilation, grave robberies, ritual rape, trafficking in persons and body parts. These are reported cases alone. Many cases have not been reported because of the involvement of family and community members in perpetrating these crimes.

These 700 cases of attacks have been reported across 28 countries in the Africa region. These are cases reported, for the most part, in the last ten years. The attacks happen in particularly violent circumstances.



BACKGROUND

- Close to 700
- Reported cases
- 28 Countries
- Types of attacks: Murder, Muti, Rape, GR,Tr
- Witchcraft
- Organized Crime
- Children
- Women
- Other Issues beyond attacks

■ Organized crimes are often involved. Women and children targeted.

They begin primarily with the belief that persons with albinism, due to their appearance, can become ingredients in witchcraft practices. The attacks happen often times with the use of machetes or large knives.

People are monitored and then hunted, and their body parts are cut with the intension of selling it, to use it in witchcraft related practice. These are organized crimes surrounded by secrecy in the same way as secrecy surrounds the drug trade. The majority of the victims of attacks are women and children.

What is Albinism?

Albinism is simply a genetic condition that happens when both mother and father carry the genes for the condition. When the mother and father carry the gene for albinism, there is 25 % chance on each pregnancy that the child will have albinism.

■ People with albinism are all over the world, regardless of ethnicity or race. ©Under the Same Sun/Rick Guidotti

Albinism occurs in all ethnicities everywhere in the world. As you can see, there are persons with albinism in Japan. There are also persons with albinism in Africa, North America, South America, — all over the world.

However, the frequency of occurrence varies depending on the type of albinism and how many people carry the gene. In some countries where study has been conducted, such as in Tanzania, one in 19 people have the gene for albinism. I don't know what the data is in Japan. Hopefully, I will find out in the future.

Nowadays, we say "person with albinism" not albino, because albino was found to confuse the person and the condition mixing them as one thing, whereas person with albinism puts the person before the condition.

There are different types of albinism with varying degrees of residual pigmentation and vision impairment. There is also the type that affects the eyes alone. Therefore there is a diversity within albinism, often labelled as Type 1 all the way to Type 7. I learned that here in Japan, Type 4 is the most common type, even though it is rare everywhere else in the world.

There are two main impairments linked to albinism. The first one is vision. Most people with albinism have low vision. In some countries, they are classified as legally blind. But the level of vision in each person with albinism is different.

Another problem is vulnerability to skin cancer or a skin impairment. Skin cancer is one of the deadliest conditions faced by person with albinism worldwide. In several countries in Africa where preliminary studies have been conducted, and where interventions on health have not been made, only about 2% of people with albinism live beyond age 40, majority die before that age to this preventable condition.

Vicious Cycle of Life

Now what kind of discrimination do persons with albinism encounter? I would like to propose that this is something that happens on a spectrum.

Discrimination is on a spectrum because on one end, you have, what I call, the day to day discrimination that people with albinism face, which is what my colleague from Japan has just explained such as being forced to dye one's hair black to attend school or to get a job. On the other extreme end, you have physical attacks perpetrated solely on the fact that one has albinism. In between, these two ends of the spectrum, you have various levels of discrimination.

For instance, closer to the first end of the spectrum, we have socially entrenched name calling. People with albinism are called very dehumanizing name

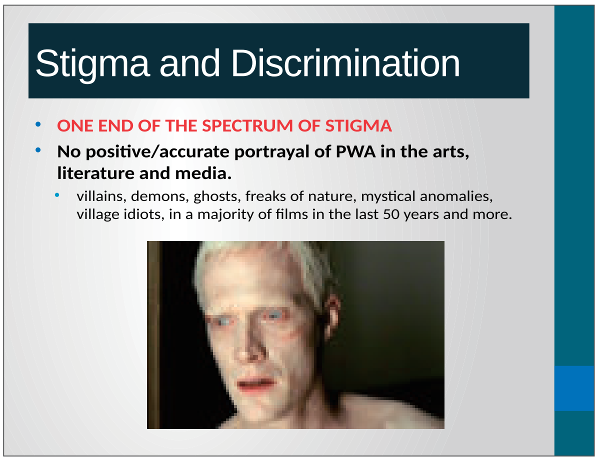
■ Person with albinism reading a book. ©Under The Same Sun

■ African sun creates serious damages to their skin. ©Under The Same Sun across the world. Some names include *ghosts* due to their coloring or *money*, because of the myth that their body parts are sellable for witchcraft-related practices in some countries. In other countries, they are called *monkeys* or *ape*.

In Hollywood, misrepresentation of people with albinism as supernatural, magical or mystical is not unusual. This sometimes happens also in anime.

In the middle of the spectrum, you have what I call "the vicious cycle of life," where the person with albinism is born, and in many cases, they are faced with the prospects of abandonment.

I have received reports even from China on abandonment. In other countries, it is infanticide or the killing of the child because they look different. "Why is this white baby born to parents that are significantly darker?" they ask. Without satisfactory answers or support from the health or social system, infanticide or abandonment becomes an option.



Stigma and Discrimination

- ONE END OF THE SPECTRUM OF STIGMA
- **No positive/accurate portrayal of PWA in the arts, literature and media.**
    - villains, demons, ghosts, freaks of nature, mystical anomalies, village idiots, in a majority of films in the last 50 years and more.

■ Stereotypes often lead to misconception and discrimination.

Photo from whatculture.com

Before and after - only 3 weeks of sunscreen use

■ Incredible power of sunscreen lotion: Before and After.

Photo ©KiliSun/Beyond Suncare

If they survive infanticide, and they go to school, and they are not provided necessary care in school for vision, many of them drop out. Some studies show in some countries, as high as nearly 50% of person with albinism drop out of school due to the absence of reasonable accommodation, as well as bullying from both students and teachers alike. When they drop out of school, they are often unable to get good employment indoors which is important for persons with albinism.

In the end they work outdoors in the sun, risk skin cancer and in many cases die anearly death to skin cancer.

Moreover, many are poor, because they do not have a good education. This poverty exposes many in Africa to attacks, because they live in insecure homes where perpetrators can easily break in. The victims of most reported attacks are poor.

On the final end of the spectrum is the issue of physical attacks. The last record of attack I received was just last month. I received one, two weeks ago, but it is still under investigation.

As mentioned, there are close to 700 reported attacks in several countries. The highest number of attacks is reported from Tanzania, 173 is reported by civil society.

I dare to propose that this relatively high number could be because the country had a very good press freedom for a long time. Now the press freedom has declined. Malawi also has relatively good press freedom and has a high number of reported cases-well over 100.

Many countries do not have good press freedoms, therefore, a lower number of attacks should not be taken as no attacks are happening. I will show you some pictures now of some victims of attacks so I warn you that they are graphic although not extremely. (※*The photos were displayed at the conference venue only.*)

This is a boy from Tanzania whose arm was cut off with a machete some years ago. Next is another boy, whose hand and his fingers were cut off. As I mentioned, most cases are not reported because family members are involved, possibly because of an attraction to the possibly of making a profit from selling the body parts.

In 2008, the Red Cross published an advocacy report indicating that body parts of persons with albinism have value on the black market in east Africa. Limbs have particular prices in thousands of dollars while the whole body is about 75,000 US dollars in value.

Many people ask why this is happening. First, I want to make it clear that the majority of Africans are not involved in this, but rather there are indications of the involvement of very few but powerful participants. From my preliminary analysis, here are some reasons why this is happening.

One, there has been a history of lack of understanding of albinism, and no large scale support to the persons with albinism, and more work needs to be done in this regard.

Secondly, there is the issue of poverty of the victims who are unable to afford secure homes. There is also the poverty of the attackers or who are attracted to the idea of making a profit from the sales of body parts of persons with albinism.

Sometimes, people who fall in this group are attracted to money, even though they do not believe the body parts have any supernatural value as promoted by certain believers and practitioners of witchcraft.

Witchcraft as Harmful Practice

Another reason is witchcraft. People believe in witchcraft. This is a big problem not only worldwide for various marginalized groups, but also in cases of attacks against persons with albinism.

Addressing this issue is one of the priorities I have on this mandate. We have heard of female genital mutilation as harmful practice, we have heard of early childhood marriage as harmful practice, but witchcraft in this context is also a harmful practice, but very few action is taken on it, even though the victims are so many, even beyond people with albinism.

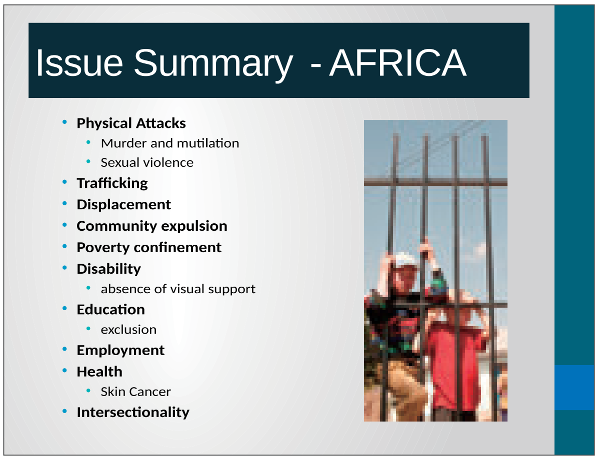
The fourth reason for these human rights violations against persons with albinism is the issue of weak civil society, because they do not have the capacity. Many of them are volunteer-driven with little-to-no-resources to run operations that fully protect and promote the rights of persons with albinism.

Finally, there is the problem of weak government systems, even when they want to help.

By way of summary, here are some key human rights issues on the African Continent in particular: Discrimination, stigmatization, mystification, infanticide, abandonment, health, education, disability, employment, physical attacks, trafficking in person and body parts, and poverty.

The UN Committee on the Rights of Persons with Disabilities has discussed albinism in several country contexts, and in relation to one or more of human rights issues. The UN Committee on Elimination of Racial Discrimination has also discussed albinism as one of the issues falling within their mandate because persons with albinism face "racial discrimination." This is a type of discrimination not based on race but on color as the key word here is "racial" and not race.

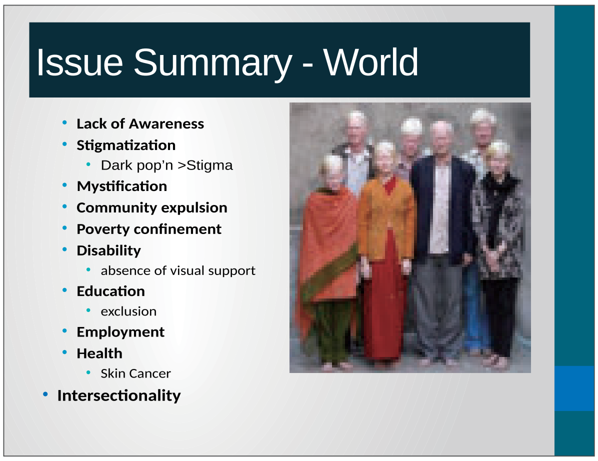
Here is the list of human rights problems worldwide concerning albinism. These include a deep lack of awareness about the condition and the resulting stigmatization, mystification, and barriers to equal access in the key domains of social inclusion, disability, health, and employment among others.



Issue Summary - AFRICA

- Physical Attacks
    - Murder and mutilation
    - Sexual violence
- Trafficking
- Displacement
- Community expulsion
- Poverty confinement
- Disability
    - absence of visual support
- Education
    - exclusion
- Employment
- Health
    - Skin Cancer
- Intersectionality

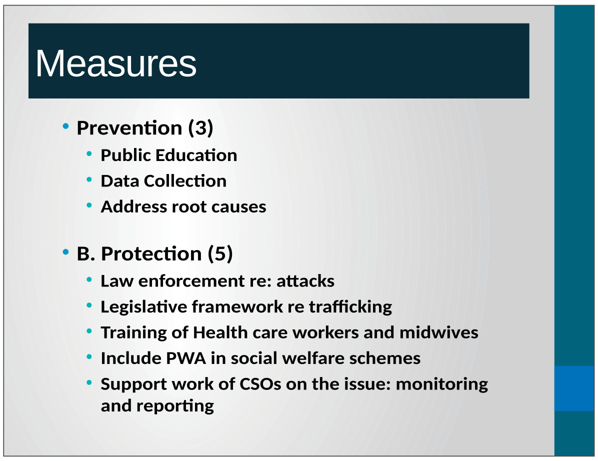
■ List of issues in Africa. Photo ©Jean Francois Mean



Issue Summary - World

- Lack of Awareness
- Stigmatization
    - Dark pop'n >Stigma
- Mystification
- Community expulsion
- Poverty confinement
- Disability
    - absence of visual support
- Education
    - exclusion
- Employment
- Health
    - Skin Cancer
- Intersectionality

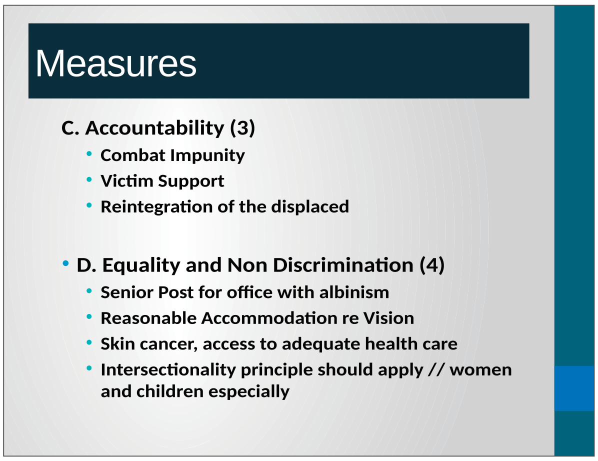
■ List of issues globally. Photo ©Tanzeel Ur Rehman/Shariq Allapaband



Measures

- Prevention (3)
  - Public Education
  - Data Collection
  - Address root causes
- B. Protection (5)
  - Law enforcement re: attacks
  - Legislative framework re trafficking
  - Training of Health care workers and midwives
  - Include PWA in social welfare schemes
  - Support work of CSOs on the issue: monitoring and reporting

■ Prevention and protection measures.



Measures

C. Accountability (3)
- Combat Impunity
- Victim Support
- Reintegration of the displaced

- D. Equality and Non Discrimination (4)
  - Senior Post for office with albinism
  - Reasonable Accommodation re Vision
  - Skin cancer, access to adequate health care
  - Intersectionality principle should apply // women and children especially

■ Accountability measures and equality-and-non-discrimination measures.

I would dare to say that the only difference between people with albinism outside of Africa and those in Africa is the physical attacks. Everything else is, to varying degrees, similar.

Here are some of the ways forward as I conclude. I am pleased to announce that the African Commission on Human and People's Rights, together with myself in capacity as UN mandate-holder on this issue, and stakeholders around the region have come up with a regional action plan to combat many of these issues as they exist on the African continent.

This regional action plan was made with the recommendations of the African Union (AU), as well as the recommendation of UN in all resolutions that these entities and their mechanisms adopted to-date on this issue.

The regional action plan has four ways of helping the issue, namely through prevention measures, protection measures, accountability measures, equality and non-discrimination measures. Under each of those measures, we have particular tasks to carry out.

So, for example, under prevention, we have public awareness, education, data collection, and work to address the root causes of attacks, such as witchcraft.

When you have time, I encourage you to go on the website, actiononalbinism.org and you can see the entire regional action plan. From there you might better understand how countries are faring on these measures and help both as individuals and through your various organizations.

I hope that the regional action plan will eventually inform a global action plan. We need a global action plan, so that all the issues we have in common with others around the world can also be reflected and dealt with.

I wish to conclude by quoting from the UN Sustainable Development Goals which Japan, as a country and member state of UN, has signed on to in its practices and development strategies.

The Sustainable Development Goals are a continuation of the work of Kofi Annan, former Secretary General of UN. They aim to make development around the world, real and lasting for all. In doing so, no one is to be left behind. Not only do the SDGs aim to leave nobody behind, they aim to do so with an emphasis on the furthest behind first.

Persons with albinism are some of the furthest behind. I hope that with your help, your support, your awareness raising, we will be able to collectively tackle these issues worldwide, particularly where there are extreme violations, namely in several countries in Africa. Thank you.

Personal Testimony of Mariamu

—In Conversation with Vicky Ntetema

PROFILE Ms. Mariamu Staford is an entrepreneur engaged in a small-scale knitting business. As a person with albinism, she was denied the right to education and health from a tender age. Her parents and teachers did not understand that she had low vision and she did not complete her elementary education. As a pregnant unmarried young woman, she was regarded by her mother as a burden. She subsequently gave birth unaided to a son without albinism. In October 2008, she was brutally attacked by four men, one of them a Burundian neighbor. She lost her arms and unborn baby. She got her first functioning prosthetic arms in 2009 in the USA and joined Under The Same Sun Education Program. She graduated with an Advanced Certificate in Knitting from Imani Vocational Training Centre in Moshi, Tanzania. She knits sweaters and scarves as a business.

Entrepreneur
Mariamu Staford

“Don’t struggle. I just want to cut off your arm.”

Ms. Vicky Ntetema Can you tell us how you were attacked, please?

Ms. Mariamu Staford On October 17, 2008, some men came into my house. They broke into my house and attacked me. There were four men. One of them was a man from Burundi, who had been my neighbor for ten years. They came to my place and attacked me.

The neighbor was the one who cut off my arms. He began with my right arm, which he threw outside to the other men. He then started cutting my left arm. When I struggled with him he said, “Don’t struggle, I just want to cut off your arm.”

At that time, I was six months pregnant. I also had a child, a son. He was there and witnessed everything when I was being attacked.

Ms. Vicky Ntetema Earlier, I forgot to translate the part where she said she lost the baby.

■ Totally in shock: Mariamu after the brutal attack.

Ms. Mariamu Staford It took about seven hours before I was taken to hospital. When I went there, the first doctor who saw me said I was dead, so they could not treat me.

Later on, the police came and took me to the district hospital. This is where I was treated for five months.

When I was discharged from the hospital, I could not go back to the village, because it was not safe for me. The district government gave me an unused building to live in. This is the government house where I was kept for six months.

In the meantime, they said they would make sure to find another safe place for me. Six months later the government told me to leave the building, because I was not a government employee, and people like me are not supposed to be staying inside the house.

On October 19, before I was moved out of the house, I spoke to Vicky Ntetema, who worked for the BBC, and what happened to me became known to the outside the world. After that, people started helping me. And that is how I was eventually helped by Under The Same Sun, (UTSS) who brought me to Dar es Salaam.

“I decided I could do it.”

Ms. Vicky Ntetema Mariamu, can you tell us what happened after the attack? How did you manage to live like a normal person?

Always with a smile: Photo time with friends and supporters. ©Elia Saikali

Ms. Mariamu Staford It was not easy to live a normal life after the attack. But ABC News from the United States came and reported about the attack.

Then, UTSS helped me and took me to a vocational training center where I started knitting, I learned how to knit sweaters, and that is the business that I am doing right now. I knit sweaters and scarves.

And also, UTSS built a house for me in Kilimanjaro, away from the village where I was attacked. They also bought me machines which I use now for knitting. So, I am now in the knitting business.

Ms. Vicky Ntetema Mariamu, thank you very much. But can you tell us about the Kilimanjaro climb? How did it come about that you climbed Mt. Kilimanjaro?

Ms. Mariamu Staford I did manage to climb Mt. Kilimanjaro, along with five other women. I succeeded, because although I was attacked, I never gave up. I never gave up and I believe in myself. And I decided I could do it. I decided I would succeed in climbing Mt. Kilimanjaro. And so I climbed the mountain, which is more than 4,000 meters high. I didn't reach the peak but I reached Mawenzi Tarn. So, I believe in myself, and I've never given up.

I have two younger sisters who are supported by UTSS. They are in school. And my son is also supported by UTSS education program. I have brought some sweaters with me today, and if you want to buy one, you are welcome. Thank you very much.

Rongai Route Itinerary

Day 1 - Nalemoru (1950 m/6400 ft) - First Cave Campsite (2650 m/8700 ft)
Walking distance: 6.5 km/4 miles
Walking time: 3-4 hours
Altitude gain: 700 m/2300 ft

Day 2 - First Cave Campsite - Kikelewa Caves (3600 m/11810 ft)
Walking distance: 9 km/5.6 miles
Walking time: 6-7 hours
Altitude gain: 950 m/3110 ft

Day 3 - Kikelewa Caves - Mawenzi Tarn (4330 m/14210 ft)
Walking distance: 6 km/3.7 miles
Walking time: 3-4 hours
Altitude gain: 730 m/2400 ft
Afternoon acclimatization walk to about 4500 m/14760 ft

Challenging Mt. Kilimanjaro: The route

Mariamu and friends heading to Mt. Kilimanjaro. ©Elia Saikali

Posing at 3,600m elevation. ©Elia Saikali

My Story: How I Got Involved

PROFILE Ms. Vicky Ntetema is the Executive Director of Under The Same Sun, a journalist by profession and also a human rights defender. She completed her MA in Journalism at the Belarusian State University in Minsk, Belarus and her MSc in Information Systems Development at the London School of Economics in Britain. She joined the BBC in 1991 as a BBC Swahili radio producer and presenter. As BBC Tanzania's Bureau Chief, she learned about the attacks against persons with albinism, reported it undercover and has remained a passionate activist on the issue. She is the winner of multiple awards including the International Women's Media Foundation award for Courage in Journalism and International Women of Courage award for her work for persons with albinism.

Journalist; Former Director General, Under The Same Sun (UTSS)

Vicky Ntetema

Not the Tanzania I know

When I heard about persons with albinism being murdered and mutilated in Tanzania, I thought to myself, "This is not the Tanzania I know." Tanzania is a peaceful country, and Tanzania does not entertain racism.

So I wondered, "Why are people with albinism being murdered?" Then, as a journalist working for the BBC World Service, I needed to understand why people with albinism were being murdered.

The first report that came was in September 2007, and that is when I heard about a teacher who killed his own 18-month-old son for use in witchcraft. That was in Arusha, in northern Tanzania.

Then, we kept on hearing about the murders and grave robberies in western Tanzania. And also the killings and mutilations in November 2007 in north-western Tanzania. Many people, including these people on the screen, became victims. Mariamu was one of these victims.

I started investigating the murders of persons with albinism in December 2007, and Mariamu was attacked in October 2008. I am now going to show you very graphic photos of people who have been mutilated. If you cannot bear to look, please don't, as they are really graphic. (**The photos were displayed at the conference venue only.*)

I.K. mentioned that the people who are being attacked are the most vulnerable and weak, many of them women and children. What you see here is just a few of those who have been attacked.

Kija Marachu, seven months old, was attacked in 2008. She was ripped from his mother, who was asked to choose between allowing the attackers to kill just this baby, or start killing three of her children, one by one until she releases the baby. The mother had to let the baby go, and then the attackers killed the baby.

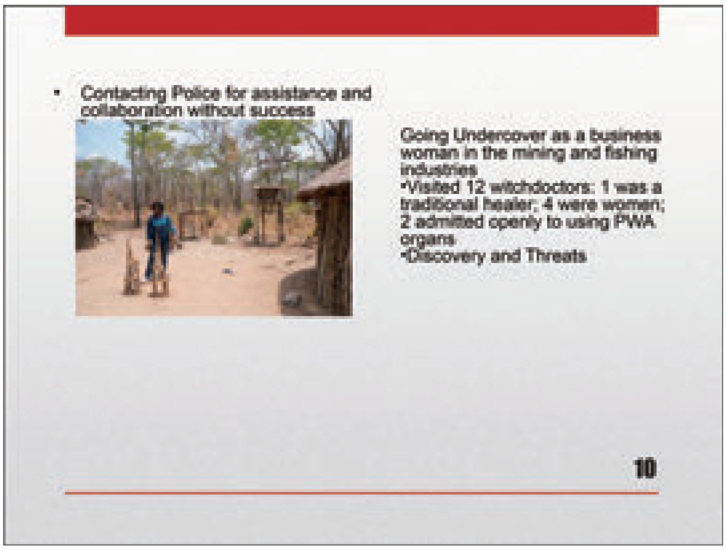
This photo is of Lugolola Muzari. He was only seven years old when he was attacked in 2013. When he was attacked, he was defended by his 95-year-old great grandfather. The great grandfather was murdered along with Lugolala. And Lugolala's father, who went to his defense, was shot, but he survived. This photo is of Yohana Bahati, who was attacked in 2017.

Some of those attacked did survive. These are just a few of them: Kabula was 13 when she was attacked in 2010. Kulwa was 15 when she was attacked in 2011. Mwigulu was attacked when he was ten, in 2013, and I can show you a photo of him too. When Limi was attacked in 2015, she was 28. And of course, Mariamu.

They are survivors, and almost all of them have had help or support from UTSS. The kids, for example, have been given prosthetic arms and are now in school thanks to UTSS.

Going Undercover

So where was the government?
The Tanzania Albinism Society said that if science



- Contacting Police for assistance and collaboration without success

Going Undercover as a business woman in the mining and fishing industries
•Visited 12 witchdoctors: 1 was a traditional healer; 4 were women; 2 admitted openly to using PWA organs
•Discovery and Threats

■ Visiting witchdoctors in rural Tanzania.

©Under The Same Sun

can prove that organs of persons with albinism can make people rich and successful, then persons with albinism, though there are only a few of them in Tanzania, will sacrifice themselves so that Tanzanians can become rich and successful. This comment was made at a press conference on December 17, 2007 that I attended as the BBC World Service Bureau Chief for Tanzania.

And that for me was a cry for help. No one would ever say kill me so others can get rich. That was the thing that prompted me to go undercover, to find out what was happening.

I was shocked. How can people in the 21st century believe in witchcraft? And I am talking not only about people without education, but also the elite, political and religious leaders, and also rich people, some of whom consult witchdoctors.

In March 2008, then president Jakaya Kikwete said that people were being murdered and mutilated for witchcraft purposes in five particular regions in north-western Tanzania. I went there to find out more. I visited the witchdoctors to investigate why they were killing persons with albinism.

Of course, I went there not as a journalist. I pretended to be a businesswoman engaged in the fishing and mining industries. At that time, as President Jakaya Kikwete said, people in the mining and fishing industries would consult witchdoctors, who would give them potions containing the organs of persons with albinism, so that they could become successful and their businesses could boom.

Going undercover, I visited 12 witchdoctors: Only one of them was a traditional healer; four were women; two admitted openly to using organs of persons with albinism, and they promised that they could get me organs of persons with albinism. Of course, I didn't wait around for them to do so. I was eventually discovered, threats started, and I had to leave the country.

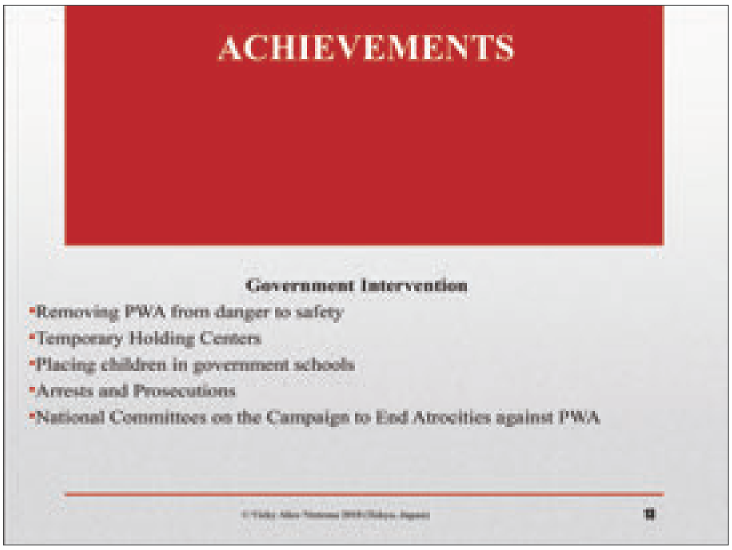
They Are All Afraid of Witchdoctors

I.K. has already pointed out most of the challenges surrounding albinism. But in our case, the president at that time ordered the arrests of witchdoctors who were involved in the killings.

There was also a secret ballot for people to name the killers of persons with albinism. The government of Tanzania asked the public to name these killers by writing their names on a piece of paper and putting it anonymously in a box. The government then gathered up the papers with the names and handed them to the police for investigation. It couldn't have gone well, because we still haven't heard of any results.

The police admit that there is corruption when it comes to cases going to court. Some of the police and the judges go to witchdoctors themselves and are afraid of them. Therefore, it is very difficult for people with albinism to get justice.

I was told that the government had intervened by taking persons with albinism out of danger to safety, taking them from villages to temporary holding centers. They also placed children in government boarding schools rather than going home to be



ACHIEVEMENTS

Government Intervention

- Removing PWA from danger to safety
- Temporary Holding Centers
- Placing children in government schools
- Arrests and Prosecutions
- National Committees on the Campaign to End Atrocities against PWA

■ Government intervention
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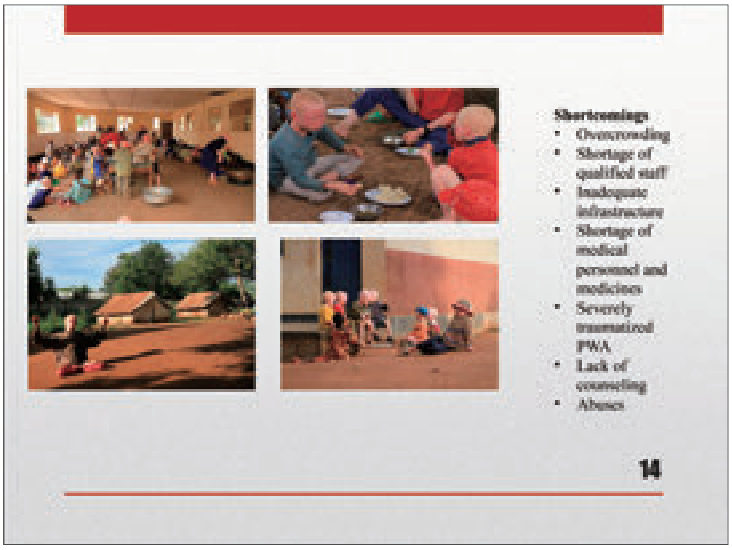

Shortcomings

- Overcrowding
- Shortage of qualified staff
- Inadequate infrastructure
- Shortage of medical personnel and medicines
- Severely traumatized PWA
- Lack of counseling
- Abuses

14

■ Number of shortcomings in the temporary held centers
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attacked. Arrests and prosecutions also took place. The National Committees on the Campaign to End Atrocities Against Persons with Albinism started much, much later, in 2015.

However in the centers that the children were sent to, were overcrowded and a lot of abuse were going on. Physical abuse and even sexual abuse against the children. The centers were inadequate for hosting children with albinism, and there were also adults with albinism in the same facilities. The centers were not meant for hosting children.

The UTSS Certainly Did a Lot

And so, what was done during this time? Well, UTSS came to the rescue. UTSS is an international organization, and you will hear all about it later from Peter Ash. I started working for UTSS because I had been threatened and the BBC said they could not protect me unless I left the country. I did not want to leave the country because it is *my* country, where people with albinism were murdered and mutilated. I had to stay. And I also had to resign from the BBC.

Peter Ash appointed me as an Executive Director at UTSS at that time. We were involved in public awareness and also advocacy. We contacted the government, as well as the villages and people throughout the vast country of Tanzania. Now, ten years have passed since the establishment of UTSS, people with albinism are educated. Some of them are government employees, even a deputy minister, and lawyers.

And in ten years , there have been a lot of success stories. I would say that yes, the government did something, but UTSS did a lot. Thank you very much.

Q&A ❶ Moderated by Mr. Isaac Mwaura, Senator in Kenya and the first member of Kenya's Parliament living with albinism

Personal Sacrifices

Moderator **Before I open the floor for Q&A, I want to ask you, Vicky, as you recently retired from UTSS after ten years, if you would kindly share with us your own individual journey? What have you taken on in your life? What are the sacrifices you had to make as a person, because clearly you put your life and your destiny in the center of the issues of people with albinism?**

Threatened and Rejected by Family Members

> "Killing PWA and keeping quiet about it is a national secret? How could that be?"

Ms. Vicky Ntetema I was threatened by many witchdoctors from all over Tanzania when they realized that I was not a businesswoman.

It was one of the police officers who informed them that they were dealing with a journalist, an investigator, not a business woman. "Your secret is out," they said.

I was threatened by government officials including ministers and politicians and the police, including high-ranking police officers. They said that I had tarnished the image of Tanzania, as Tanzania is now known as a country where people practice witchcraft and kill persons with albinism, while before it was known as a country of peace. The police were more interested in keeping the image and the reputation of the country but not in saving the lives of persons with albinism. It was a shock for me.

The Minister of Home Affairs said to me that I had revealed national secrets, so they can take me to court for treason. What are these secrets? Killing persons with albinism and keeping quiet? I didn't understand how that could be a national secret.

I was also rejected by some of my family members. They rejected me first of all as they do not understand what albinism is. As some of them

■ Ms. Vicky Ntetema responds to questions at the conference.

believe in the power of witchcraft, they thought that if the witchdoctors could not harm me, and if I was not afraid of them, I must be stronger than the witchdoctors.

Other family members were unhappy that I took home some children with albinism before Under The Same Sun came to their rescue. At one point, Mariamu was living with me at my place as well as two girls with albinism who were fleeing the atrocities after their sister had been murdered. They were staying with me at home, so some of my relatives refused to come to visit me and severed our relationship. At that time, as I pointed out earlier, they did not understand what albinism is. Thanks to Under The Same Sun, people are now have more understanding that albinism is just a genetic condition.

As regards to my personal life, I had to resign from the BBC. I love my job as journalist. From the time I was little, I dreamt of becoming a journalist. I had to resign because the BBC said they could not protect me if I still worked in Tanzania. I had to choose between going back to London, where I had begun my journalistic career, to work for the BBC, or stay in Tanzania and keep up the advocacy work and activism to promote the rights of persons with albinism. I chose to stay in Tanzania, because those who had been murdered were Tanzanians. They were my brothers and sisters, although I was not directly related to them.

> "All PWA are my brothers and sisters because they are human beings, first and foremost."

Many people have asked me, "Do you have a child with albinism?" No, nor a brother or sister. But for me, all PWA are my brothers and sisters because they are human beings, first and foremost.

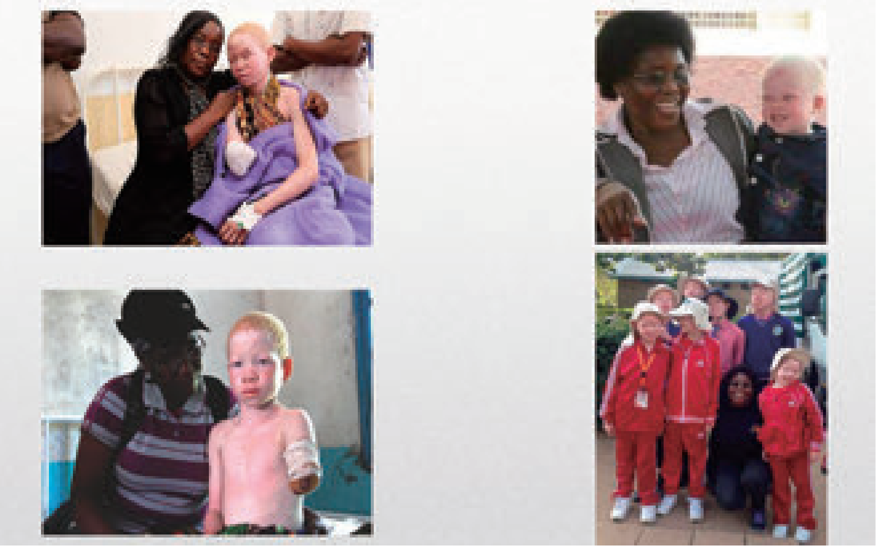
Importance of Press Freedom

Moderator **Vicky, allow me to ask another question. Obviously, Tanzania has been mentioned a lot with regards to the issues of persons with albinism. And I.K. alluded to the fact that of late, there has been limited press freedom in the country.**

The fact that you were told by the state that you are actually exposing national secrets, does that allude to some collusion between politicians and people high up in the government with regards to these killings and them being beneficiaries of the same? And what do you think is going to happen now that there is this gag on the media? Are you anticipating more attacks or do you think they will be silent?

Ms. Vicky Ntetema I don't think I should say here I am anticipating an attack! I am praying that there will be no more attacks.

Press freedom is vital in reporting these attacks. I.K. pointed out that there used to be more freedom when we reported about persons with albinism being attacked. But even at that time, I was receiving threats. Right now, we don't know whether attacks are still taking place, and just that people are not reporting them. Because there are two things here.



■ Snapshots from activities of Under The Same Sun.

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First, a government official said that if there is an attack, anywhere in the country, those who work for the government, the leaders from village level to the regional level and on to the national level, will be held accountable. The government will deal with them so that people are not afraid of reporting. I will give you an example.

A 12-month old boy was killed on May 21, 2015 in Singida in Central Tanzania, but people did not report it. It was only in 2015 when Under The Same Sun, the director of Public Prosecution, and the director of Investigation were going around the regions where people with albinism had been murdered and the judicial cases had stalled that they came to know that there was a boy who was killed in the area in 2014. People kept it secret because they were frightened.

Second, remember the myth that persons with albinism don't die—they disappear. If people go somewhere and don't see Vicky with albinism there, for instance, they just assume that Vicky has disappeared.

> Not hearing about killings does not mean they are not happening.

And because the killings and all these attacks are being done in secrecy, we will never know the truth. Just because we don't hear about killings in Tanzania does not mean that they are not happening. I wish they were not. Now with the less press freedom that I.K. mentioned, I don't think we will ever find out the truth. Did I answer your question?

The More Visibility, The Better

Moderator **Thank you very much. Final question. You have alluded to the fact that there have been a lot of improvements, such as persons with albinism now being part of the government, including one Deputy Minister. I think Tanzania has had three members of the Parliament so far, and even a Deputy Solicitor General who had albinism. Is this really helping in the fight against the killings and the seclusion of persons with albinism?**

Ms. Vicky Ntetema Of course it's helping. It's helping because more people can see persons with albinism. And parents who were hiding their children with albinism are now taking the children to school. Long ago, people thought that if you sent a child with albinism to school they wouldn't study.

Mariamu, for example, was not sent to school by her parents. Her grandmother sent her to school, but her parents did not. She was ten years old and was not even able to study in school. But now we see that under the educational program of Under The Same Sun, more kids are going to school. And government is now appointing quite a lot of people to posts that we would never have imagined being held by

■ Eight-year old Marthe needs to complete domestic chores her siblings go to school.

Photo © Patricia Willocq

persons with albinism.

The visibility is there, because of advocacy and public awareness. The visibility is also there, because more persons with albinism in Tanzania are going to school and getting educated, going on to universities and even getting Master's degrees and PhDs in various fields. There is a social welfare officer with albinism working in the Ministry and the Prime Minister's office, and an economist with albinism also in the Prime Minister's office. One lady with albinism, who is also a singer and artist, was recently appointed to the National Executive Committee of the ruling party, CCM.

Persons with albinism are more visible now and they have more confidence. People with albinism are now bankers. In the past, who would share a chair or a table with a person with albinism? So, there have been quite a lot of changes.

I forgot to mention whether politicians are involved. As I said before, yes, politicians are involved. Some government ministers are involved, as are some religious leaders.

■ Mariamu and her sweaters

These people consult witchdoctors, especially during elections. And those who want to stay in power, whether in a faith-based institutions or in politics, and those who want to be more successful as business men and women consult witchdoctors. It's a vicious cycle. And these witchdoctors have come up with their own magic solution to everything: The organs of persons with albinism.

Forgiven the Attackers?

Moderator **Thank you very much. Finally, Mariamu, I will ask you a question in Swahili and repeat it in English. Have you forgiven those who attacked you, and going forward, what contribution do you feel you have made in the fight for the rights of persons with albinism?**

Ms. Mariamu Staford I forgave all those who attacked me the first day after the attack, because without forgiving them, I wouldn't be where I am now. I had to forgive them. If I had not forgiven them, I would not be able to do what I want to do in life. I think I will be very successful in the next ten years. I want to open a school to teach people with albinism how to be confident and build their self-esteem. And I want to teach them how to become entrepreneurs so that they can depend on themselves. They will be independent. This is what I want to do.

> "I forgave those who attacked me the first day after the attack. I had to. Otherwise I wouldn't be where I am now."

Moderator **Thank you very much. It has really been amazing.** *Asante* **(※ Thank you in Swahili), Mariamu. And Vicky Ntetema, thank you very much for sharing your experience.**

■ Mariamu replies to the question.

Acceptance at Home Truly Needed

PROFILE As former president of the Association of Persons with Albinism in Malawi (APAM) from 2009 to 2016, Mr. Bonface Massah contributed to building a foundations of Malawi's first association for persons with albinism. In 2016, he launched the national secretariat office for APAM and became National Director.
Mr. Bonface Massah is one of Africa's notable youth experts on rights of persons with albinism and social inclusion. His work with communities and policymakers has helped to develop inclusive community-based programs and policies that are promoting the rights of persons with disabilities in Malawi and Africa. He has conducted research aimed at debunking mistaken stereotypes about persons with albinism. He has also contributed to developing innovative strategies to respond to the educational, health and social needs of persons with albinism.

Executive Director, Association of Persons with Albinism of Malawi (APAM)

Bonface Massah

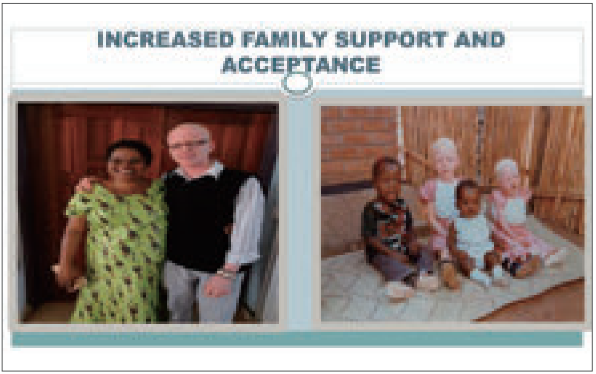
Parents Involved in Killings

I come from Malawi. We are a relatively small country in Africa with a population of around 17 million and an estimated 134,000 persons with albinism.

The Association of Persons with Albinism of Malawi has close to 2,500 to 3,000 members. It is a voluntary organization, so members are recruited on the basis of their desire to join and by joining us they accept to become part of the movement.

A lot has been said and I think shared around what has happened in Africa. Malawi has not really been spared the killings of persons with albinism. The most critical part that I am going to focus is what we have achieved as a country and what things we feel are important to ending, or contributing to ending, the attacks in Africa.

One of the most important things, I am sure everybody agrees, is the issue of parents being involved in the killings. We need to promote the issues of acceptance and family support within the context of our homes.



INCREASED FAMILY SUPPORT AND ACCEPTANCE

■ Acceptance starts from family.

Working with Parents

Our relatives, our parents, our brothers and sisters, our cousins really need to understand what albinism is and where we are coming from.

Because that is where the complications start, when it comes to them being promised a lot of money for body parts. And this is one thing that we have been using as an organization. We work with parents to really get them to accept their own children with albinism.

In my family, we have three children with albinism. We are six children in total, so three have albinism, and three don't. This is the setup in most African countries, where we have quite a number of people with albinism within the same family.

Use of Media

Another element that we have done a lot of work on is use of the media. We have really had a chance to collaborate with the media. We use them a lot to expose the attacks. We straightforwardly engage with the media concerning any attacks that have happened in Malawi. We make sure we involve the media. We report the attacks, we publicize them and that way we have done a lot to raise the profile about what is happening in our context.

Luckily, there have been good responses from the

■ Engaging media is very important.

media, and we had no resistance from them to covering our issues, even free of charge. So, we have that space where we have created that momentum and engaged the media in raising our issues.

It is All about Creating Relationships

We have also worked a lot with religious leaders. Traditionally, the attacks have been in both rural and urban areas. Our role has been really going back to the grassroots. We ask: What have been our norms; what has been our culture as a society; why are the chiefs not now protecting us; why are our own brothers, sisters and neighbors not protecting us.

So, we went back to engaging with the chiefs, making sure they understand what albinism is. We have used them as champions of albinism. Some of them have really contributed by setting up bylaws that will protect persons with albinism, but also by making sure that the chiefs work with the community police structure to raise the profile of persons with albinism.

It is all about creating relationships. If they don't really understand us, it will be very difficult for them to protect us, and even love us as another person in their own community.

We have collaborated a lot with different partners. I think the major one is the UN Family. We have done a lot of awareness raising. I.K. visited us and produced a very good report about the challenges PWA face in Malawi, and the urgent action the government and its partners should take to end the attacks.

Following I.K.'s visit to Malawi there has been increased support from the UN Family in Malawi. They are working to strengthen community policing structures, along with the Ministry of Justice, Malawi Parliament and civil society.

■ Positive collaboration with the United Nations family gives power.

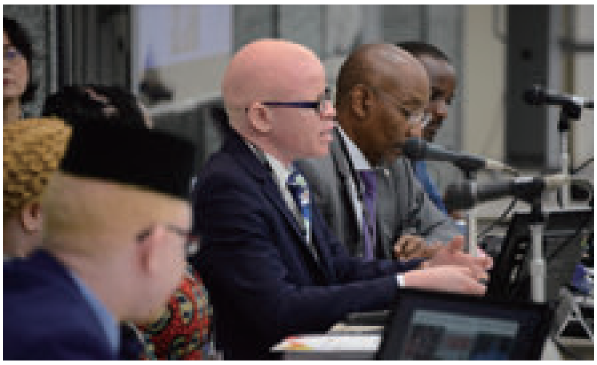
■ Having visibility is vital.

The collaboration with the UN also helped us a lot to ensure that we raise the profile of the attacks locally and internationally, including the situations of the victims of horrific attacks.

We have received political commitments. The president has been condemning the attacks at different forums. The government of Malawi has engaged with us as an organization in so many ways. We have also been participating in International Albinism Awareness Day, which is now on the government's calendar. The president and ministers have been attending the functions.

Working closely with the political structure has helped us to win moral support. We try to convince the police and the criminal justice system to ensure that this is an issue of national interest. It is a crisis to which everyone has to respond. We need to work together to ensure that those political commitments are really translating into tangible outputs or services to persons with albinism.

As a movement, we have been operating without an office for 20 years. It was only in 2016, thanks to Peter Ash, that this changed. When I met Peter Ash, I was working somewhere else. We had a discussion, and I was convinced that we should start this office. Peter Ash directly paid for my time when we set up the Association of Persons with Albinism of Malawi in 2016.



■ Mr. Bonface Messah making presentation at the conference.

Our association has been participating in International Albinism Day. It all started from the support we get from Under the Same Sun. It helped us a lot to ensure that we participate and raise the visibility of albinism through International Albinism Day on June 13.

National Action Plan

We used a lot of evidence in our advocacy and we have been involved in a lot of research. We have worked with the International Bar Association (IBA) and I think a lot of reports are also online that highlight the challenges in Malawi.

We have worked with Amnesty International to really uncover what is happening in terms of the atrocities being done to persons with albinism in Malawi. The report by Amnesty International entitled "Malawi: We are not animals to be hunted or sold" describes the gross human rights violations that have taken place and lays out a set of recommendations as to what the government and all stakeholders need to do to end the attacks.

All these studies and reports contributed to the making of the African Regional Action Plan. Our association worked with the Malawian government and created the National Action Plan for Malawi. The main idea was taken from the African Regional Action Plan. We domesticated it.

Malawi has also developed a handbook on albinism which introduces specific laws that prosecutors and investigators can use to ensure uniformity in handling cases of attacks on persons with albinism in Malawi.

Delays in the Criminal Justice System

What are the gaps that we still see? I think the biggest challenge is the delays in the criminal justice system. All the reports we have done through Amnesty International clearly show the delays, the lack of resources, the negative attitudes that are there in the criminal justice system. Many PWA believe that the delays are caused by corrupt officers in investigating and prosecuting the cases of attacks to PWA, causing a lot of stress and fear for people with albinism. It has also even created a space for more attacks to occur in Malawi.

We had a missing child case that occurred on July 6, 2018. The child in this case was abducted by his stepfather. This is how close the attacks have been happening.

We also have the case of MacDonald Masambuka, which also happened in 2018. It was one of the best-known cases in Malawi that shows us the layers of those involved in the killing. The suspects in this murder case include a police officer, a Catholic priest and a medical officer.

It is complicated. There are high-level individuals involved, as you can see. I.K. mentioned how this syndicate is organized. There are some international people who have also been mentioned in the case, which involves body parts being sold. All these are issues we are still struggling with. We really need to break this cycle when it comes to the investigations and the collusion over evidence that has been produced in the courts.

Victims Are Left Behind

There is no victim support for persons with albinism. Take the case of Mercy Banda, who was murdered. When I met her mother on June 13 in 2018, celebrating International Albinism Awareness Day, she only said, "Okay, but what I wanted is to see the people who killed my daughter."

More than two years since the murder, she has never been contacted or given support. She is still just there in the village. The police or the social workers have never returned. She doesn't even know where the suspects are.

But police records show that they arrested the suspect and the accused appeared in court. I know that. But the family of the victim has never been informed. The victims are basically left behind. Such a situation increases the risk of being discriminated against further, or even being attacked again, and I think it is one of the weaknesses of our criminal justice system.

Coordination and Leadership Needed

There is also lack of coordination and leadership. For us to win, we need to have proper coordination and leadership, as a country, as Africa. Issues of albinism have not really reached the level of bringing synergy and staying a priority in terms of the resources and time required to end the attacks. We need to do a lot of work in the institutions of the criminal justice system, the Ministry of Gender and the Ministry of Disability.

So far, out of all the cases that I.K. has mentioned regarding Africa, 24% have happened in Malawi and within a short period of four to five years, despite our small population. And as I.K.'s data only pertains to the last few years, there are many more killings that have gone unreported. And this is why Malawi is regarded as a "hot spot." We need to do more in terms of the response structures. We need to build an effective system to protect persons with albinism against attacks both at the community and national level.

Our association has issued a few recommendations. Government and stakeholders must make commitments to ensure full financial and technical support. They need to take strategic action, short-term and long-term, to end the attacks.

Only 20% Have Access to Health Care

The government must ensure education and health care services for persons with albinism. Many still die from skin cancer due to limited access to quality health care. Educating about rights to healthcare is critical, as it promotes acceptance while building confidence among persons with albinism and family members.

We are working a lot to ensure access to free sunscreen. We are engaging with the Minister of Health to ensure that we are provided with sunscreen. We are also advocating for local production of sunscreen, a kind of a social model where we want to employ and empower persons with albinism.

We also started working on a small scale with the international NGO Standing Voice, which is working on skin cancer prevention clinics in some of the municipal districts. But that is still the biggest challenge. Most people with albinism are not getting access to dermatological services or any other services. The pilot project we have done so far with Standing Voice shows that only 20% of the 134,000 persons with albinism in Malawi are getting access to proper care.

The voice of civil society must be strengthened so that civil society is able to take the lead in promoting and protecting the rights of persons with albinism. We should unite our voices and work together. Leadership is also needed. We need someone who can engage with the government and monitor the implementation of our national action plan.

Capacity Building of Civil Society

We need to increase the capacity of our organization at the national and local levels. The Association of Persons with Albinism of Malawi has a comparative advantage over other civil society organizations in terms of trust among persons with albinism and their families as it is the only association led by persons with albinism themselves.

Standing Voice has been working in Malawi for the past two years and has a specific focus on rights of persons with albinism in health, education, empowerment and advocacy.

However, having a few NGOs working on the human rights of persons with albinism has also led to a weakening of voices to influence change, limited resource mobilization for NGOs and a lack of programs for persons with albinism that target specific areas like health, education, and safety.

We need to protect the victims and the witnesses, because they are very vulnerable. We are handling a case where a witness also happens to be a person with albinism. She is living in fear, and in hiding. Yet, she is one of the witnesses in a high-profile case: the murder of MacDonald Masambuka.

We need to increase policy advocacy and programming, access to health, access to education and even in vocational skills. The majority of PWA in Malawi are still living in severe poverty and are excluded from mainstream society. And the level of stigma is still high.

Finally, we need to champion disability inclusion. We need to do a lot of work in terms of mainstreaming. There are so many programs on disabilities that are not focused on albinism. We need to put ourselves within the broader disability movement and ensure that even those other people with disabilities understand and accept us.

We need visibility in the political sphere. Unlike Tanzania, Kenya, and South Africa, Malawi does not have a political representative with albinism. We are forced to fight outside the system and it becomes very complicated for us to convince some government officials.

We still have a lot of work to do.

Thank you.

Q&A ②

Moderated by Mr. Isaac Mwaura, Senator in Kenya and the first member of Kenya's Parliament living with albinism

Moderator **Thank you very much. Now we have some questions.**

Audience: Dr. Yukie Nakao My name is Yukie Nakao and I'm a sociological researcher at Kyoto University. The focus of my research includes people with disabilities in Tanzania. My question is, were there any other self-help group supporting people with albinism in Malawi before the establishment of Association of Persons with Albinism of Malawi (APAM), and if there were, how are they related to APAM?

Moderator **Thank you very much. Next question, please raise up your hand. Yes, Patricia**

Audience: Ms. Patricia Willocq Hi, my name is Patricia Willocq and I am a photographer. I did a photo report of people with albinism in Democratic Republic of Congo. I was wondering about the witchcraft surrounding people with albinism. Do you think this has happened recently or in the past 50 years, or has it always happened in Africa?

Moderator **Thank you very much, next, another question? Yes, sir.**

Strange Attitude of Tanzania and BBC

Audience: Ambassador Ahmed Araita Ali I am the Ambassador of Djibouti to Japan. And I'd like to first of all thank Mr. Sasakawa for this very important initiative and of course his concern for the African continent. I'd like to seize this opportunity to let you know that we are 38 ambassadors here in Japan, and Japan is doing a lot for Africa within the framework of Tokyo International Conference on African Development (TICAD).

I think this kind of initiative should have a link with African diplomatic corps here. The TICAD summit will to be held in August 2019 here in Yokohama, Japan. I recommend that you address a very sensitive matter that I am about to discuss. My question is related to the concept of national secrets that Tanzania has given as general information.

When something happens in all over the world, journalists focus on it. But this concerns assassination: People are dying. The BBC should continue to condemn it. I'd like to know what you think about the attitude adopted by the BBC. Are they following up on this issue, or they have forgotten about it?

■ Honorable Ambassador from Djibouti Mr. Ahmed Araita Ali, asking a question at the conference

I would like also to congratulate Mariamu. She said she has forgiven the attackers, but it would be also interesting to know what happened to them. We don't know what the government did after that. I hope the attackers have been arrested.
I would like also to thank Bonface from Malawi for his presentation. Thank you very much.

Moderator **Thank you very much, Ambassador. Any other questions? Okay. Thank you. The first question was from a lady sociological researcher from Kyoto University, asking whether there were other groups before Association of Persons with Albinism of Malawi came into place. Bonface Massah, that is your question. Patricia, you also asked the question whether the practice of witchcraft surrounding albinism is new or old. Then Ambassador, you asked several questions relating to attitude, in terms of national secrets, Vicky I think you should answer that one, and also whether the BBC has changed. Let us hear your experience. Let's start with Bonface. You have the floor.**

Mr. Bonface Massah Thank you. I think, unfortunately, before the organization was set up, there was no momentum for albinism. The organization was set up without office in 1996. It was completely a voluntary structure, so it has been really a struggle to reach where we are today.

The association became more visible and more organized during the last ten years, and it was in this period when the attacks started. In some ways the attacks helped us as leaders in the association to become structured to command and challenge the attitudes around killings of persons with albinism.

Concerning witchcraft, speaking from my personal experience in Malawi, I think there have always been cases in Malawi. When I chat with parents and those with the age of 60, 70 years old and older, they all tell the same story that we used to kill people with albinism.

Malawi used to have the tradition of birth attendants. When they were born in a traditional setting they were killed naturally. And most of them come and confess that it was normal, like it was traditional and was not done for rituals as the case now.

They were not feeling offended, it was really done in secret with only the elders knowing. Few people or relatives would know that there was a white "thing" that was born and that thing was killed. For them, the baby was not completely valued as a human being, but as a strange thing that was born as abnormal, so they were able to kill it naturally.

Secrets: Not Limited to Tanzania

I just want to quickly comment on what Vicky mentioned, about this secrecy for the case of Malawi. I know Vicky will comment about secrets in Tanzania. We still see that growth I think around most African governments, really trying to close this space.

If you see the part in Malawi when we started in 2013, 2014, there was that strong momentum, and now they are really trying to close up the system. They are really even trying to make sure that, yes, we use the media, but the moment you start using the media more is when they also try to close you down more.

That is why one of the recommendations was to address this shrinking civil society space amongst us as PWA. The fortunate part is that we are fighting for our own rights. And we are very few PWA who are joining that movement. So the moment they close us down I think that is the end of the fight. So that is the most difficult part we are facing now. Thank you.

Moderator **Thank you. Vicky?**

Ms. Vicky Ntetema Yes, national secrets. When a secret exists, in the African context, you have to keep everything within the family, within the four walls. So, for them, it was a shameful thing that the report about the killings of persons with albinism reached the outside world.

They wanted me to give them my investigative report. Then it would die there. It wouldn't go anywhere. The fact that the international community responded, demanding answers from the government, for them, was a mistake that they thought I had made. If it hadn't gone out, they would have kept it in the family. That is what I understand as the national secret in this case.

The BBC, what happened, and why? You know everywhere you get media fatigue according to the media houses. One issue every time you talk about that issue, and if it has got no maybe commercial benefit for the media house, it is tiring for the media. They can't be reporting about albinism, albinism all the time.

And I think what the BBC did was to report it, the report was out, and let the people take action. But they cannot go back to the same thing. So maybe the domestic media should take up. But the domestic media also is that, shrinking space even within the media, fraternity. No government wants their bad reputation to be known outside of their country. And the media is the only conveyor belt that can do that very well.

Witchdoctor as Counsellor

Witchcraft. As Bonface has explained, is not a new thing. Those murdered when they were babies because they looked different from the parents. The science of albinism was not there at that time.

Because they were born with different colors: the skin, the hair, the eyes, and did not resemble their parents, they were murdered. But who were consulted? It was the same witchdoctors. They were consulted. If there is something happening that is not understood by the community, and is not normal that nobody can explain, witchdoctors are consulted. And so children with albinism are murdered with the help of traditional midwives and the fathers of the children. And the mothers will be told they had a stillborn, that baby died when you were giving birth, and you are not supposed to mourn. That is the African way of doing things.

And so, later on, when the Europeans came as missionaries, those witchdoctors were shocked, and they thought, "These are the babies whom we killed. Now they have come as adults." The notion of ghosts started, coming from there – that the persons with albinism are ghosts. "We killed them as babies. How can they come now as adults?" Because they didn't understand albinism is a genetic condition, and that albinism is a worldwide phenomenon. Every nationality has persons with albinism. They did not understand that.

The witchdoctors were again consulted, and they said, "Okay, what are we going to do now, because you said we should kill them?"

The Hanging Tree

By the way, we had a woman who worked for UN Habitat, who said that when she was ten years old and living in Northern Tanzania, there was a hanging tree in the village. They were hanging persons with albinism when they had floods, hurricanes, draughts, and locust destroying crops. Every natural disaster was blamed on persons with albinism. So they were hanging them there, and nobody was supposed to go and take the body after they die to bury them. They were just left there. And the bones dropped to the ground. It happened many, many years ago when she was ten. Now she is seventy-plus.

Misbeliefs Developed in Stages

Now, going back to the witchdoctors, they then said, "Okay if that is the case, we have to bury them alive, with the chiefs." Because chiefs don't die. And that is when the notion started that persons of albinism don't die but rather disappear . So it is in phases, in stages. It depends on what is happening in the community.

Then capitalism multi-party system and other new things were introduced in Africa. Witchdoctors were again consulted. Because all leaders, all traditional leaders, and political leaders consult witchdoctors.

So, they were consulted: How can we win elections, now that there is multi-party system? How can we become successful, now that there is capitalism? In Tanzania for example, we don't have any more socialism. And witchdoctors were consulted. And the thing was, "You have to have organs of persons with albinism in this magic potion."

I think there was an attempt of removing persons with albinism from the earth, from long time ago. So, I think witchcraft started long time ago, working against persons with albinism.

Moderator **Thank you very much. Time is running out. So now, let's move on now to Mozambique.**

Demystification through Education is Crucial

PROFILE Mr. Djaffar Moussa-Elkadhum is an economist and a demographer with more than 25 years of professional experience in development mainly at the United Nations Educational, Scientific and Cultural Organization (UNESCO). He is a member of the Task Force of the Regional Action Plan on Albinism in Africa, the first-ever regional mechanism to proactively address eradicating discrimination and violence against persons with albinism in Sub Saharan Africa.
He is also a member of several scientific and professional associations, in particular the International Union for the Scientific Studies of Population (IUSSP) and the Union for African Population Studies (UAPS).

*The title on the right is at the time of the Tokyo Albinism Conference. Mr. Djaffar Moussa-Elkadhum is currently serving as Country Representative and Head of Office at UNESCO Namibia.

Country Representative and Head of Office
UNESCO Mozambique (As of Nov, 2018)
Djaffar Moussa-Elkadhum

Ignorance Combined with Poverty

My presentation will have a general focus on albinism, and some specifics about what we are doing in Mozambique. The general focus is to indicate the importance of education in changing the mindset of people and in demystifying all what you heard about since this morning. Most presentations concluded on the fact that one of the major root causes that trigger violations of the human rights for people with albinism is ignorance combined with poverty. Because albinism is still misunderstood socially and medically.

In other parts of the world, especially in dark-skinned dominant communities, not only in Africa, you see a higher prevalence of discrimination against people with albinism. I am not saying that in the white-dominant skin communities you do not have discrimination, we still have discrimination in various forms. But in black-skinned dominant communities, persons with albinism are more visible and can be easily targeted and/or discriminated against. This is the case in Sub-Saharan Africa, where you have all these issues related to killings linked to harmful practices.

We saw during the presentations this morning that when it comes to Africa, the issue is serious as it relates to infringement of human rights to such magnitude as violence, killings of vulnerable persons with albinism. These are very complex issues combining socio-economical, cultural and anthropological factors that need to be definitively addressed. The issues concerning the myths and harmful practices are clearly linked to ignorance, and also to poverty.

■ UNESCO Mozambique works to realize well-being of the persons with albinism.
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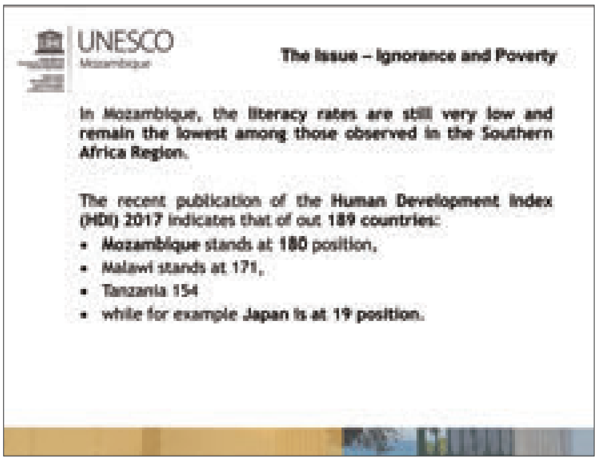

UNESCO
Mozambique

The Issue – Ignorance and Poverty

In Mozambique, the literacy rates are still very low and remain the lowest among those observed in the Southern Africa Region.

The recent publication of the **Human Development Index (HDI) 2017** indicates that of out **189 countries:**
- **Mozambique** stands at **180** position,
- Malawi stands at 171,
- Tanzania 154
- while for example **Japan** is at **19** position.

■ Human Development Index tells us important background.
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Way Forward

I do not want to repeat the market value of a body or an arm cut from a person with albinism, because unfortunately in places like Africa with a high prevalence of poverty and ignorance such information could encourage traffickers. It is for this reason that we should teach the journalists not to mention such market values when reporting on these atrocities, as we can create the opposite of the intended effect.

We have to work with communities, with individuals, and with parents to demystify the whole issue through education. Indeed, this might not be enough, because, as I had mentioned the whole issue is also linked to poverty.

Let me now take a case of Mozambique. When we talk about ignorance, the literacy rate in Mozambique is still very low. According to the data available at the time of this presentation, we have an overall literacy rate of around 56% of the population. It means you have 43% or 44% of the population who are illiterate, meaning not having enough knowledge to understand the issues or to participate in the development and understanding very complex matters such as the issues concerning albinism. In other countries, Japan for example, has literacy rates reaching almost 100%. It is easier to educate people on subjects related to albinism.

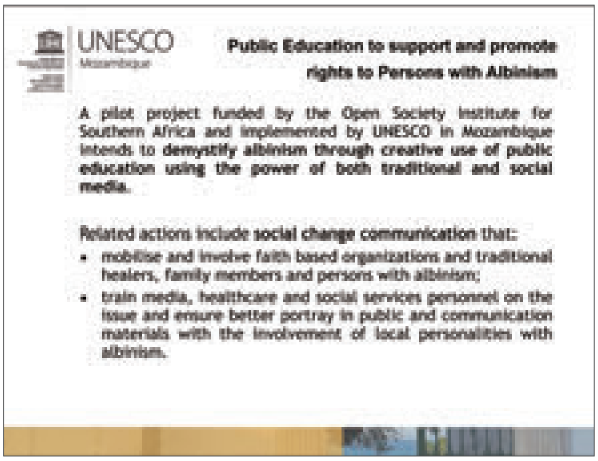
In Malawi, the literacy rate was estimated in 2017 to be around 62% or 63%, meaning that you can see the gap here. When we come to the issue of poverty, then you see again such gaps.

All these facts indicates, clearly, the approach, the way we have to move forward is to use education as a transformative factor to demystify albinism, and also to empower people.

In order to change people's mindset, it is important to undertake more research on knowledge, attitude, and practices in relation to albinism so that appropriate communication and information materials can be developed and used for public awareness campaigns in collaboration with communities, families, and activists.

This is actually the approach that has been identified as priority number one to support the change of mindset. It is also to recognize the fundamental transformative and catalytic power education has in other aspects of socio-economic development, as highlighted in Agenda 2030.

I do not want to elaborate more on this, because I believe that in this audience everybody sees the catalytic role of education and how important it is.



UNESCO
Mozambique

Public Education to support and promote rights to Persons with Albinism

A pilot project funded by the Open Society Institute for Southern Africa and implemented by UNESCO in Mozambique intends to **demystify albinism through creative use of public education using the power of both traditional and social media.**

Related actions include **social change communication** that:

- mobilise and involve faith based organizations and traditional healers, family members and persons with albinism;
- train media, healthcare and social services personnel on the issue and ensure better portray in public and communication materials with the involvement of local personalities with albinism.

■ Using public education and the power of traditional and social media is crucial.
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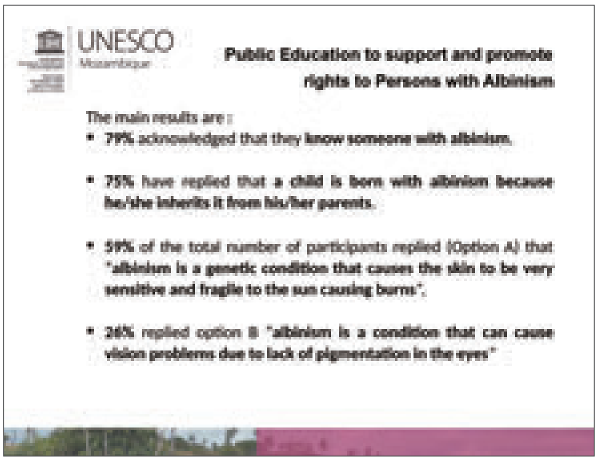
Pilot Project near National Borders

Now, I want to take an example of a pilot project that we are now implementing in Mozambique, which is financed by the Open Society Institute for Southern Africa (OSISA).

In this pilot project, we decided to focus our interventions in working with the communities in the northern part of Mozambique bordering Malawi so that we can not only create synergies with similar interventions in Malawi, but also learn from Tanzania's experiences. The idea here is working with communities to demystify issues surrounding albinism through public education and also mobilizing healthcare and social services personnel including the media through training, using the local dominant spoken language.
The approach is supported with evidence coming from various reports and from ad-hoc surveys.

Only 54% say PWA Should be Treated Equally

In the case of the small-scale survey that we conducted during the International Albinism Awareness Day to 25,000, young persons from the age of ten to 24 years old in Mozambique, we can see some very interesting results. 79% of the respondents said they know somebody with albinism. What is interesting is that although at least three-quarters said they understand what albinism



Public Education to support and promote rights to Persons with Albinism

The main results are :

- 79% acknowledged that they know someone with albinism.
- 75% have replied that a child is born with albinism because he/she inherits it from his/her parents.
- 59% of the total number of participants replied (Option A) that "albinism is a genetic condition that causes the skin to be very sensitive and fragile to the sun causing burns".
- 26% replied option B "albinism is a condition that can cause vision problems due to lack of pigmentation in the eyes"

■ 79% of the respondents say they know somebody with albinism.
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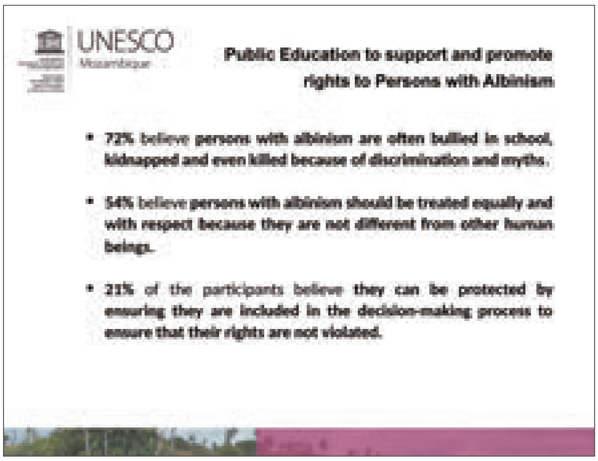

Public Education to support and promote rights to Persons with Albinism

- 72% believe persons with albinism are often bullied in school, kidnapped and even killed because of discrimination and myths.
- 54% believe persons with albinism should be treated equally and with respect because they are not different from other human beings.
- 21% of the participants believe they can be protected by ensuring they are included in the decision-making process to ensure that their rights are not violated.

■ Only 54% of those who has knowledge about albinism answered PWA should be treated equally.
© D. Moussa-Elkadhum

is, only 54% of them said people with albinism should be treated equally, because people with albinism are not any different from them. This means that we really need to improve education on this subject.

In conclusion, investment is highly needed in education in general. Sustained public education and awareness raising campaigns in Sub-Saharan Africa are necessary to support plans to address attacks and related violations against persons with albinism. Public education, information and communication to understand albinism should empower individuals and communities toward behavioral change. We should and must demystify albinism and support rights-based arguments aimed at protecting and promoting the rights of persons with albinism.

In order to ensure sustainability, such public education programs on albinism should be reinforced by the inclusion in curricula of formal national education of initiatives such as the Global Citizenship Education promoted by UNESCO. This is to empower learners of all ages to become active promoters of more peaceful, tolerant, inclusive, secure and sustainable societies.

This initiative in Mozambique is aligned and supports the implementation of the regional plan of action presented earlier. We hope that larger interventions will help address the issue globally.

Conclusion

A larger regional intervention that would consolidate and expand such promising experience is crucial and immediately needed. This requires the mobilization of additional resources and partners.

■ A larger public awareness is urgently needed.
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Vast Challenges in Mozambique

PROFILE Having initiated various projects including support for children at risk and vulnerable persons, Mr. Wiliamo Tomas founded the NGO, Centro Cultural Mozion Mozambique-Israel in 2015. He also founded the first organization that works to defend persons with albinism in Mozambique, ALBIMOZ, and now serves as its president.

Mr. Tomas is a member of a political party, the Mozambique Democratic Movement, and has been a member of the Municipal Council of Maputo since 2014.

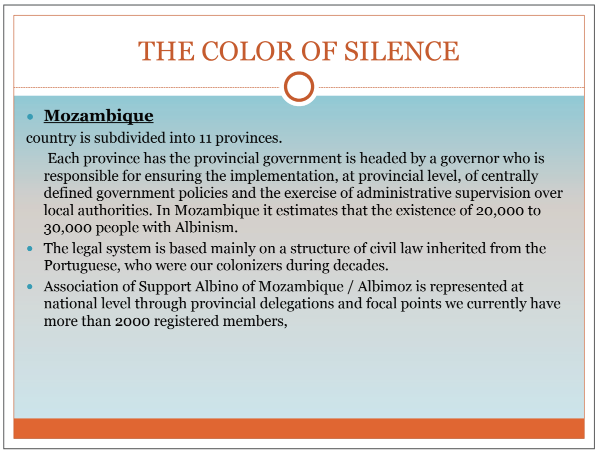
Founder and President, Albinos Support Association of Mozambique(ALBIMOZ)

Wiliamo Tomas

Biggest Challenge: Finding Those Ordering the Attacks

Mr. Wiliamo Tomas There are eleven provinces in Mozambique and we have some 20,000 to 30,000 persons with albinism (PWA). We currently work with 2,000 PWA in the area of health, social welfare and laws for people with albinism.

We are lobbying the government so that we can receive support from them, and at the same time we are looking for partners. Some governments in Africa provide support to the victims of an attack, but that is not the case in Mozambique. It should be noted that since the creation of Albimoz in 2013 we have never had financial support.



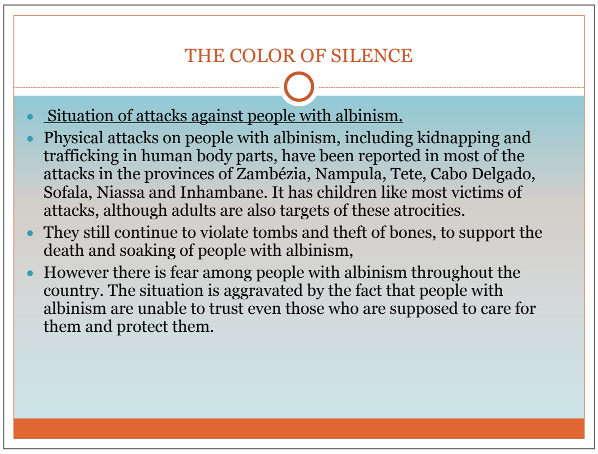
THE COLOR OF SILENCE

- **Mozambique**

country is subdivided into 11 provinces.

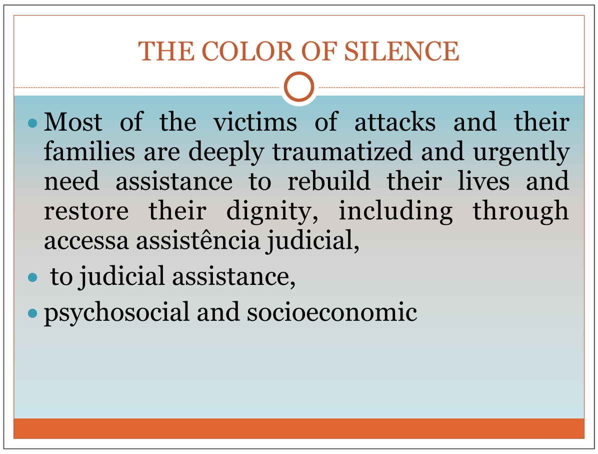
Each province has the provincial government is headed by a governor who is responsible for ensuring the implementation, at provincial level, of centrally defined government policies and the exercise of administrative supervision over local authorities. In Mozambique it estimates that the existence of 20,000 to 30,000 people with Albinism.

- The legal system is based mainly on a structure of civil law inherited from the Portuguese, who were our colonizers during decades.
- Association of Support Albino of Mozambique / Albimoz is represented at national level through provincial delegations and focal points we currently have more than 2000 registered members,



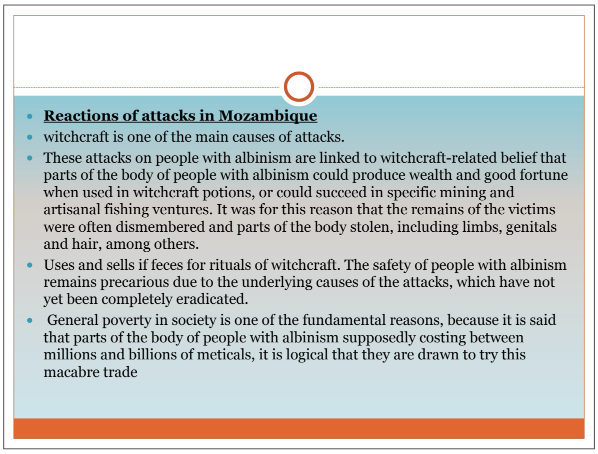
THE COLOR OF SILENCE

- Situation of attacks against people with albinism.
- Physical attacks on people with albinism, including kidnapping and trafficking in human body parts, have been reported in most of the attacks in the provinces of Zambézia, Nampula, Tete, Cabo Delgado, Sofala, Niassa and Inhambane. It has children like most victims of attacks, although adults are also targets of these atrocities.
- They still continue to violate tombs and theft of bones, to support the death and soaking of people with albinism,
- However there is fear among people with albinism throughout the country. The situation is aggravated by the fact that people with albinism are unable to trust even those who are supposed to care for them and protect them.

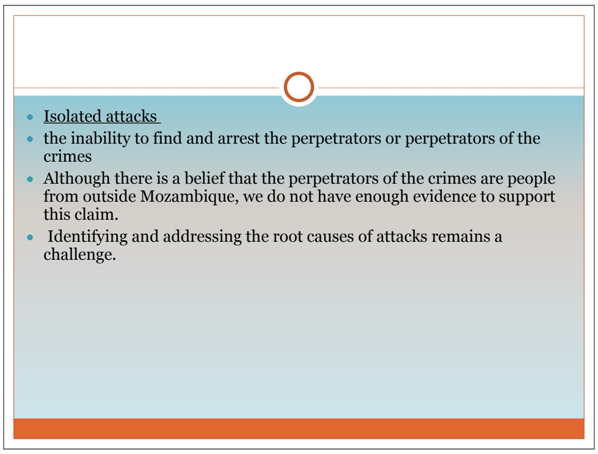


THE COLOR OF SILENCE

- Most of the victims of attacks and their families are deeply traumatized and urgently need assistance to rebuild their lives and restore their dignity, including through accessa assistência judicial,
- to judicial assistance,
- psychosocial and socioeconomic



- **Reactions of attacks in Mozambique**
- witchcraft is one of the main causes of attacks.
- These attacks on people with albinism are linked to witchcraft-related belief that parts of the body of people with albinism could produce wealth and good fortune when used in witchcraft potions, or could succeed in specific mining and artisanal fishing ventures. It was for this reason that the remains of the victims were often dismembered and parts of the body stolen, including limbs, genitals and hair, among others.
- Uses and sells if feces for rituals of witchcraft. The safety of people with albinism remains precarious due to the underlying causes of the attacks, which have not yet been completely eradicated.
- General poverty in society is one of the fundamental reasons, because it is said that parts of the body of people with albinism supposedly costing between millions and billions of meticals, it is logical that they are drawn to try this macabre trade



- Isolated attacks
- the inability to find and arrest the perpetrators or perpetrators of the crimes
- Although there is a belief that the perpetrators of the crimes are people from outside Mozambique, we do not have enough evidence to support this claim.
- Identifying and addressing the root causes of attacks remains a challenge.

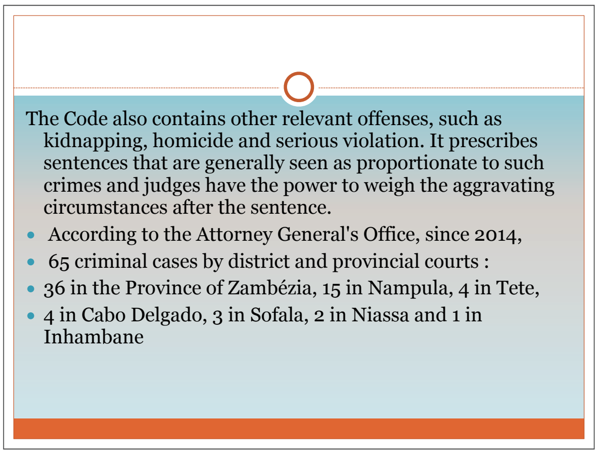
Those people, often women and children, are attacked for witchcraft purposes. Some people wish for success in business such as in fishery and mining. At the same time, we have poverty. Poverty, when coupled with witchcraft, can result in attacking PWA. We have women who are raped, because in out-of-town districts, it is thought that if a man has sex with a woman with albinism, he can be cured of deadly diseases such as HIV / AIDS. This often leads to the transmission of sexually transmitted diseases to the victims.

The biggest challenge is to find out the ones ordering the attacks. Not the ones that actually do it, but those ordering the attack on PWA.

A lot of attacks are reported in the northern part of the country. Discrimination isolates PWA, depriving them of the opportunity to live proactively, to go to school, or to get a job. Vocational training is a must for those people. It would have to be an obligation for these people as most are limited and have no access to job opportunities in government as well as in the private sector.

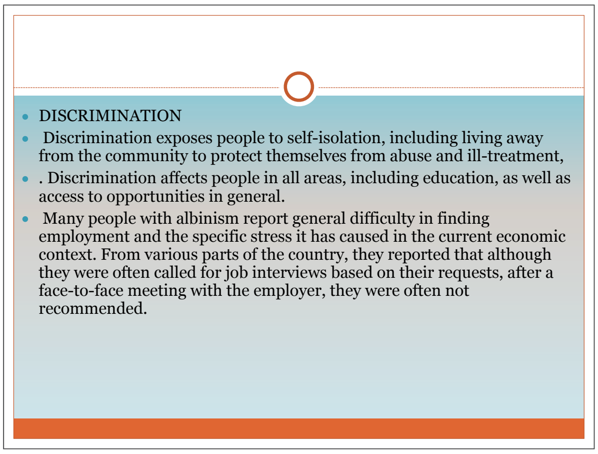
Strong Need for Awareness Raising

Awareness raising is necessary on every level. The government is no exception. We need to train teachers, traditional doctors, community leaders and public opinion makers on the subject of albinism, because not everyone understands albinism. Some people consider PWA as a source of money and success in their work. For example, it is thought that with a body part of a PWA, fishermen may catch more fish and producers may produce more than they normally do. These groups work directly with communities so we think they can cause behavior change if they are trained in albinism.

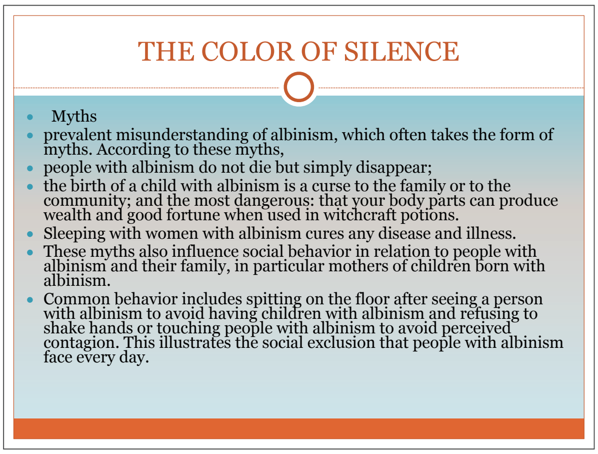


The Code also contains other relevant offenses, such as kidnapping, homicide and serious violation. It prescribes sentences that are generally seen as proportionate to such crimes and judges have the power to weigh the aggravating circumstances after the sentence.

- According to the Attorney General's Office, since 2014,
- 65 criminal cases by district and provincial courts :
- 36 in the Province of Zambézia, 15 in Nampula, 4 in Tete,
- 4 in Cabo Delgado, 3 in Sofala, 2 in Niassa and 1 in Inhambane

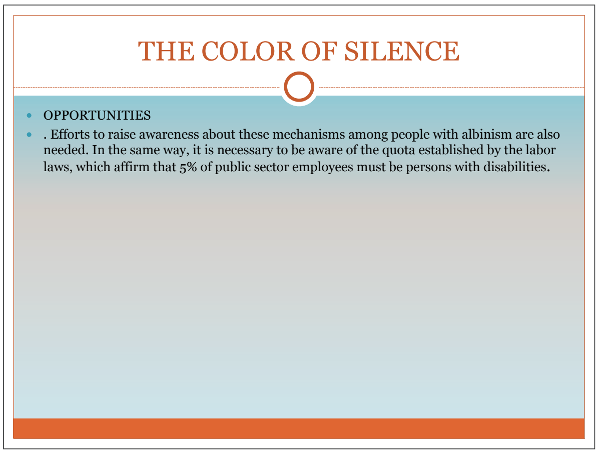


- DISCRIMINATION
- Discrimination exposes people to self-isolation, including living away from the community to protect themselves from abuse and ill-treatment,
- . Discrimination affects people in all areas, including education, as well as access to opportunities in general.
- Many people with albinism report general difficulty in finding employment and the specific stress it has caused in the current economic context. From various parts of the country, they reported that although they were often called for job interviews based on their requests, after a face-to-face meeting with the employer, they were often not recommended.



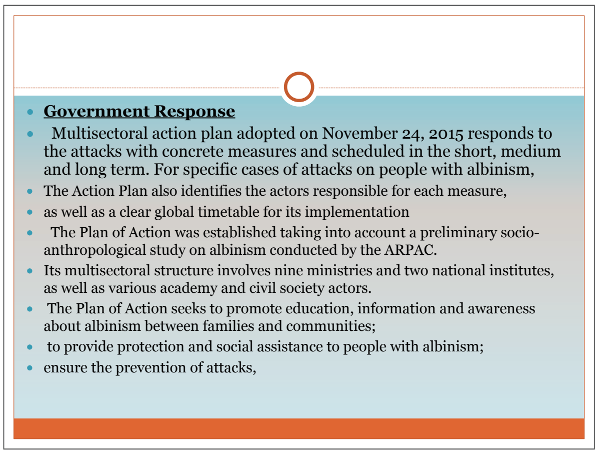
THE COLOR OF SILENCE

- Myths
- prevalent misunderstanding of albinism, which often takes the form of myths. According to these myths,
- people with albinism do not die but simply disappear;
- the birth of a child with albinism is a curse to the family or to the community; and the most dangerous: that your body parts can produce wealth and good fortune when used in witchcraft potions.
- Sleeping with women with albinism cures any disease and illness.
- These myths also influence social behavior in relation to people with albinism and their family, in particular mothers of children born with albinism.
- Common behavior includes spitting on the floor after seeing a person with albinism to avoid having children with albinism and refusing to shake hands or touching people with albinism to avoid perceived contagion. This illustrates the social exclusion that people with albinism face every day.

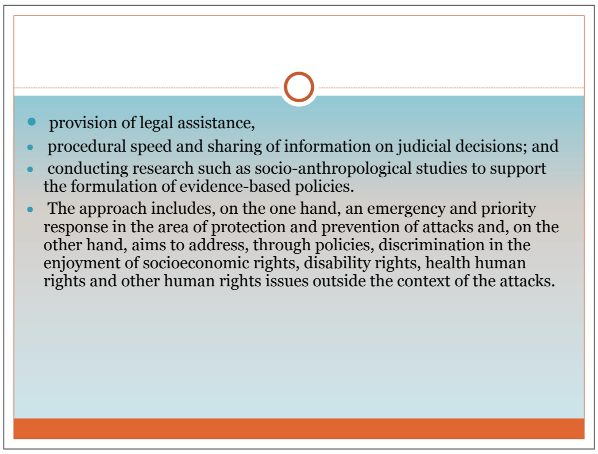


THE COLOR OF SILENCE

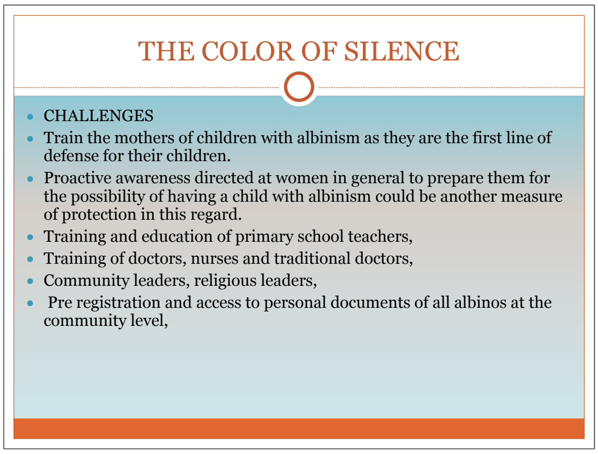
- OPPORTUNITIES
- . Efforts to raise awareness about these mechanisms among people with albinism are also needed. In the same way, it is necessary to be aware of the quota established by the labor laws, which affirm that 5% of public sector employees must be persons with disabilities.



- **Government Response**
- Multisectoral action plan adopted on November 24, 2015 responds to the attacks with concrete measures and scheduled in the short, medium and long term. For specific cases of attacks on people with albinism,
- The Action Plan also identifies the actors responsible for each measure,
- as well as a clear global timetable for its implementation
- The Plan of Action was established taking into account a preliminary socio-anthropological study on albinism conducted by the ARPAC.
- Its multisectoral structure involves nine ministries and two national institutes, as well as various academy and civil society actors.
- The Plan of Action seeks to promote education, information and awareness about albinism between families and communities;
- to provide protection and social assistance to people with albinism;
- ensure the prevention of attacks,

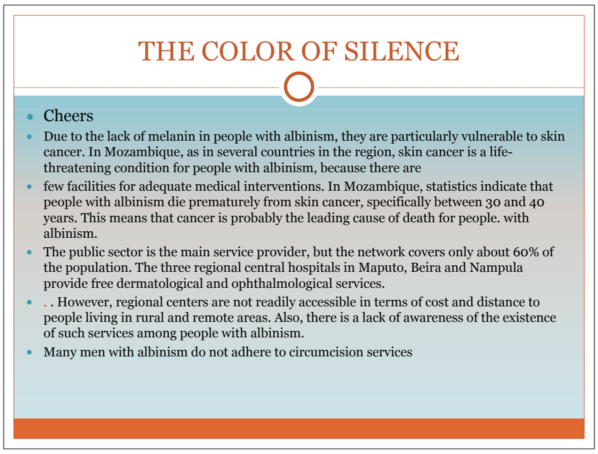


- provision of legal assistance,
- procedural speed and sharing of information on judicial decisions; and
- conducting research such as socio-anthropological studies to support the formulation of evidence-based policies.
- The approach includes, on the one hand, an emergency and priority response in the area of protection and prevention of attacks and, on the other hand, aims to address, through policies, discrimination in the enjoyment of socioeconomic rights, disability rights, health human rights and other human rights issues outside the context of the attacks.



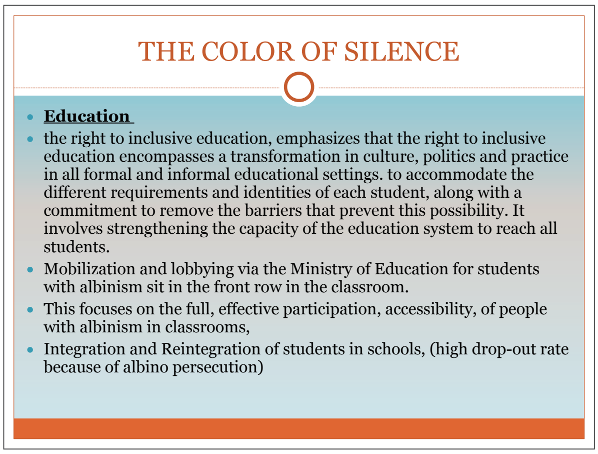
THE COLOR OF SILENCE

- CHALLENGES
- Train the mothers of children with albinism as they are the first line of defense for their children.
- Proactive awareness directed at women in general to prepare them for the possibility of having a child with albinism could be another measure of protection in this regard.
- Training and education of primary school teachers,
- Training of doctors, nurses and traditional doctors,
- Community leaders, religious leaders,
- Pre registration and access to personal documents of all albinos at the community level,



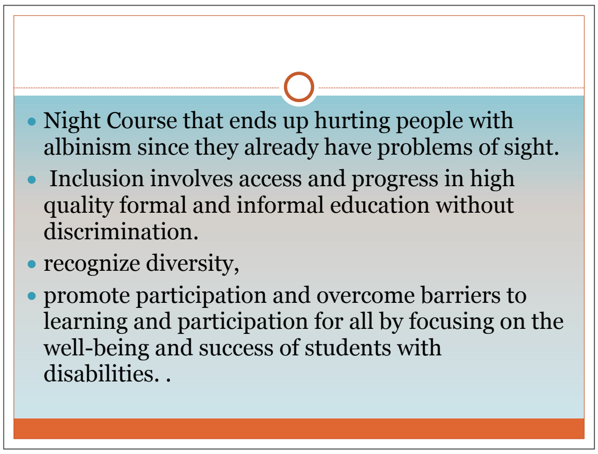
THE COLOR OF SILENCE

- Cheers
- Due to the lack of melanin in people with albinism, they are particularly vulnerable to skin cancer. In Mozambique, as in several countries in the region, skin cancer is a life-threatening condition for people with albinism, because there are
- few facilities for adequate medical interventions. In Mozambique, statistics indicate that people with albinism die prematurely from skin cancer, specifically between 30 and 40 years. This means that cancer is probably the leading cause of death for people. with albinism.
- The public sector is the main service provider, but the network covers only about 60% of the population. The three regional central hospitals in Maputo, Beira and Nampula provide free dermatological and ophthalmological services.
- . . However, regional centers are not readily accessible in terms of cost and distance to people living in rural and remote areas. Also, there is a lack of awareness of the existence of such services among people with albinism.
- Many men with albinism do not adhere to circumcision services

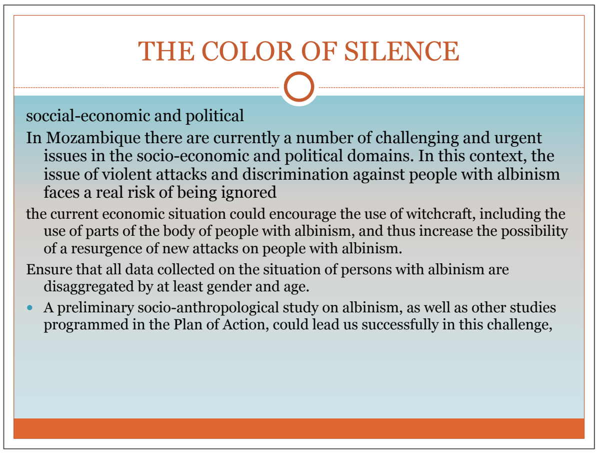


THE COLOR OF SILENCE

- **Education**
- the right to inclusive education, emphasizes that the right to inclusive education encompasses a transformation in culture, politics and practice in all formal and informal educational settings. to accommodate the different requirements and identities of each student, along with a commitment to remove the barriers that prevent this possibility. It involves strengthening the capacity of the education system to reach all students.
- Mobilization and lobbying via the Ministry of Education for students with albinism sit in the front row in the classroom.
- This focuses on the full, effective participation, accessibility, of people with albinism in classrooms,
- Integration and Reintegration of students in schools, (high drop-out rate because of albino persecution)



- Night Course that ends up hurting people with albinism since they already have problems of sight.
- Inclusion involves access and progress in high quality formal and informal education without discrimination.
- recognize diversity,
- promote participation and overcome barriers to learning and participation for all by focusing on the well-being and success of students with disabilities. .



THE COLOR OF SILENCE

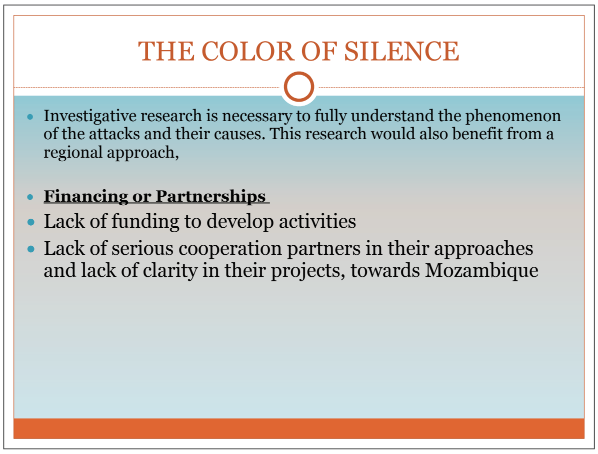
soccial-economic and political

In Mozambique there are currently a number of challenging and urgent issues in the socio-economic and political domains. In this context, the issue of violent attacks and discrimination against people with albinism faces a real risk of being ignored

the current economic situation could encourage the use of witchcraft, including the use of parts of the body of people with albinism, and thus increase the possibility of a resurgence of new attacks on people with albinism.

Ensure that all data collected on the situation of persons with albinism are disaggregated by at least gender and age.

- A preliminary socio-anthropological study on albinism, as well as other studies programmed in the Plan of Action, could lead us successfully in this challenge,



THE COLOR OF SILENCE

- Investigative research is necessary to fully understand the phenomenon of the attacks and their causes. This research would also benefit from a regional approach,

- **Financing or Partnerships**
- Lack of funding to develop activities
- Lack of serious cooperation partners in their approaches and lack of clarity in their projects, towards Mozambique

In Mozambique, students are assigned their seats in alphabetic order. Teachers do not always seat students with albinism in the front row. We need to raise the awareness of those teachers so that they know what their students with albinism need.

There is also the issue of sunscreen. PWA need free medical care: dermatologists, ophthalmologists and opticians. They need free sunscreen and eyewear as well. We are lobbying the government to make this possible.

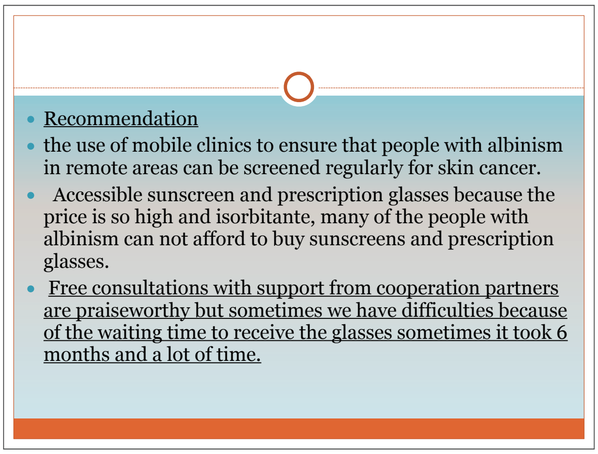
The Issue of Circumcision

There is this issue of circumcision. All males in Mozambique are circumcised. It is our custom. But PWA are not, since they are afraid of getting it done at hospital. Remember that what motivates murders are the small body parts of PWA that the evildoers want. If a man is going to be circumcised in a hospital unit where doctors are not aware of albinism, this creates a business opportunity, because after the skin is removed from the man's penis, it is taken out and used for shady dealings, and thereby promotes trafficking.

The government issued an action plan on November 24, 2015. It is ambitious, but has not yet been implemented. All the actions need to be integrated.

Protecting Babies with Albinism

Another challenge concerns mothers. After they are born, children with albinism need to be closely guarded so that they are not in danger of disappearing while they are still in hospital, or kidnapped, by family members and by potential PWA killers.



- Recommendation
- the use of mobile clinics to ensure that people with albinism in remote areas can be screened regularly for skin cancer.
- Accessible sunscreen and prescription glasses because the price is so high and isorbitante, many of the people with albinism can not afford to buy sunscreens and prescription glasses.
- Free consultations with support from cooperation partners are praiseworthy but sometimes we have difficulties because of the waiting time to receive the glasses sometimes it took 6 months and a lot of time.

Three hospitals are ready to see PWA. They are located in Maputo, Beira and Nampula. All of them are located in the center of the city. But there are no dermatologists, ophthalmologists or opticians in rural areas. It is often difficult to go to hospital or a health centers, as they do not cater for PWA. Also, it is difficult for PWA to go to school at night.

Moderator **Thank you, thank you very much Mr. Tomas.**

How Albinism Changed My World

PROFILE Mr. Peter Ash founded an international faith-based NGO with offices in Vancouver, Canada and Dar es Salaam, Tanzania, and now serves as its CEO. He holds an undergraduate degree in theology and a graduate degree in psychology. His background includes ten years of work in the church ministry followed by twenty years in business leadership. His current passion, via advocacy and education, is to work towards the day when people with albinism will take their rightful place throughout every level of society, and that the days of discrimination against persons with albinism will be a faint memory.

Founder and CEO,
Under The Same Sun (UTSS)
Peter Ash

If someone had told me ten years ago when I sat at my home in Vancouver, reading an article about my brothers and sisters with albinism who were being persecuted in Tanzania, that one day I would be speaking about it at a conference in Tokyo, I would have told them they were crazy.

You need to understand that none of this really existed ten years ago. This might all seem kind of normal to you, that we are talking about the human rights of people with albinism, that we are analyzing it, writing reports about it, having academic conferences about it, having discussions at the UN about it, but ten years ago there was virtually nothing being said about this issue by anybody, anywhere at all. This is all very, very new.

I have albinism myself, in case you didn't realize. Some of my African brothers and sisters think I am just a white guy, or a *mzungu*, as they would call me in Tanzania. But I am actually a person with albinism. So, my white hair is not to be misunderstood as me being Swedish. I am actually a Canadian, my ancestors are English and Irish, who are very dark-haired people. My father had black hair, my mom had brown hair, and they were very surprised when two of their children were born looking like me.

How It All Started

So, what is this Canadian guy, who had never been to Africa in his life until ten years ago, doing talking about this here today? Well, it is kind of an interesting story. For you to understand why I am here and what I have to say, it would probably be useful for me to tell that story, very, very briefly.

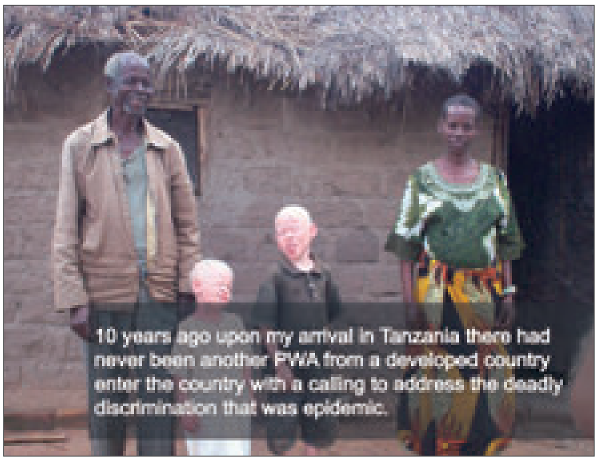
You see a picture here that tells a story. Ten years ago, upon my arrival in Tanzania, no PWA from a developed country had ever entered the country with a calling to address the deadly, yet epidemic, discrimination against people with albinism. How did that happen?

I was on my computer one day in my home office, doing some research on the internet. I had been successful in business for a long time and felt that God was asking me to consider serving others in a deeper way. I was examining the possibility of getting involved with the community of persons with disabilities, or more specifically people with albinism, in developing countries. I was exploring countries that do not have the opportunities that I had, being born and raised in Canada.

As a PWA I experienced persecution, I was called cruel names, I was bullied, and beaten up. Things weren't easy for me as a child with albinism in Canada, but I wanted to see what it would be like for people in other parts of the world, suspecting it would probably be more difficult.

I was on my computer and googled words like albino, and suddenly, this article came up. The BBC World Service had just published an article on their homepage about people with albinism being murdered. Vicky Ntetema, my colleague and friend at the end of the table who spoke to you earlier this morning, was at that time a BBC journalist who had gone undercover. She reported that her life was in danger, because she had exposed how people with albinism were being killed. I read the article and I watched the video clip she had posted of a witchdoctor, who was willing to provide her with the body parts of persons with albinism in exchange for large sums of money.

I saw her impersonating a businesswoman discussing the exchange of money for albino body parts. I was, needless to say, intrigued and horrified, and I realized that evening that something had to be done. I went to bed, and I didn't sleep very well. The next morning my wife asked me, "Peter, how come you didn't sleep very well last night?" and I said, "Something very disturbing is going on in Tanzania."


10 years ago upon my arrival in Tanzania there had never been another PWA from a developed country enter the country with a calling to address the deadly discrimination that was epidemic.

■ Family photo. Mariamu standing next to the tall man.

Photo © Under The Same Sun

The Grizzly Crime Scene

Now, during my theological education, I heard many missionaries talk about work in Sub-Saharan Africa but that was not on my list of places to go. I had travelled various countries, but not yet made it to that part of the world, and I didn't see that being the focus of my life's work.

I guess God had other plans. I remember picking up the phone to my executive assistant at that time and saying, "Book me a ticket to Tanzania." I didn't have any idea where it was. I knew it was somewhere in Africa, but I didn't know where, or what the language or the culture was, but I was going to go there. And so I went and travelled up to North-Western Tanzania, in the rural areas outside the city of Mwanza, and met this family in front of you.

No one with albinism from a Western country had ever come to Tanzania and addressed the problem in any significant way. In fact, as I mentioned earlier, most Tanzanians didn't really believe I had albinism. They thought I was just a white guy from North America.

On my first visit to Tanzania in 2008, the very first family I visited had just lost their little five year-old girl with albinism. Her name was Mariamu. It was a grizzly scene that shook me to the core of my being. A scene that I would never forget. In this slide, you see the little girl depicted beside a tall man. She was five years old in this family photo. Shortly after this picture was taken, she was brutally murdered in her own home.

I am now going to show you a graphic image that will disturb you. I'm showing you this image to illustrate the gravity of the crime that was occurring ten years ago, and what faced me when I first went to Tanzania. This is the mutilated body of Mariamu, at five years of age. Her arms had been cut off, her legs cut off, her throat slit, and her body lay on the dirt floor in her home. (**The photo was displayed at the conference venue only*.)

It was clear to me that the initiatives that were underway in the country at that time to address this deadly discrimination were inadequate. When I visited Mariamu's home, I went to her bedroom. And when I saw underneath the bed where she had been murdered, the blood was still fresh on the floor. I kid you not. Her blood was splattered on her bed and on the wall. I interviewed the grandfather and the uncle. They were in shock. They told me how men had broken down the door in the middle of the night and gone after this girl, removing her arms and legs and cutting her throat. They brought cooking pots for the occasion to collect her blood and some of them drank it on the spot. Her arms and legs would have soon fetched thousands of dollars on the black market in illegal organs in Tanzania.

The Core Issue

It became evident to me that something had to be done to address the epidemic, deadly discrimination that was taking place. It occurred to me that it would have been unwise to fund local organizations, as at that time, they were not well established or well organized, and it would not have been an efficient use of my resources. So, I decided to start my own organization, Under The Same Sun. Now here's a Canadian guy who had been in a church ministry as well as the business world for a long time, who had never been to this part of the world before, and who had no experience starting an organization of this nature.

I did what all entrepreneurs do, I figured it out as I went along. As a PWA myself and a trained therapist with a graduate degree in counseling psychology, and as a Christian minister, I understood that we needed to diagnose and treat the core issue of the deadly discrimination and not simply address its symptoms.

When I read about albinism in Africa at that time, the focus was mainly on the treatment of skin cancer, which is a noble and worthy goal. As I.K. mentioned in her comments this morning, skin cancer is by far the largest killer of persons with albinism in Sub-Saharan Africa: I have seen patients with massive tumors on the sides of their head and neck who are in incredible agony because of their untreated skin cancer.

But I realized you could treat skin cancer all day long. You could set up thousands of clinics to treat the disease. You could set up low-vision clinics and dispense glasses and low-vision aids all day long all over the continent, but if you didn't get to the core problem, people would still get skin cancer.

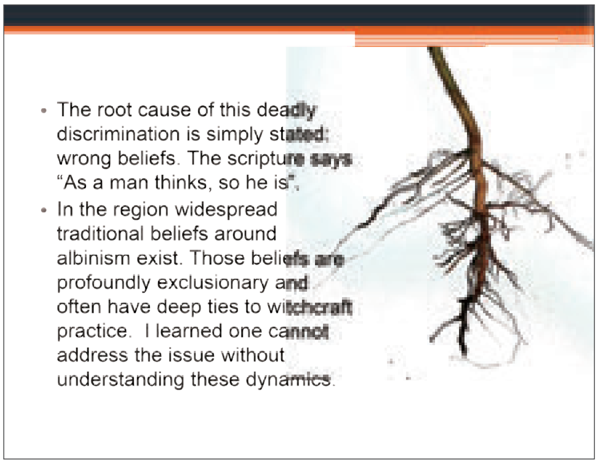
More students wouldn't get educated. More people would never get jobs. More people would continue to be excluded. What was the core problem? What was the main issue? Why were they not being treated for skin cancer? Why were they not getting low-vision devices? Why were they not going to school? Why were they not getting jobs? What was the core, root cause?

The root cause of this deadly discrimination is, simply stated, wrong beliefs. The scripture says, "As a man thinks, so he is." Cognitive behavioral psychology tells us this also. In Tanzania and sub-Saharan Africa, there are widespread traditional beliefs surrounding albinism. Those beliefs are profoundly exclusionary and often have deep ties in the practice of witchcraft, which Vicky talked about at length this morning as did I.K. I learned one cannot address the issue without understanding those dynamics. To try and deal with albinism in this part of the world, and indeed all over the world, you must address wrong thinking.

And wrong thinking about albinism exists in every culture. All the Hollywood films show people like me as being deranged, mentally ill, or evil. They have people like me firing a gun and driving a car. Have you ever seen the movie "The Da Vinci Code"? There was a person with albinism who is an evil villain. He drives a car at 60 miles an hour while shooting a gun. They don't realize that we are actually legally blind, most of us can't even drive a car, let alone aiming a gun straight.

The misinformation around this condition, even in countries that have access to incredibly high levels of medical service, is profound. I went to see a doctor a few years ago at the emergency department of my local hospital who knew nothing about albinism. He didn't even know what the word meant, and Canada has a great medical system.

Wrong beliefs and misinformation are at the core of the problem, and, particularly in Tanzania, they are the real cause. We heard stories about people with albinism going to clinics for treatment where the nurse didn't want to touch them because they believed that albinism is a contagious disease. We heard stories of students with albinism going to school where other students were allowed to bully them, and sometime the teachers actually participated in the bullying. In another situation, a PWA applied for a job and submitted their CV, but



- The root cause of this deadly discrimination is simply stated: wrong beliefs. The scripture says "As a man thinks, so he is".
- In the region widespread traditional beliefs around albinism exist. Those beliefs are profoundly exclusionary and often have deep ties to witchcraft practice. I learned one cannot address the issue without understanding these dynamics.

■ The root cause is what we must deal with. © Under The Same Sun

- **ADVOCACY**: this takes a wide variety of forms. Public education at every level of society starting at the village level with in person teaching. No sector is ignored – schools, universities, hospitals, churches, government leaders, families. We do this in every way possible – radio, TV, in person training. Understanding Albinism seminars which we have developed are the cornerstone and have proved to be highly effective.

■ Public education at every level is needed.

Photo © Jean Francious Mean

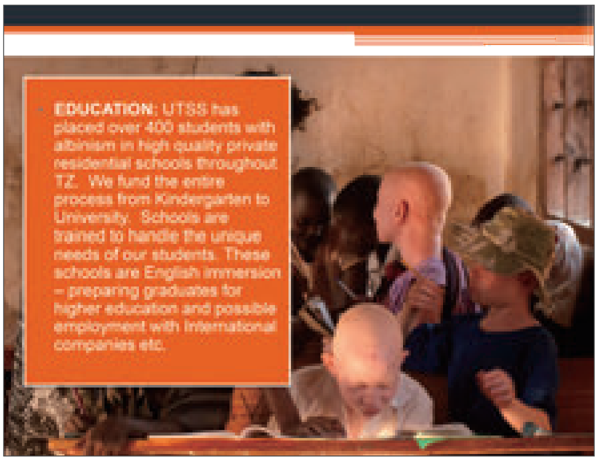
when they arrived for the interview and it became apparent that they had albinism, suddenly the job position was “filled.”

This discrimination was systemic. I would preach in churches of various denominations throughout the country and there would not be a single person in the congregation with albinism, even though one in 1,400 people in the population have it. They would be walking outside on the streets in front of the church but not included in the church activities. I would challenge the church asking, “Why is this the case? This is wrong!”

Advocacy and Education

At UTSS, we have a clear vision of where to focus our primary funding and human resources: Ending discrimination via advocacy and education. Advocacy takes a variety of forms. Public education at every level of society, starting at the village level with in-person teaching. No sector is ignored: Schools, universities, hospitals, churches, government leaders, families. We do this is in every possible way: Radio, TV, newspapers, in-person training. The *Understanding Albinism* seminars that we developed are the cornerstone of our work and have proven to be highly effective.

The next program we have is our education program. UTSS has placed over 400 students with albinism in high quality, inclusive, private residential schools throughout Tanzania. We are funding the entire process from kindergarten to university. The schools are trained to handle the unique needs of our students. Moreover, they use an English immersion model, preparing graduates for integrated encounters in higher education and possible employment in international companies.



- **EDUCATION:** UTSS has placed over 400 students with albinism in high quality private residential schools throughout TZ. We fund the entire process from Kindergarten to University. Schools are trained to handle the unique needs of our students. These schools are English immersion – preparing graduates for higher education and possible employment with International companies etc.

■ Education leads to empowerment of PWA.

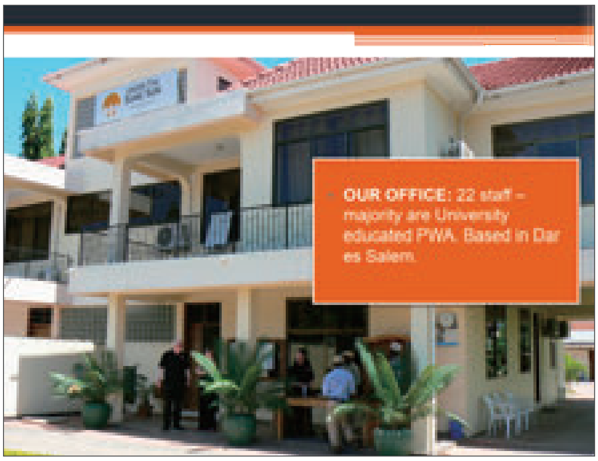
Photo © Jean Francious Mean

One of the students that is in our program now is the brother of Mariamu, the girl shown earlier who was murdered in 2008 at five years of age. The boy in this picture, the tall one standing next to me, is Mariamu’s brother. He is presently in our education programand is one of our brighter students and top performers. The girl at the very far left, is Mariamu’s sister and a member of our education program.

■ The boy with albinism in the middle is a brother of Mariamu who was murdered at five.

Photo © Under The Same Sun

In this next slide you see a picture of our office in Dar es Salaam, Tanzania. We have 22 employees, over half of whom have albinism.

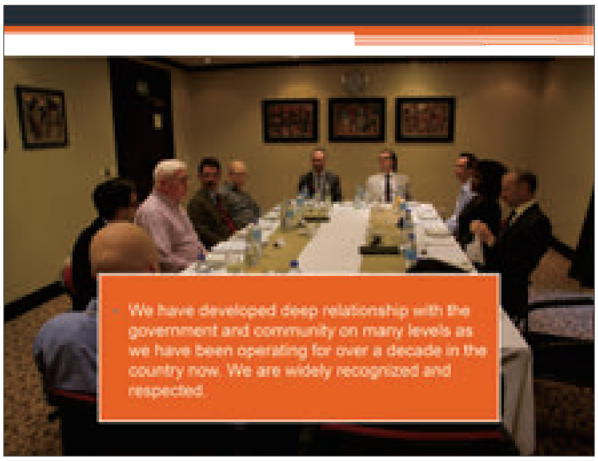


- **OUR OFFICE:** 22 staff – majority are University educated PWA. Based in Dar es Salem.

■ The UTSS Tanzania office also equipped with security, as majority of workers are PWA.

Photo © Under The Same Sun

In the next slide you can see that we had close relations over the last decade with the government, international actors, ambassadors, international organizations including the African Union, United Nations, UNICEF, and others. We are recognized for our contributions to finding solutions, not just talking about the problem.



- We have developed deep relationship with the government and community on many levels as we have been operating for over a decade in the country now. We are widely recognized and respected.

■ Developing deep relationship is critical for successful intervention.

Photo © Under The Same Sun

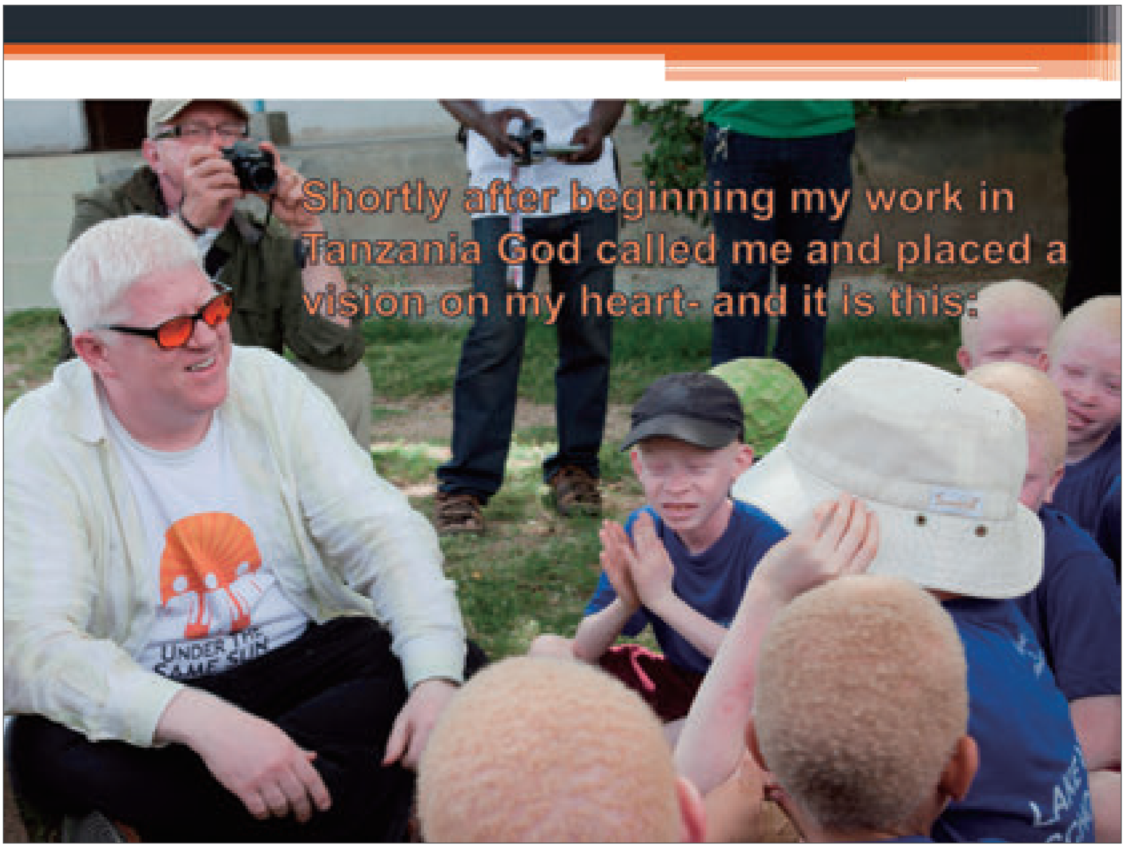
I will conclude with what we have found in the last ten years. There has been a massive decline in the killings of people with albinism. Now we know that some of that is because of underreporting of the killings due to the declining freedom of the press, but we do believe the number of killings in Tanzania has declined. Attacks still occur, but there has been a significant decrease. Sadly, in nations nearby such as Mozambique and Malawi, there have been increases. There is a higher degree of public awareness generally about the issue than there was ten years ago, and many of our graduates are academically outperforming their peers without albinism in private schools. Teachers in fact often comment that, "These kids with albinism are very bright." Dozens of our graduates are now gainfully employed in diverse careers.

What is the way forward? We need partners to support our work. In the last couple of years, large organizations have sought out UTSS, such as the governments of the United States, European Union and Canada and others, because of our demonstrated track record in doing what we do.

In conclusion, shortly after beginning my work in Tanzania, God called me and placed a vision in my heart. I impart this vision to each of the children in our education program from the time they are in kindergarten, and this is it. Please listen carefully:

"I have a dream that one day people with albinism in Tanzania, Africa, and around the world, will take their rightful place in every level of society and that the days of discrimination against people with albinism will one day be a faint memory."

Thank you and God bless you.



Shortly after beginning my work in Tanzania God called me and placed a vision on my heart- and it is this:

■ Working to realize a dream: PWA takes their rightful place in every level of society.

Photo © Jean Francious Mean

Q&A ③

Moderated by Mr. Isaac Mwaura, Senator in Kenya and the first member of Kenya's Parliament living with albinism

A Thin Defining Line

Audience: Dr. Mihaela Serbulea Thank you very much for the wonderful presentations. My name is Mihaela Sebulea, and I teach at a university. I was once engaged in a project in West Africa that aimed to integrate traditional medicines into the public health system. We looked into the associations of traditional medical providers, and found the defining line between the traditional healers and witchdoctors to be very thin. I have not been to Tanzania or East Africa yet. Could you comment if you think educating them all would help in stopping this horrible discrimination against PWA?

Moderator **Thank you very much, next question? Next person, yes please.**

The Demand Approach

Audience: Diplomat Thank you very much. I came from an embassy in Tokyo, from a Sub-Saharan African country. I have been listening to all the presentations. In conclusion, they all seem to have ended up with the need of educating the perpetrators.

I know what I am thinking would be very difficult to implement, but can we try to tackle the, let me call it the "demand"? Can we try to kill the demand? Because if there is no demand, then there won't be a product. Though I know that the demand is higher-ranking people who are the powerful ones, and it would take a miracle to talk to them, but can we at least try to think of it in that direction? Thank you.

Moderator **Thank you very much.**

Advice for Outsiders

Audience: Mr. Shota Nakayasu My name is Shota Nakayasu, from the Nippon Foundation. It is my understanding that the issue of albinism is deeply rooted in the cultural, religious and social aspects that are often indigenous to local communities in Africa. My question is, how would you advise a non-African international organization to successfully intervene in this issue? For instance, is there a specific list of things that such an organization must keep in mind?

Moderator **Thank you very much, another question? Yes, next.**

A Contradiction in Witchcraft Beliefs

Audience: Mr. Ishii My name is Ishii, and I am a reporter from the *Sekai Nippo* newspaper. My question is about the practice of witchcraft. I heard on the one hand that albinism is considered a curse on children, yet their body parts are sold because they are believed to bring good luck, which I found contradictory. So, how are the persons with albinism regarded in witchcraft practices? Are they viewed differently in different countries?

Moderator **Thank you very much. Next question? Any other person? Yes, sir.**

Is a Stern Approach Possible?

Audience: Mr. Yu Kobayashi My name is Yu Kobayashi. Thank you for your presentations. I am wondering, what is the *best* way to stop witchcraft practices against the persons with albinism. I know a good approach is to use education and advocacy. But the matter is urgent. I think we should adopt a more powerful approach such as make an arrest of the practitioners of witchcraft or to impose strong sanctions against the business and political leaders who are connected to the practice of witchcraft. Do you think this approach would be useful in African communities? Thank you.

Moderator **Thank you. These are the questions, Mr. Moussa, Tomas and Peter Ash, please feel free to answer any of them. We can start with Peter.**

"Witchdoctor" or "Traditional Healer"?

Mr. Peter Ash Let me first speak about how we should work with witchdoctors. There has been some debate in academia around the term witchdoctor versus traditional healer. As you know, there are various terms.

They are all English words, of course. But in various African countries, various words are used in their local languages. There are various views on this matter, various opinions and I respect them all. Under The Same Sun as an organization has an official position on this matter. We had to examine it early on.

We do not cooperate with witchdoctors or traditional healers. Here is the issue in Tanzania, and I am sure it's true in other countries. The problem is that there are many traditional healers that simply use herbal medicines to treat illnesses. Someone might come with an upset stomach and they give them some mixture of local herbs to settle their stomach.

> "There are two kind of ignorance. The chosen ignorance is hard to change."

We would call that naturopathic work in Canada. We have naturopathic doctors in Canada. The challenge we would have in Tanzania is that there are a lot of natural healers or traditional healers, some of whom do not practice witchcraft, but many do. And only some of the ones who practice witchcraft would kill persons with albinism and use their body parts, but many wouldn't.

The Perpetrators are Hard to Recognize

The problem is you can't tell one from the other. Of course, everybody who would use the body parts of someone with albinism would say they don't. It's illegal to do so. It is against the laws of Tanzania to harvest body parts, to sell them, to kill people. All of that is against the penal code of Tanzania.


■ Mr. Peter Ash responds to a question at a conference.

The problem we have is that the people who do it are not going to say they are doing it. Not all witchdoctors kill people with albinism, but to the best of our knowledge, all people with albinism who have been attacked in countries like Tanzania have been ritually attacked and or killed by witchcraft and witchcraft-related activities. You get my dilemma?

It's like saying during the Second World War not all Nazis were killing Jewish people. But the problem for the Jewish people was they sometimes didn't know which ones were killing Jews and which ones weren't. As an organization, because the majority of our staff have albinism, we have to exercise great caution when we are in the field, and for our own safety, avoid people who are engaged in these practices.

Traditional healers and witchdoctors have attended our public *Understanding Albinism* Seminars. Since you can't usually tell who they are by sight, they are occasionally in the audience and we don't even know it. In that sense, they are being educated by our work. They are also exposed to our public education via watching the television advertising, radio advertising, newspapers and our other public education venues. We certainly want them to be educated, we want them to learn, we want them to be enlightened, but we do not want to intentionally expose our staff to them on an ongoing basis. Ideally, this could be the work of another civic service organization without PWA staff.

Actions Rather than Words

There are two kinds of ignorance. There is chosen ignorance where "I have a belief system and am not willing to change, because I am benefitting from it." And there is also legitimate ignorance where people just have never heard of the truth and are very open to changing their mind. The second kind of ignorance is easily corrected in our experience, with education. The first kind of ignorance is hard to change. Witchcraft is a deeper religious belief system for some of these politicians, so this answers your other question about how we go after the politician and the businesspeople, how do we go after the users, or the demand, as my colleague from Sub-Saharan Africa said.

I have met with politicians in Tanzania all the way from the prime minister to the president, to ministers, to members of parliament, to regional directors. I have met many of them during the last decade. All of them say it is a horrible problem, all of them say it should stop, all of them say they hate it.

But actions, rather than words, right? Politicians are good at saying all kinds of things. The real proof comes in the putting what they say into action that makes a difference for people with albinism. So yes, I am with you, we must identify the source of the problem. Our dilemma is, the people who use some of these witchcraft potions made of these body parts are in the very, very, very highest levels of power and finance in both business and government. Some of the very people we are depending on to implement the law and prosecute the offenders may also be the ones involved in the crime. It's a tricky issue.

> Young blood brings more luck, they say.
> Children are the target.

Moderator **Thank you very much. Tomas?**

More Good Luck

Mr. Wiliamo Tomas Let me explain about the attacks on children, and how they are perceived. It is said that young blood, such as that of young boys and girls, bring more good luck, compared with that of adults. That is why children are often targeted.

How do we educate them? Through workshops and symposiums. It is also important to see PWA in wide variety of areas, including discussions on TV, for instance.

International Albinism Awareness Day, June 13, is a good opportunity to raise awareness of many people, government or private. We try to invite as many people as possible.

Speaking of advocacy, we have been lucky, as Ali Faque, one of the most revered musicians in Mozambique who is PWA himself was appointed as the Director of the Culture for Nampula City.

Moderator **Thank you very much, finally, Moussa?**

Trans-border Trafficking and Election

Mr. Djaffar Moussa-Elkadhum Yes, let me go back to the issue concerning the demand for body parts of persons with albinism.

How to stop the demand, how to kill the demand, I do not want to use the word killing. Definitely this implies many actions. What is most important is that in addition to education and communication, I think the government has a major role to play to ensure that real investigations are conducted and sanctions are taken.

Also, we should allow strong collaboration between the journalists who have to report, and the activists who have to report on the case, and of course the judiciary part that has to conduct the required investigation and prosecution. So, this is how we could try to stop the demand.

Because when you look at the issue we were mentioning during the discussion this morning we are referring to cases occurring in Northern Mozambique: That is to say, Southern Tanzania and the Western and Eastern Malawi. This is like a triangle where you have a problem of trans-border trafficking of human body parts. This happens, because of the weakness of the border control between Tanzania, Mozambique and

■ Increased border control is necessary to stop trafficking of human body parts.

Malawi. We could of course talk about the borders between Mozambique and Zimbabwe, or Mozambique and South Africa, but you have more control there.

This is definitely linked to the political cycle. When you come to election periods, then some people who want to be elected, go to witchcraft for support. Many witchdoctors think and advise that using body parts of persons with albinism in their magic portions would help them win the elections. You might have heard the recent case of Mali that coincided once again with the period of elections. Therefore, there is a necessity to involve the political and the government people who need to understand and stop this crime with strong persecution and involvement of the media to better report on those cases.

Moderator **Thank you very much. It seems that we already passed the closing time. Let's now give a final round of applause to all our panelists in the morning session. Thank you very much.**

Session 2

Government Engagement, Legal and Other Tools

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Political Will is Required

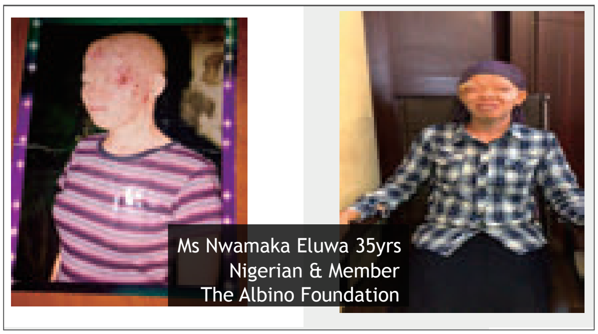
PROFILE Mr. Jake Epelle works to empower persons with albinism and educate society on albinism- related issues in Nigeria and the rest of the world. In 2006, he founded The Albino Foundation, whose vision is “A society with equal opportunities for persons with albinism.” He felt a passionate urge to embark upon an aggressive advocacy campaign to correct the negative impact of many years of discrimination and stigmatization.

Founder and CEO, The Albino Foundation, Nigeria

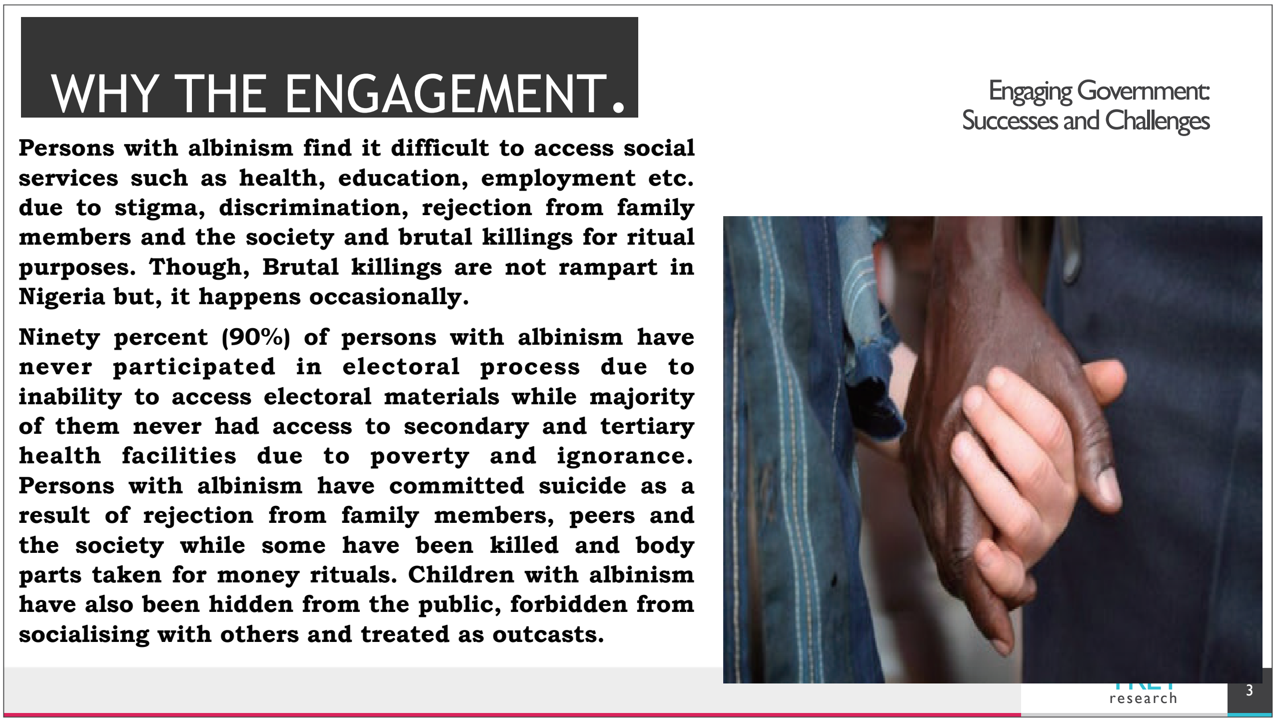
Jake Epelle

Let me start with a story of a young woman with albinism in Nigeria named Ms. Eunice Nwokeocha, who had received free treatment for skin cancer. Her story as a survivor is that of joy and enthusiasm as a beneficiary of our ongoing free skin cancer intervention programme with the Federal Republic of Nigeria. She is just one among the 4,300 patients (※*The number has been updated for this report.*) who have been treated for skin cancer to date through the foundation and the government of Nigeria.

Why does the government need to be involved?



■ Ms. Eluwa is another proud survivor of skin cancer who went through several surgeries.



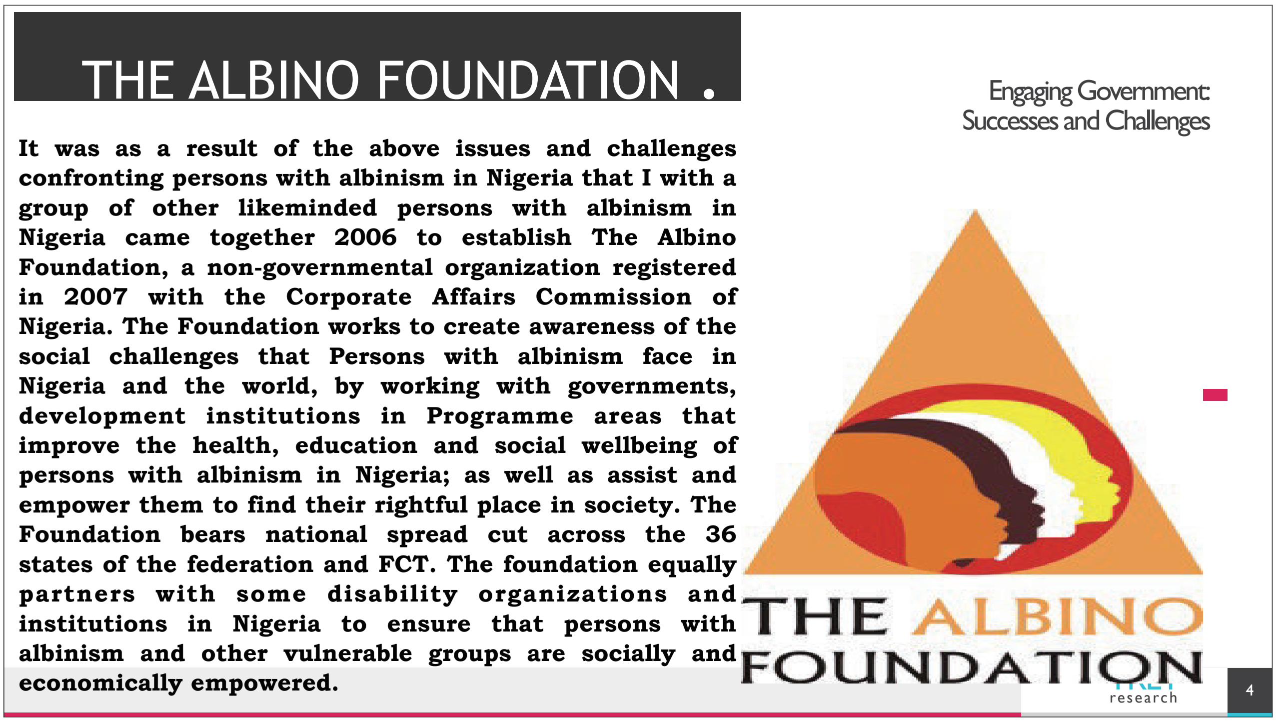
WHY THE ENGAGEMENT.

Engaging Government: Successes and Challenges

Persons with albinism find it difficult to access social services such as health, education, employment etc. due to stigma, discrimination, rejection from family members and the society and brutal killings for ritual purposes. Though, Brutal killings are not rampart in Nigeria but, it happens occasionally.

Ninety percent (90%) of persons with albinism have never participated in electoral process due to inability to access electoral materials while majority of them never had access to secondary and tertiary health facilities due to poverty and ignorance. Persons with albinism have committed suicide as a result of rejection from family members, peers and the society while some have been killed and body parts taken for money rituals. Children with albinism have also been hidden from the public, forbidden from socialising with others and treated as outcasts.

■ Needs to increase access for social services for persons with albinism.



THE ALBINO FOUNDATION .

Engaging Government:
Successes and Challenges

It was as a result of the above issues and challenges confronting persons with albinism in Nigeria that I with a group of other likeminded persons with albinism in Nigeria came together 2006 to establish The Albino Foundation, a non-governmental organization registered in 2007 with the Corporate Affairs Commission of Nigeria. The Foundation works to create awareness of the social challenges that Persons with albinism face in Nigeria and the world, by working with governments, development institutions in Programme areas that improve the health, education and social wellbeing of persons with albinism in Nigeria; as well as assist and empower them to find their rightful place in society. The Foundation bears national spread cut across the 36 states of the federation and FCT. The foundation equally partners with some disability organizations and institutions in Nigeria to ensure that persons with albinism and other vulnerable groups are socially and economically empowered.

THE ALBINO
FOUNDATION

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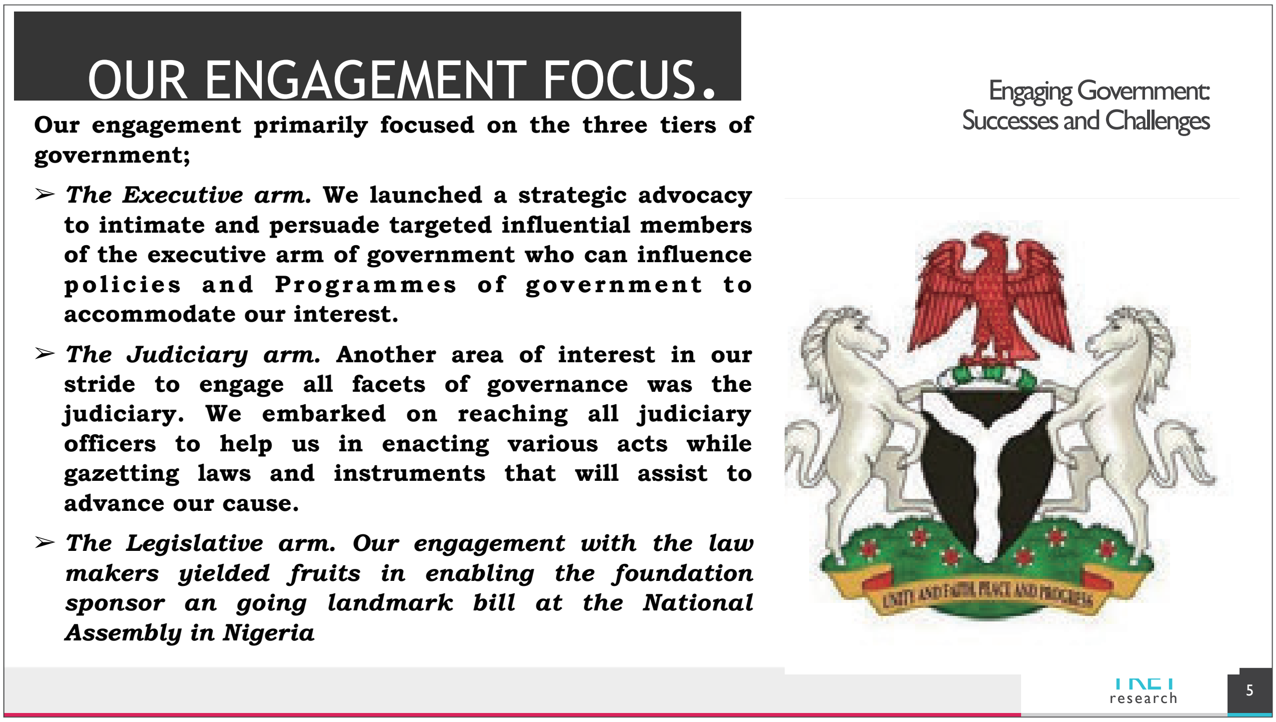
■ Established in 2007, the foundation works with the government and development institutions.

The issue of albinism requires more than the contribution and intervention of individual organizations. It requires political will. It requires that we engage with the government of our respective countries where we work, and have them help us intervene. This is why we decided to engage with the government of Nigeria.

Let me talk a little bit about our foundation. We started in 2006, and got incorporated in early 2007. We have 54 chapters across the country. We have 120 volunteers in leadership positions nationwide and 18 paid staff. We have three operational offices. The foundation is currently supported by the European Union, Disability Trust Fund, CBM, British Council the Rule of Law and Anti-Corruption (ROLAC) Project,



OUR ENGAGEMENT FOCUS.

Engaging Government:
Successes and Challenges

Our engagement primarily focused on the three tiers of government;

- ➢ ***The Executive arm.*** **We launched a strategic advocacy to intimate and persuade targeted influential members of the executive arm of government who can influence policies and Programmes of government to accommodate our interest.**
- ➢ ***The Judiciary arm.*** **Another area of interest in our stride to engage all facets of governance was the judiciary. We embarked on reaching all judiciary officers to help us in enacting various acts while gazetting laws and instruments that will assist to advance our cause.**
- ➢ ***The Legislative arm. Our engagement with the law makers yielded fruits in enabling the foundation sponsor an going landmark bill at the National Assembly in Nigeria***

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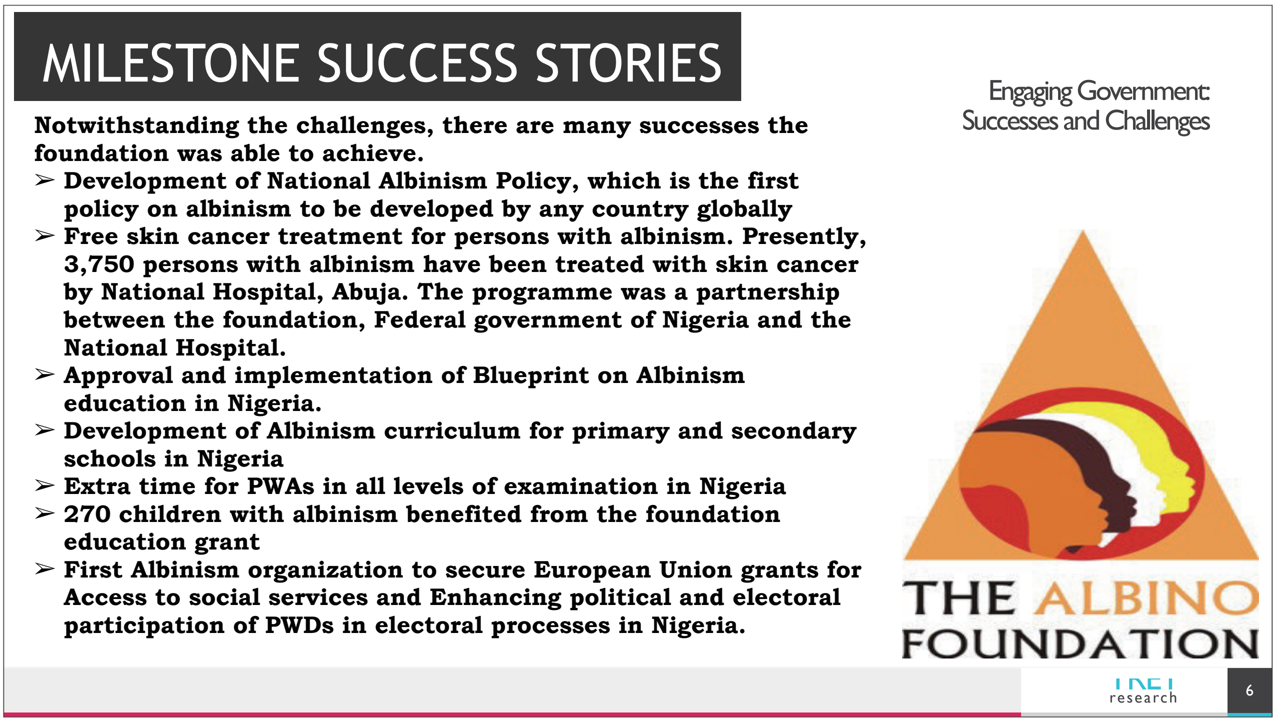
■ Work to engage three tiers of the government.



MILESTONE SUCCESS STORIES

Engaging Government: Successes and Challenges

Notwithstanding the challenges, there are many successes the foundation was able to achieve.

- **Development of National Albinism Policy, which is the first policy on albinism to be developed by any country globally**
- **Free skin cancer treatment for persons with albinism. Presently, 3,750 persons with albinism have been treated with skin cancer by National Hospital, Abuja. The programme was a partnership between the foundation, Federal government of Nigeria and the National Hospital.**
- **Approval and implementation of Blueprint on Albinism education in Nigeria.**
- **Development of Albinism curriculum for primary and secondary schools in Nigeria**
- **Extra time for PWAs in all levels of examination in Nigeria**
- **270 children with albinism benefited from the foundation education grant**
- **First Albinism organization to secure European Union grants for Access to social services and Enhancing political and electoral participation of PWDs in electoral processes in Nigeria.**

THE ALBINO FOUNDATION

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Successes of The Albino Foundation of Nigeria.

Australian government Direct Aid Program project, FGN Head of Service, and other organizations. We are endorsed by over ten embassies in Nigeria. The ambassador, from time to time, speaks on our behalf including our advocacy meeting with the Japanese ambassador.

Our engagement focus feeds on three tiers of government: executive, judiciary, and the legislation. In the executive arm, we engage with ministries, departments, and agencies, including other arms of government to mainstream albinism issues. In the judiciary, we engage with law enforcement and judges, and we've trained some of them. We trained members of parliament to enforce the rights of persons with albinism as well as persons with disabilities (PWD) and those without albinism.

In the legislative arm, we have a bill currently in the National Assembly that will give an agency to persons with albinism and other vulnerable groups. (The pending bill at the National Assembly in Nigeria elapsed in December 2018 and was reintroduced in 2019.)

Some of our milestones include the development of national albinism policy, which is the first policy on albinism globally. The policy is currently under review by all relevant government agencies, NGOs and international development partners. We offer free skin cancer treatment for persons with albinism, and 4,300 persons have been treated with documentary evidence in both the National Hospital in Abuja and the headquarters of the foundation.

Approval of implementation of Blueprint on Albinism education in Nigeria. The albinism blueprint was first developed and published in partnership with the Nigerian government and the foundation, in order to understand and analyze the situation regarding albinism and to provide a template for needs assessment of persons with albinism in Nigeria. Currently, we've sent approximately 570 children to school. The development of an albinism curriculum is in the pipeline so that albinism can be taught to children in primary and secondary schools as well as tertiary institutions. This process has not begun yet.

Extra time for every examination in Nigeria including workplace interviews. We are the first albinism organization to secure European Union grants on access to social services and enhancing political and electoral participation of persons with disabilities. The two projects are in their second year of implementation.

Advocacy, Budget, Data Gathering and More

Challenges of engaging government. Albinism is often not recognized as a thematic program for governments. When you go to the government, it is difficult to engage them because they don't know

Challenges of engagement

Engaging Government: Successes and Challenges

The challenges of engaging government to understand and intervene hitherto in an issue relatively unknown to decision makers at the herm of affairs is a herculean task. Hence our greatest challenge with those in authority in Nigeria at the commencement of our engagement was to convince the authorities to take ownership of albinism cause.

Others are;

- ➢ **Albinism is not captured in any government's development policy framework, projects and programmes.**
- ➢ **No budgetary allocations and financial assistance in support of albinism cause.**
- ➢ **Lack of political will and apathy on the part of politicians and policymakers to support a cause relatively unknown to majority of people in authority.**
- ➢ **Lack of demographical data detailing various characteristic of persons with albinism and needs assessments.**

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■ Mainstreaming albinism is a herculean task.

what to do and that's why high level advocacy is required.

Budgetary allocation. Most of my counterparts, like Senator Isaac Mwaura, who has worked hard in Kenya, were able to secure budgetary allocations from their respective governments. Nigeria just gave the approval, but is yet to implement the relevant directives, and as such, there have been no budgetary allocations to date to implement any albinism interventions.

There is an obvious lack of political will and apathy on the part of politicians and policymakers in the public and private sectors to support present and emerging issues as well as the challenges facing persons with albinism in Nigeria.

Lack of data. We have just started collecting and collating data on PWA in eight states in Nigeria. And the outcomes of our findings have been transmitted to various arms of the government in Nigeria that are in dire need of data. The cost of the exercise has been underwritten by both the European Union and the Australian government. We are making concerted efforts to find funding from any interested funder to carry out the exercise in the remaining 28 states in Nigeria.

Talking about the European Union, I led the Albinism Forum Africa to the European Union Parliament two weeks ago. After the presentation, most of our projects were chosen as the best practice in Africa by the EU parliament of the Human Rights Sub Committee. They advised that our access to social services and PWD electoral participation projects should go to other African countries. This is what an engagement of this nature can do.

What's the way forward? We must maintain this momentum, and we must continue to engage African governments and relevant stakeholders, including international development organizations, to support albinism interventions, not only in Nigeria but in the whole of Africa. We must fight to stop discrimination, rejection and ritual killings. We must continue to push to increase the political will to promote an inclusive society, especially as it concerns albinism.

May I humbly call on all of us here to support the albinism cause in Africa, especially free treatment for skin cancer patients, education and economic well-being of persons with albinism.

Let me round up with four critical interventions.
Data, data, data. We have started the work in Nigeria. We've done six states, and currently have two more states to do and there are others to come. A similar project is also needed in other African countries. Funding of skin cancer, funding of education, funding of albinism rights projects.

Before I end, let me remind all of us that the day we

A way forward…

Engaging Government: Successes and Challenges

The way forward is to continue the momentum to engage the relevant stakeholders including international development organizations to support albinism cause in Nigeria and other developing countries where stigma, discrimination, rejection and killings are pronounced. This will help to promote inclusion and improve access to social services for persons with albinism.
We humbly appeal to NIPPON FOUNDATION to fund albinism cause in Africa, especially skin cancer outbreak, education and economic wellbeing of persons with albinism.
You did it for Leprosy, you can do it for albinism the largest most underserved group of people in the world.

FOUR KEY PROJECT OF INTEREST IN NIGERIA

1. **COMPLETION OF DATA GATHERING OF PWAS IN NIGERIA**
2. **FUNDING OF SKIN CANCER PREVENTION AND TREATMENT**
3. **EDUCATION OF THE LESS PRIVILEGED PWAS.**
4. **FUNDING ALBINISM RIGHTS PROJECT**

ありがとう宜しく.

THE ALBINO FOUNDATION

■ Coordination and support are needed.

were born, we cry. Everyone around us rejoices. If we live our lives very well, when we die, we will rejoice. And everyone around us will cry. That's the life of contribution, that's the life worth living. Let me ask you to take up the challenge of going home today and writing your obituary. The reason for that is simply this: you write what you want people to remember you for if you exit the world. Thank you. God bless.

Disability Approach: Successes and Challenges in South Africa

PROFILE Ms. Nomasonto Mazibuko, an educator, has worked for the Department of Education for over three decades. She has devoted her life to fiercely advocating for persons with albinism in South Africa and throughout the African continent. Inspired by the spirit of Africanism, she founded the Albinism Society of South Africa (ASSA) and the Pan African Albinism Alliance (PAAA). Her advocacy has ensured the recognition of persons with albinism by the United Nations through the declaration of June 13 as International Albinism Day. Her passion for disability rights resulted in her being appointed a member of the Presidential Working Committee, the National Disability Policy review panel, and of several boards and initiatives in support of social justice.

Head, Albinism Society of South Africa;
Head, Regional Forum on Albinism in Africa
Nomasonto Mazibuko

Thousands of PWA Have Suffered in Silence.

"It always seems impossible until it is done."
These are the words of Nelson Mandela.

Thank you very much for the opportunity to participate in this first ever Japanese albinism conference.

Upon reflecting on the work that has been done by our organization in South Africa, it's evident that all of us attending this conference have done great work all over the continent. Having listened throughout the morning, we all have made an impact in our own countries.

My name is Nomasonto Mazibuko. I am the founder and the National Director of the Albinism Society. I am one of ten siblings, five of us had albinism and five were normally pigmented. I thank God for my position: I'm the ninth child in the family, fourth child with albinism in the family and one who became very vocal about the condition.

I have experienced discrimination, by being denied a position of Deputy Principal in a school where I had taught for 15 years. Only then did it dawn on me that I'm different and how many persons with albinism have experienced what I have experienced. How many are suffering in silence and how do you quantify their pain.

Two Significant Cases in South Africa

We have 11 official languages in South Africa. Albinism, accordingly, has a number of derogatory names to describe the condition. There is a bad stigma associated with albinism.

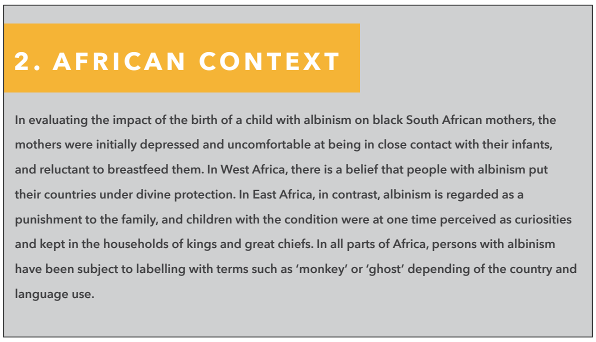
Due to the myths and wrong beliefs in South Africa, we have only two reported cases which have highlighted the killings of persons with albinism.

The first, in 2015, was the case of Thandazile

2. AFRICAN CONTEXT

The persistence of myths regarding persons with albinism in Africa is of critical concern. It is imperative to note that each part of Africa has its culture and beliefs. However, in general all cultures have some similarities and beliefs regarding persons with albinism. In central Africa for instance, they are regarded as mysterious persons with specific powers and intelligence, and as providers of good luck in a family. In Southern Africa several myths exist in relation to the powers and the fate of persons with albinism: for instance, that they have special spiritual powers and will not die naturally, but they will just disappear when the time comes; that albinism results from a black woman sleeping with a white man; and that having intercourse with a woman with albinism cures HIV/AIDS (with the result that many such women are at high risk of rape).

■ Misconception in Southern Africa on PWA includes: PWA don't die, but disappear; PWA are born because a mother slept with a white man.



2. AFRICAN CONTEXT

In evaluating the impact of the birth of a child with albinism on black South African mothers, the mothers were initially depressed and uncomfortable at being in close contact with their infants, and reluctant to breastfeed them. In West Africa, there is a belief that people with albinism put their countries under divine protection. In East Africa, in contrast, albinism is regarded as a punishment to the family, and children with the condition were at one time perceived as curiosities and kept in the households of kings and great chiefs. In all parts of Africa, persons with albinism have been subject to labelling with terms such as 'monkey' or 'ghost' depending of the country and language use.

■ In West Africa, PWA is regarded as divine, while in East Africa, punishment to the famiy.

Mpunza, who was killed at the request of a pastor and a traditional healer. The traditional healer escaped to Mozambique, but fortunately the pastor was arrested and taken to custody and is serving a life sentence.

The second one was a very tragic case of a 13-year-old girl who was kidnapped from home at one o'clock in the morning and killed. This happened in January 2018, but we were only able to bury this little girl in July. Nevertheless, the perpetrator is in jail now, and what pains South Africans is that he is a Swazi national. The case is still ongoing and is going through the court process.

Background

My task today is to talk about the successes and challenges regarding albinism in South Africa from the perspective of the rights of persons with disability.

The background that I would like us to look at is the UN:

(1) The Human Rights Council adopted a resolution A/HRC/RES/23/13 in 2013 on attacks and discrimination against persons with albinism;

(2) The General Assembly updated the resolution A/RES/69/170 on December 18, 2014, proclaiming June 13 as International Albinism Awareness Day.

In South Africa:

(1) The white paper on the rights of persons with disabilities was approved by the South African Cabinet on December 9, 2015;

(2) The prevention and combating of hate crime and the hate speech bill, April 18 2018
This bill will assist with the criminalization of hate speech. Persons with albinism face some form of discrimination daily, which can be viewed as a form of hate crime to a certain degree.

■ Ms. Nomasonto Mazibuko explains important background with regard to the UN and South Africa.

Let's Unite and Educate People

As an organization, we have ensured that the government recognizes June 13 as International Albinism Awareness Day and appears in the national calendar.

In the past, people thought of a white cane and wheelchair when they heard the word disability. It was only through the United Nations declaration of June 13 that we were able to have albinism fully incorporated in the disability sector. This cemented the advocacy work that we had been doing prior to the declaration of June 13.

The strategy employed by the organization was to target four government departments mainly:
Department of Social Development
Department of Education
Department of Health
Department of Arts and Culture

Disability in South Africa is housed in the Department of Social Development and all our organization's programs are in partnership with this department. The white paper was approved by

6. SUCCESSES IN SOUTH AFRICA

A conference on albinism was held as a milestone in South Africa, government recommitted itself in effectively implementing its policies and programmes in protecting the rights of persons with albinism and for better service delivery, this is part of the strategic pillar in the white paper on the rights of persons with disabilities that it purports to protect the rights of persons at risk of compounded marginalisation.

■ The South African government recommitted itself to effectively implement the policies and programs for PWA.

6. SUCCESSES IN SOUTH AFRICA

There has been an improvement in the judicial system, particularly the prosecution of those who have been involved in the killings of persons with albinism.

The South African cabinet approved the Hate Crimes and Hate Speech Bill, which aims at criminalising hate crimes and speech committed against persons with albinism.

■ There has been improvement in prosecution of the PWA cases. Hate Crime and Hate Speech Bill is another success.

■ Ms. Nomasonto Mazibuko making a powerful address: She expects that the hate crime and hate speech bill will encourage more reports and realize justice for the PWA.

cabinet through this department. This ensured that issues on albinism are elevated and incorporated.

Africa believes in color, persons with albinism have different complexion to our immediate brothers and sisters. Persons with albinism stand out, in their families and communities. Therefore they have a higher risk of being attacked.

In South Africa, September is Heritage Month. As an organization, we have advocacy programs that speak to cultural beliefs on albinism. We partner with the Department of Arts and Culture as custodians of our culture, in order to demystify some of the beliefs that stem from cultural background on or about albinism.

The program incorporates our traditional healers, as killings are motivated by the belief that persons with albinism possess supernatural powers and wealth. When we educate them they will in turn educate their clients that this belief is not true to ensure that they do not practice it as well.

There is a need to educate our immediate families that albinism is a genetic condition and we are born to them as they are carriers of a particular gene. As a country, we can say that we have the political will on issues of albinism.

Combating Hate Crimes and Hate Speech

Due to our colonial history, we are cautious of how we would like to be called as individuals. The incidence of discrimination might be higher than it seems as it goes unreported. The hate crime and hate speech bill will assist in such cases. We should not have to wait for a person to be killed to only to establish that he/she had suffered some form of discrimination. The bill will allow us an opportunity to report the matter and have it investigated. And it will provide an opportunity for the South African Police Services to monitor the number of cases reported.

When I was a child during apartheid, the Immorality Act posed a great problem for parents of children with albinism. At that time our parents had to shield us from all sorts of harm. However, we are now liberated.

As a country, we are still battling with the correct terminology of what to call a person with albinism. Currently the name albino we view as being derogatory, including the names in the 11 official languages of our country. The word albino stripes us of our dignity.

Within the South African police service, we have now a section that deals with vulnerable groups, with a mandate to ensure the protection of persons with albinism. They are tasked with educating all police officers about albinism. We would like to view our safety as being as high as that of the rhino. Not the best analogy, but you understand the commitment by our government on the rhino issue.

I'm a member of the Presidential Working Group on Disability; the group advises the President on the strategy that government should follow to ensure that persons with disability are reasonably accommodated in his term in office. The group also conducts monitoring and evaluation on the implementation of UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the white paper by the government. We ensure that disability is incorporated in government programs.

Challenges to Tackle

What are the challenges?

We still need to have the disability sector incorporate albinism as a disability, and educate the sector of the challenges of persons with albinism. And we need to amplify advocacy and educational programs with genetic counseling for persons with albinism.

The incidence of albinism is high in certain ethnic groups in our country.

Our borders are porous. The influx of people from all over Africa and the world coming to South Africa highlights the different cultural practices that increase the number of incidents involving persons with albinism.

In terms of education in South Africa, we have an inclusive educational policy that stipulates that children should attend school within three kilometers from home, and that their needs must be catered for by the educators. For children with albinism, this means ensuring they sit at the front of the classroom and are provided with large print text.

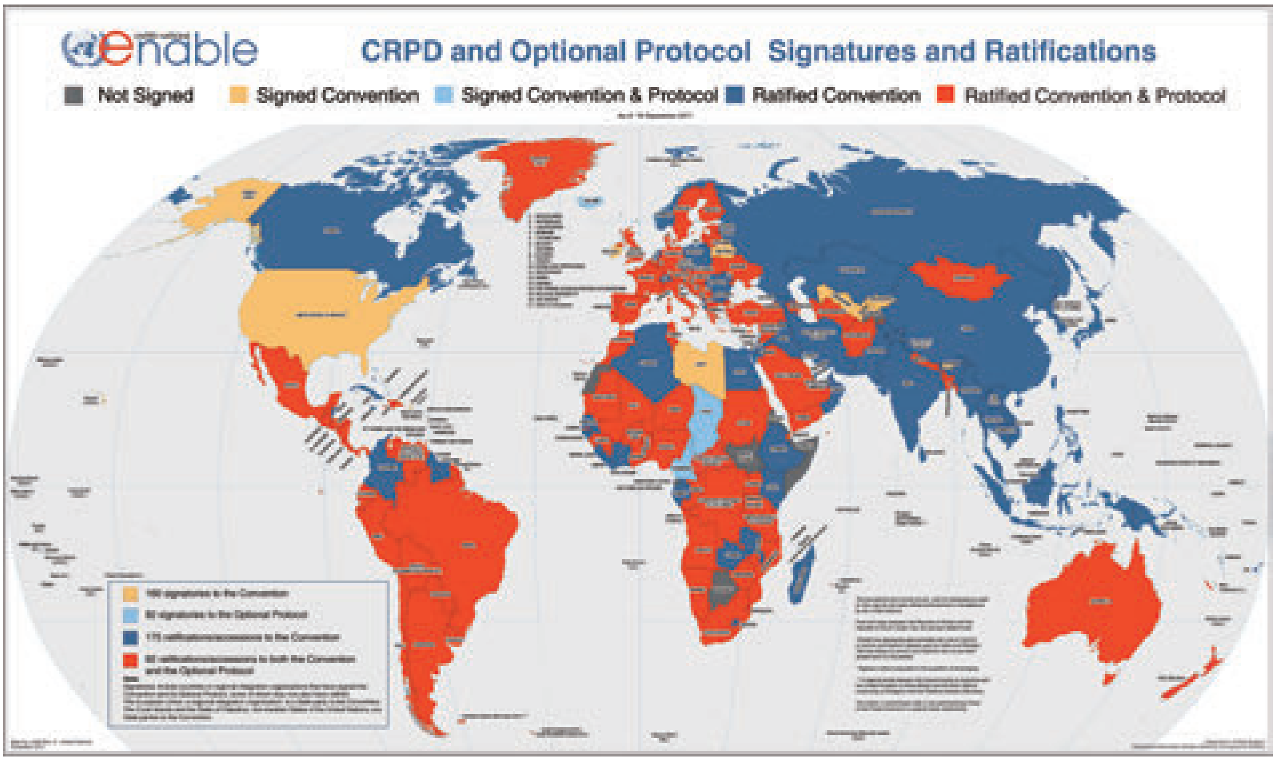
South Africa has one of the best policies, and has ratified the UNCRPD. We have the right to life, why are we being killed? We have a right to dignity as well and we should not be intimidated by the looks that we get in the mall.

My appointment as a Gender Commissioner highlighted the plight of women, not only women with albinism. Women suffer multiple forms of discrimination, especially when they have a disability.

Everyone is equal before the law and has the right to equal protection and benefit from the law. This includes their full enjoyment of all rights and freedoms, to promote equality legislation and other measures designated to protect or to advance persons or categories of persons with disadvantages against unfair discrimination. That's the constitution of the republic of South Africa.

Thank you very much.

Moderator **Thank you very much.**
Now we have a good amount of time to go through the Q&A. I see one question over there. Name and then question please.



■ Signatories and ratifications to the Convention on the Rights of Persons with Disabilities (UNCRPD)

From UN Website

Q&A 4

Moderated by Mr Djaffar Moussa-Elkadhum, Country Representative and Head of Office Mozambique UNESCO

Why Not in the Disability Sector?

Audience: Dr. Yukie Nakao Thank you for the great presentations. My name is Yukie Nakao, a researcher at Kyoto University. My research includes albinism in Tanzania.

My question is to Ms. Nomasonto. Your presentation was particularly interesting to me, because I also share your recognition that albinism is a disability. You mentioned that the disability sector in South Africa does not recognize albinism as a disability. Could you elaborate on this? Because in Tanzania, albinism is broadly accepted as a disability. Tanzanians, including the mass media, sometimes call people with albinism "*watu wenye ulemavu wa ngozi*," or people with a skin disability. But I understand in South Africa, the situation is very different. Could you explain more about how albinism is rejected by the disability sector in South Africa?

EU Grants, Hate Crimes and Hate Speech

Audience: Mr. Takada My name is Takada. I am a teacher in Tokyo. I have two questions.
One question is for Jake. Could you explain why you were able to receive grants from the EU when you could not receive support from the Nigerian government? From what I have been hearing all this morning, I think I could understand the difficulty in getting support from the Nigerian government, but how were you able to receive the grants from the EU?

Another question is for Ms. Nomasonto. Could you elaborate on the hate crimes and hate speech against PWA?

Moderator **Thank you for the questions.**
Let me also ask a question to Ms. Nomasonto. You explained the involvement of the government of South Africa in creating a number of policies, however you said that they are not really being implemented. Do you think the sensitivity of the government of South Africa is linked to the country's history, vis-à-vis people's color or what do you think? What have been their successes?

Unity Amongst PWA Needed

Ms. Nomasonto Mazibuko Can I start with disability? It's not in South Africa only, but throughout Africa. Disability is viewed as a wheelchair and a white cane. Albinism has been here. It was only when the United Nations adopted Resolution A/HRC/RES/23/13 that everyone took notice of persons with albinism. Through the high incidence of killings of persons with albinism did we begin to have a voice? Was it only after the United Nations intervention that albinism became recognized as a disability?

Africa believes in color. Persons with albinism have a different complexion to their immediate brothers and sisters. Persons with albinism stand out in their families and communities, therefore they have an increased risk of being attacked.

The disability sector, through ignorance, is unaware of our challenges, therefore poses the question of how persons with albinism are disabled. We need to educate the disability sector about our challenges in terms of low vision.

The challenge of low vision impacts directly or indirectly on other parts of our well-being, such as education, employment and health. How do we address the high incidence of skin cancer?

We need to constantly engage with the government to have preventable measures in place to assist persons with albinism. We should be able to access sunscreen in all government hospitals. Sunscreen should be readily available, like condoms.

We all agree albinism is a disability; however we need to be conscious of the different types of albinism, therefore we need to have a holistic approach to issues of albinism. Unity amongst persons with albinism throughout the continent and the globe is paramount.

Education on the subject of albinism is necessary and should start with our families before we can engage with the community. Education and advocacy will assist in ensuring that the world understands the daily struggle of persons with albinism. The education and advocacy should focus on rural and urban areas and all classes. With the aim that they will understand why we are different.

When I started the organization in 1993, a number of people did not understand the aims and objectives of the organization. We did not know of the killings of persons with albinism until 2015, when the first case was reported in the country. Only now can South Africans appreciate the role of the organization. We have managed to debunk the myths that persons with albinism do not die, but disappear. We further engaged with the traditional healers, in acknowledging that not all but some traditional healers hunt and kill persons with albinism for *muti* practices. Culture to a certain degree contributes to the killings of persons with albinism, further noting that culture evolves.

Hate Crimes and Hate Speech Bill

In South Africa, we have a bill: The Prevention and Combating of Hate Crimes and Hate Speech Bill. This will assist with the criminalizing of hate speech. PWA face some form of discrimination daily, which can be viewed as a form of hate crime to a certain degree. This will allow for a person to report the matter to the police who would then be able to investigate. This will help the government count hate crimes and know more about their nature and prevalence, so that they can make effective plans for prevention. It provides a framework for police detection and prosecution of hate crimes. The bill has categories. Albinism is recognized as category on its own. This will be a milestone for persons with albinism in South Africa, and will eliminate some of the crimes in our country.

The Sustainable Development Goals provide a shared blueprint for peace and prosperity for people and the planet. With a focus on Goal 16, which speaks to peace, justice and strong institutions, persons with albinism have the right to life and to be protected by our governments. We need to be part of the 2030 agenda.

The Regional Action Plan was endorsed in May 2017. The main purpose of the plan is to curb violations against the right to life of persons with albinism, in the context of widespread killings and reported attacks targeting them in Sub Saharan Africa. One of its aims is to root out the common causes of the killings in order to protect persons with albinism.

Moderator **Thank you. Jake, please.**

Make Use of Social Services Platform

Mr. Jake Epelle I would like to say something on the issue of disability and the fight within the disabled community. They are fighting to recognize us. I think I'd like to present it point by point.

Point one is the ignorance within the disabled community. Most likely, many of them have not studied the UN Convention on Rights of Persons with Disabilities (CRPD) in order to know the provision that relates to accommodation of persons with albinism. It is discussed under the reasonable accommodation and other specific instruments within that convention.

Point two is about the PWA community. Many of us PWA are arguing with each other, some say we are not persons with disabilities (PWD), others say we are. This, I think, is the greatest disservice we can do to ourselves, because this gives PWD the right to further reject us.

We must agree and focus on one point as PWA: Are we part of the PWD community? If we are, let's stay

with that message.
But once we are inconsistent about our stance, some groups saying we are not, other saying we are, we will create further discord within the PWD community.

Regarding the EU grants, we competed with other NGOs to secure them.

We don't receive monetary support from the Nigerian government. However, we identified basic social services within Nigerian government programs and projects. Social services like getting free skin cancer treatment, educational opportunities, policy formulation and influencing and economic programs that will benefit PWA and ensure inclusion of our community. It may be skeletal but it's a starting point.

To get surgery done for a person with albinism with skin cancer would under normal circumstances cost an arm and a leg, but in Nigeria, I can positively tell you that these surgeries are done absolutely for free.

We don't get budgetary allocations from the government, but we have access to various social service platforms and mainstream persons with albinism to get those services at no cost to them.

Yes, we got a grant from the European Union, it was a grant that we applied for just like every other person. There were 90 organizations that applied for that grant, and we were chosen as the best applicant.

This is my advice to my colleagues, if we keep running away from taking advantage of the huge resources within the disabled community, we will do a disservice to ourselves. What we did was look for grants for persons with disability within the European Union governance projects and applied just like every other person, and we got it.

The funding that is available for PWD should be considered by every albinism organization that is smart and knows the process. It is a tedious process, but once you know it, you will be able to get a grant.

Because of the success of our project, which was only about one and half years long, it's been recorded today, as the best practice on the floor of EU parliament, and it was tabled as the best project that should be cascaded or scaled up in other African countries.

However, for you to get a grant from the EU, the government has to recognize what you are doing. In our case, the Nigerian government signed as a witness, then the EU signed and then the Albino Foundation signed.

The EU presents an opportunity for every PWA organization in Africa so let's explore it.

Moderator **More questions? There is one gentleman.**

Lack of Political Will

Audience: Mr. Awa Lubundi Thank you very much. My name is Awa Lubundi from Zambia. I am a diplomat. I'm serving at the Zambian mission here. Mine is not a question. I'm talking not as representing the position of my government. I'm happy to hear what has been said by the presenters.

What I want to put across is my experience over the years. I think from as early as 2003 and 2004, I was involved in the peace process for the Great Lakes region, if you have heard of the international conference of the Great Lakes region, which took place most years over a period of about eight to ten years in Nairobi, Kenya.

I had a chance during that period up to about 2008 or 2009 when the final agreement was adopted, to move around most of the countries around my region.

The one thing that has always touched me is the lack of political will to guarantee the safety of a person with albinism. I was touched in many of the

countries that were not necessarily my own, but even in my country this problem is there. Even if it's not been talked about, it may not be necessarily at the same level like some other countries, but we are affected, because where it's so prevalent, we share boundaries with all the countries that are being mentioned, and the spillover is being felt even in Zambia.

The biggest issue that I have is the lack of political will to guarantee life in the sense that in one of the villages where we visited, a child was practically wrestled away from a crying mother. They had to leave the parts of this child, because the mother was helpless. These people apparently attacked the father with knives.

When all that was going on, I was thinking of my own children, at that time I had just had my first born. I was thinking what would have been going on in the mind of that lady when she was fighting and having a child, somebody rips off its arm and the child is still there. Would she have been thinking of herself as still being a national, a protected national of that country of that community?

For me what I'm trying to say in short is, let's see, what was lobbying for issues that guarantee a life and they should bestow upon governments, or the authority, the right to do everything that can be done to ensure that people are not killed in that manner. Thank you very much.

Moderator **Thank you very much for the testimony and at the same time and I understand that you are a civil servant. So I think advocacy is for all of us including indeed the civil service, actually including the government. Thank you for your testimony. Thank you for also being an activist inside the system. I have a question here. We are coming close to the time for the Session 2.**

What We Need is Data

Audience: Lady I have a very short question for you. How can you explain that in some countries in Africa people actually go to such an extent that people are killed? In other countries, there are problems of discrimination and stigmatization, but they live a relatively good life in the sense that they are not hiding from their lives. What is happening in some countries like Tanzania, Malawi or Burundi but not in others?

Moderator **Let me ask Jake to answer the question. You mentioned the issue of data. Can you explain what sort of data you were talking about?**

Mr. Jake Epelle Well, make no mistake about it. People are being killed everywhere. It's just that it's not as rampant in Nigeria as it is in Tanzania. There are specific reported cases from Nigeria about infanticide. For instance, these was the woman who killed her own child because of pressure from her husband, recorded in 2010. There was another report on April 19, 2016, of a lady killed in Delta State.

This is Nigeria. So killings are taking place. The problem is that what goes on, especially in the rural areas, is not reported. As these crimes are not reported, you would think they are not happening.

In Nigeria, we don't have ritual killing at the level that goes on in Tanzania. There are some cross-cutting cases like discrimination. Discrimination is everywhere. Poverty is everywhere. Skin cancer. Skin cancer does not care whether you are from Tanzania or Nigeria.

I want to categorically say that we must make progress with the albinism cause. The issue of data gathering should be our number one goal. Without numbers, there will be no intervention at all from development partners. Data gathering needs to be strategic.

Data should be our focus. We need baseline studies as they give you disaggregated information about PWA. These studies can tell you how many men, women, and children have albinism, as well as other data such as percentage of children with albinism that are in school.

It's important that you re-examine and make sure that your study is professionally done. For instance, we did a the baseline study in just three months

with the help of technology. An organization like EU will not put their name on it if it wasn't credible. If it's not professionally done, they would not allow you to put your name on it.

So as much as possible, we should engage with our government. We should just not leave it to the census agencies, because they don't know our issues. You need to design the study and present it to them. In designing these studies, look for professionals who will give you an up-to-date study that is globally accepted, otherwise, nobody will pay attention to it. Thank you.

Moderator **Thank you very much. Let's give an applause to the participants. Allow me to go to the second round of two presentations. The first one is by Judge Mumbi Ngugi.**

Personal Journey of Judge Mumbi and Her Advice

PROFILE Ms. Mumbi Ngugi previously served for a period of five years in the Constitutional and Human Rights Division. Justice Ngugi has been involved in the emerging human rights jurisprudence in Kenya, particularly in relation to the social and economic rights guaranteed in the 2010 Constitution. Prior to her appointment to the Bench, she was a prolific writer and researcher on human rights issues including work at the Kenya Human Rights Commission. She has also been a prominent activist for the rights of persons with albinism in Kenya. She is the 2013 recipient of the International Commission of Jurists-Kenya (ICJ-K) Jurist of the Year Award, and the 2017 Law Society of Kenya Distinguished Service in the Administration of Justice Award.

*The title on the right is at the time of the Tokyo Albinism Conference. She has been the Presiding Judge, Anti-Corruption and Economic Crimes Division since March 2019. In July 2019, she was nominated for appointment to the Court of Appeal in Kenya.

Judge of the High Court of Kenya (As of November, 2018)

Mumbi Ngugi

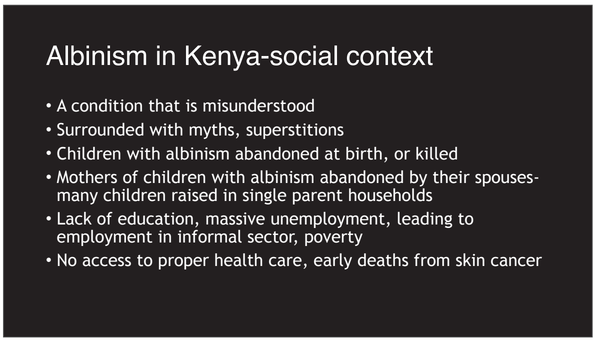
People Think It's Your Fault or Your Mother's

I want to begin by mentioning something about the misconceptions about albinism which may explain why people insult persons with albinism and sometimes even kill them. I want to do so by narrating an anecdote about something that happened to me. Around the time I was completing university, a musician called Yellowman came to Kenya from Jamaica. Some of you may probably know about Yellowman. He has albinism. A leading national newspaper carried a cartoon in its editorial page which showed Yellowman singing about how he dipped himself in sulfuric acid to become white.

People seem to think that it's your fault that you have albinism; that somehow you did something, or your mother did something wrong, and that's why you were born with albinism.

Until we get around that misconception, until we have sufficient information out there in public about the causes of albinism, I think that there will always be a problem for people with albinism.

I want to talk a little about the conditions and the context in Kenya regarding albinism. In doing so, I will speak a little about my personal experience and how I got around some of the challenges facing persons with albinism. I will also make some suggestions about how we can move forward in terms of helping people with albinism, how we can work together as different organizations to make sure there are changes in the lives and conditions of people with albinism.



Albinism in Kenya-social context

- A condition that is misunderstood
- Surrounded with myths, superstitions
- Children with albinism abandoned at birth, or killed
- Mothers of children with albinism abandoned by their spouses-many children raised in single parent households
- Lack of education, massive unemployment, leading to employment in informal sector, poverty
- No access to proper health care, early deaths from skin cancer

We've talked a lot already about how the condition is misunderstood, and the myths, the superstition, that children are abandoned at birth, and how mothers of children with albinism are usually abandoned by their spouses.

My mother faced some of these challenges. I explained to her later why there were two of us in the family with albinism; my brother and I. I explained why we had been born with albinism, and the genetic reasons for it. There were, and still are, I think, those who believe that witchcraft causes albinism, or that women who are unfaithful to their husband get a white child. The result of all of these beliefs is the infanticide that we get in many of our communities, which I suspect is still found, and of course the abandonment of children with albinism.

You'll find that in many cases, children with albinism are brought up by single mothers in poverty. Poverty, of course leads to a lack of proper education, so there is massive unemployment among people with albinism, and many end up working in the informal sector.

Working in the informal sector in Kenya means that one is exposed to the sun which often results in skin cancer. Inevitably, in a situation in which there is no proper health care, the skin cancer leads to an early death.

I.K. talked earlier about the life expectancy of people with albinism being about 40 years. We also know about the physical challenges of albinism, and visual limitations, and I need not get into that.

The biggest problem about the visual limitation for persons with albinism is in school, which also explains why a lot of persons with albinism drop out.

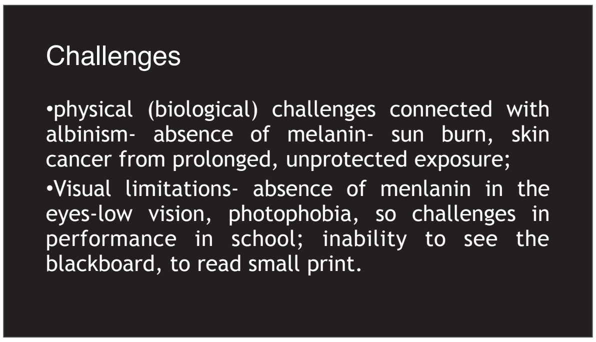
Speaking for myself, I was born in the 1960s, and I went to school in the 70s. When I was in primary school, nobody could understand why I kept peering at the papers, why I couldn't read what was written on the blackboard. The teachers didn't understand the visual challenge that I had. I can tell you at some point I was tempted to drop out at Standard Two, but luckily better sense prevailed, and I moved on.

But a lot of children will get frustrated, as they cannot read what is written on the blackboard, and they will drop out of school at a very early stage in their education. This of course brings major challenges later on in life due to poverty, since it is hard to get employment without education.

The stigma and discrimination never really goes away. From personal experience, a person with albinism cannot walk around in any part of my country without hearing rude remarks about their condition. Even today, though I am an adult and a judge, I cannot really walk around in rural parts of my country without people staring at me, without people saying rude things about my skin. I always think that it's a bit of an irony that in the United States and Europe, Africans are discriminated against because of their dark skin, but in Africa, they will not let you rest because of your white skin! I guess that is the nature of human beings.


Social challenges

- Stigma, discrimination, in a society where the majority are dark;
- Limited information on how albinism occurs;
- Belief that albinism is due to:
  - Witchcraft
  - Infidelity on the part of mothers
- Result
  - Infanticide
  - Abandonment of children/mothers
  - Poverty


Challenges

•physical (biological) challenges connected with albinism- absence of melanin- sun burn, skin cancer from prolonged, unprotected exposure;

•Visual limitations- absence of menlanin in the eyes-low vision, photophobia, so challenges in performance in school; inability to see the blackboard, to read small print.

One of the challenges that persons with albinism face is the lack of information on self-care in order to protect their skin. When growing up, until I started reading articles in magazines from Europe or America, I did not know about sunscreen and I would get badly sunburnt. I know that is probably a problem that many of us had, and many in our communities still do. When I was growing up, we didn't have a properly functioning health care system, and when one got skin cancer in a small region of the body, it would develop and spread to other parts of the body, often leading to an early death. We still do not have a properly functioning health care system, and many people with albinism still die early from skin cancer.

Not Just to Survive, but to Thrive

Many persons with albinism in our communities have a very limited education. This is because of the many challenges they face in accessing education, the stigma and visual limitations that make it hard for them to attend school and receive a proper education. It follows, of course, that the level at which one can get employment is very, very low. Then we have of course the superstitious beliefs about albinism that we have already spoken of, which have often led to attacks against persons with albinism.

There have not been so many attacks on persons with albinism in Kenya. There have been cases of


Challenges cont'd

- Lack of information on self-care;
- No sun screen, hats, protective clothing;
- No properly functioning health care system, so no early screening for skin cancer;
- Limited education no employment, discrimination in employment;
- Poverty=poor health=early death
- Life expectancy for the most part low-age 40 or thereabouts.

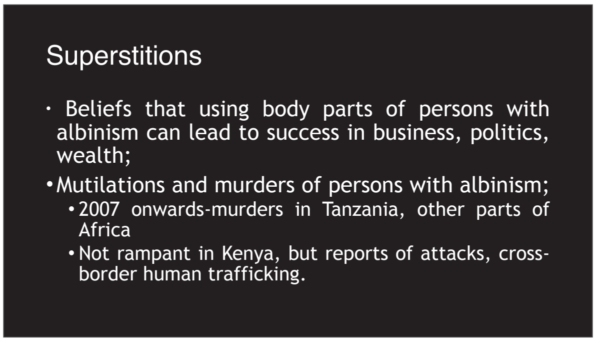
persons with albinism being attacked, and there was a case of a person with albinism who was kidnapped and taken across the border to Tanzania. Luckily, he was not mutilated and did not have his limbs hacked off. He was rescued, returned to Kenya and the person who had kidnapped him was arrested. To that extent, persons with albinism in Kenya have been 'lucky.' But there have always been challenges along the borders with Tanzania, in areas like Taita Taveta and the border area in Migori.

So, the question is "How does one survive as a person with albinism?" I think the desire in all of us as human beings is not just to survive, but we want to thrive. We want to achieve the best that we can be.

Tragedy Today

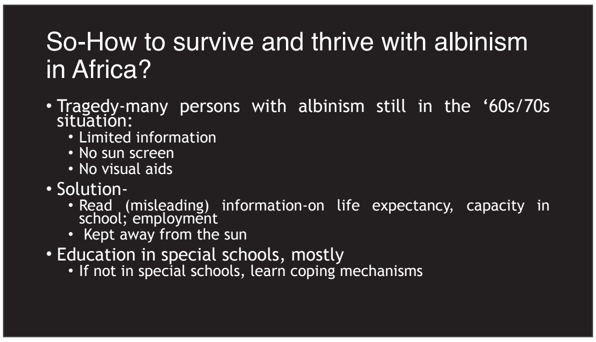
I will now speak about what I think is the tragedy today. Many children with albinism in Africa, I think, are still where we were in the 1960s and 70s: they have very limited information about albinism; their mothers have very limited information about why they have had these children; they have no access to visual aids in school; and they have no access to sunscreen.

So what do we do about this? When I was young, I would read many things, but a lot of the information available then was misleading. Misleading in the sense that you read things that left the impression that the things you read were inevitable consequences of having albinism. One of the things that I read was that if one has albinism, one will die before the age of fourty. Nobody told me that one will die before the age of fourty if you get exposed so much to the sun that you would get skin cancer. I kept thinking maybe I'm fated to die before I'm fourty.



Superstitions

- Beliefs that using body parts of persons with albinism can lead to success in business, politics, wealth;
- Mutilations and murders of persons with albinism;
  - 2007 onwards-murders in Tanzania, other parts of Africa
  - Not rampant in Kenya, but reports of attacks, cross-border human trafficking.



So-How to survive and thrive with albinism in Africa?

- Tragedy-many persons with albinism still in the '60s/70s situation:
  - Limited information
  - No sun screen
  - No visual aids
- Solution-
  - Read (misleading) information-on life expectancy, capacity in school; employment
  - Kept away from the sun
- Education in special schools, mostly
  - If not in special schools, learn coping mechanisms

I can tell you that I have passed the age of fourty, and I am still very much alive! So in a sense, the information I received was a lie, but for many people with albinism, it is the truth. People would die from an illness that was preventable, because they did not have the right information.

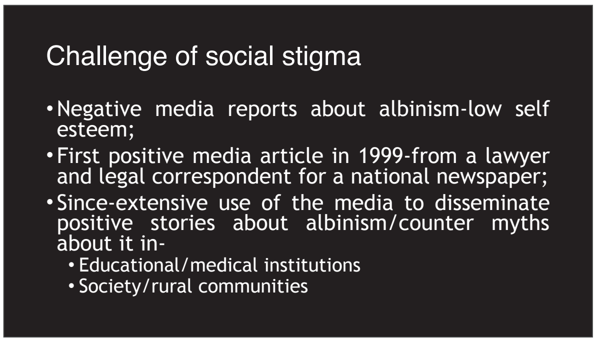
There is another challenge for persons with albinism related to education. Many of us born with albinism either did not get an education, or were educated in a special school for persons with visual disabilities. Getting an education in a special school for persons with visual disabilities is fine in a situation where the choice is between getting no education at all or getting education in a special school for the visually impaired.

The challenge that I see, however, is that we don't have a society that is made up only of persons with visual disabilities. So as a person with albinism, you need to interact with others; you need to get the world to know you and get used to you. So that for me was always the challenge. How do we get people with albinism to learn together, to interact with everybody else in society. Which brings me to this old question of the negative portrayal of persons with albinism.

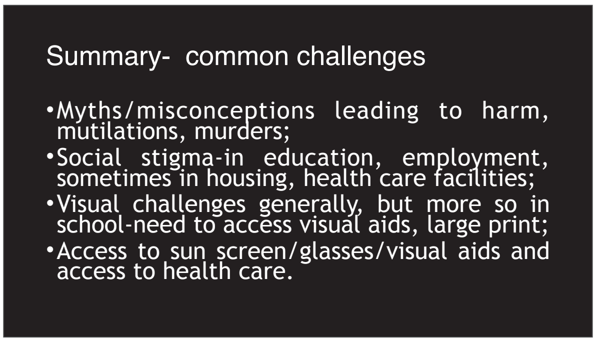
I Offered Myself as a Guinea Pig for a Positive Story

Throughout my youth, I only used to see only very negative photographs of people with albinism who were badly sunburnt, or who had cancer on their faces. There was nothing good about any person with albinism, nothing about a person with albinism who has achieved something good, who has excelled in their profession.

On one occasion, when I saw such a portrayal, I went to a media person and told him: "Look, we can't keep behaving like this, we need proper role models for persons with albinism. Why is it that every person we see in the media with albinism is poor, unemployed, and dies from skin cancer?" I was then writing a weekly column for a newspaper, and I asked him whether we could put in something different about persons with albinism: I would offer myself as a guinea pig, so that we could put my story in the paper. I was then a young advocate. That, I


Challenge of social stigma

- Negative media reports about albinism-low self esteem;
- First positive media article in 1999-from a lawyer and legal correspondent for a national newspaper;
- Since-extensive use of the media to disseminate positive stories about albinism/counter myths about it in-
  - Educational/medical institutions
  - Society/rural communities


Summary- common challenges

- Myths/misconceptions leading to harm, mutilations, murders;
- Social stigma-in education, employment, sometimes in housing, health care facilities;
- Visual challenges generally, but more so in school-need to access visual aids, large print;
- Access to sun screen/glasses/visual aids and access to health care.

think, was the first time in the late 1990s that we had a positive story about albinism.

Maybe Mwaura, sitting next to me, can tell us—he was a very young boy then— whether he saw that story, and what impact, if any, it had on him. Since then, we have tried as much as possible to have as many positive portrayals of people with albinism in our media. We tell stories about people like Mwaura, who is now a senator and a former member of parliament, and of other persons with albinism who have achieved success in life.

We also get positive stories about other people from other places. We carried a story in the newspaper when a Tanzanian woman with albinism, Shaymaa Kwegyar, became a member of parliament. We brought her to Kenya and highlighted her story in the media as we needed people with albinism to believe that they are capable, that they can do well.

So if I may summarize, we have to deal with and address, as individuals and as organizations, the misconceptions, the social stigma, and visual challenges and the lack of access to health care that people with albinism always face.

Education is Where We Need to Focus

What should we be focusing on? First, we've talked a lot about education. For me, this is where we need to focus. I cannot emphasize enough how much we need to focus on education.

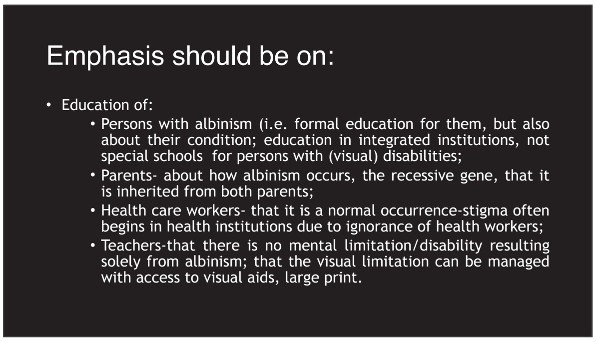
We need to educate the persons with albinism themselves. Then we need also to educate the parents of children with albinism about how albinism occurs; that it is an inherited condition and it is not the fault of the mother of the child, which is what people are always told.

We also need to educate health care workers. I met a lot of women and parents of children with albinism and I realized that a lot of the stigma and discrimination starts in our hospitals and with health care workers, because they themselves don't understand what albinism is about.

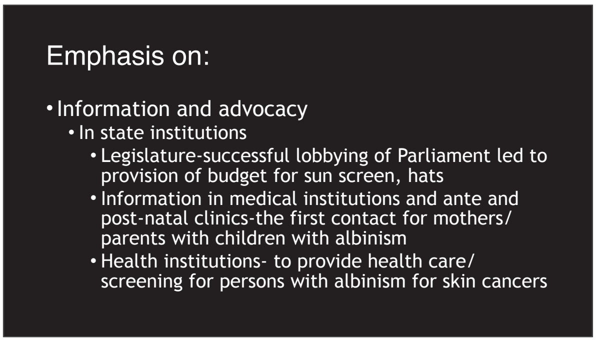
Then we need to educate our teachers that there is no mental limitation that comes with albinism. It affects our eyes, it's true. It affects our skin. But it doesn't affect our mind. It does not affect our intelligence. I keep telling people that albinism is not in the mind. Albinism is not a mental challenge. Albinism by itself will not affect what you can or cannot do.

Protect PWA, Make Government Responsible

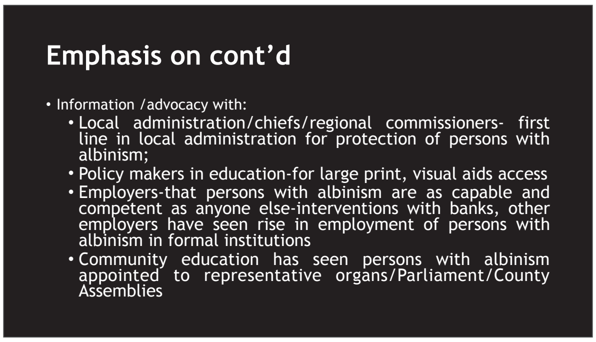
We must focus on protection of persons with albinism, from the murders, infanticides and mutilations that come with the condition in certain


Emphasis should be on:

- Education of:
  - Persons with albinism (i.e. formal education for them, but also about their condition; education in integrated institutions, not special schools for persons with (visual) disabilities;
  - Parents- about how albinism occurs, the recessive gene, that it is inherited from both parents;
  - Health care workers- that it is a normal occurrence-stigma often begins in health institutions due to ignorance of health workers;
  - Teachers-that there is no mental limitation/disability resulting solely from albinism; that the visual limitation can be managed with access to visual aids, large print.

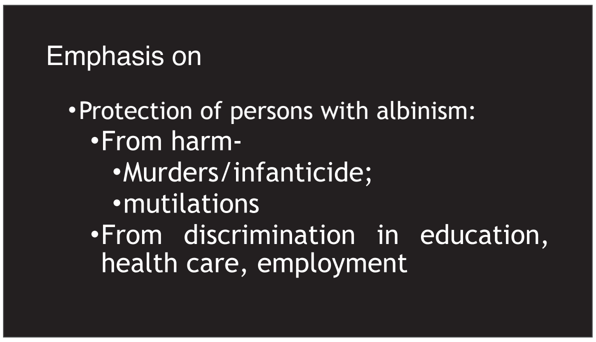

Emphasis on:

- Information and advocacy
  - In state institutions
    - Legislature-successful lobbying of Parliament led to provision of budget for sun screen, hats
    - Information in medical institutions and ante and post-natal clinics-the first contact for mothers/parents with children with albinism
    - Health institutions- to provide health care/screening for persons with albinism for skin cancers



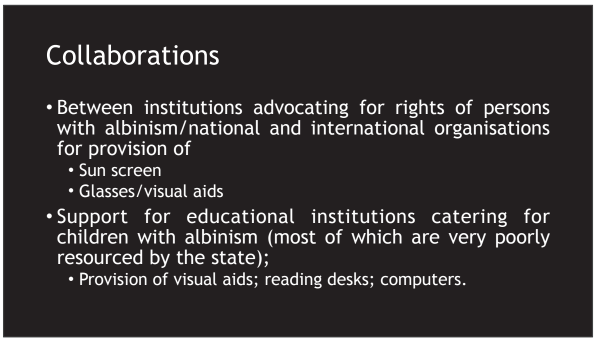
Emphasis on cont'd

- Information /advocacy with:
  - Local administration/chiefs/regional commissioners- first line in local administration for protection of persons with albinism;
  - Policy makers in education-for large print, visual aids access
  - Employers-that persons with albinism are as capable and competent as anyone else-interventions with banks, other employers have seen rise in employment of persons with albinism in formal institutions
  - Community education has seen persons with albinism appointed to representative organs/Parliament/County Assemblies



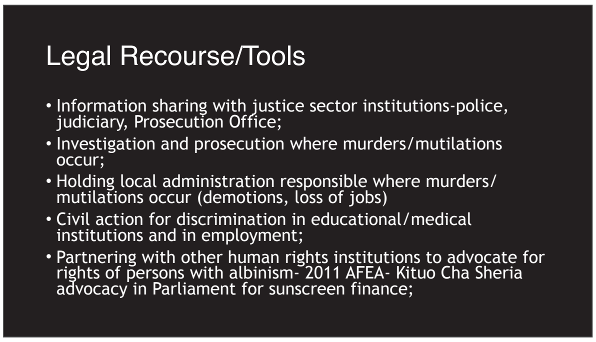
Emphasis on

- Protection of persons with albinism:
  - From harm-
    - Murders/infanticide;
    - mutilations
  - From discrimination in education, health care, employment



Collaborations

- Between institutions advocating for rights of persons with albinism/national and international organisations for provision of
  - Sun screen
  - Glasses/visual aids
- Support for educational institutions catering for children with albinism (most of which are very poorly resourced by the state);
  - Provision of visual aids; reading desks; computers.



Legal Recourse/Tools

- Information sharing with justice sector institutions-police, judiciary, Prosecution Office;
- Investigation and prosecution where murders/mutilations occur;
- Holding local administration responsible where murders/ mutilations occur (demotions, loss of jobs)
- Civil action for discrimination in educational/medical institutions and in employment;
- Partnering with other human rights institutions to advocate for rights of persons with albinism- 2011 AFEA- Kituo Cha Sheria advocacy in Parliament for sunscreen finance;

communities.

We must also look at holding local administrators responsible when they do things wrong. If killings occur in a regional community in Tanzania, why aren't we holding the regional commissioners there responsible?

We must have collaborations between institutions advocating the rights of persons with albinism, and national and international organizations on provision of sunscreen, glasses and visual aids. We must also support educational institutions like schools for children with albinism.

Investigation, Prosecution, Civil Action and Litigation

But we must also focus on investigation and prosecution of those who kill persons with albinism and those who practice hate speech. We must also bring civil actions and litigation. There have been cases filed in Nigeria, and one case in Tanzania which did not go very far, because people were frightened. We must also get angry and petition the government, and fight through demonstrations and petitions if necessary. We have the right to assemble, and to demonstrate.

If killings are happening, why aren't we out there with placards, talking about our rights? These are things that we must do.

As a judge, I know the power of having constitutional petitions to protect rights. Why are we not holding our governments responsible?

Child Maintenance Cases: Abandoned Women Should Take Their Cases to Court

Finally, for the mothers of children with albinism, it's time they started taking their cases to court and saying this man is the father of my child who has albinism but he is not paying maintenance for this child. In Kenya, when an order for maintenance has been made, we use the father's salary to pay for the education of the children.

This is because, until we take these actions and make sure that persons with albinism get a proper education, we will still be dealing with the lack of sunscreen and cancer issues.

The truth is that it is only education that makes a difference between Mwaura, myself or Nomasonto or Jake, and persons with albinism who die at fourty from cancer. We need collaboration between persons with albinism, national organizations of persons with albinism, international organizations, UNICEF and so on. Of course, organizations like the UN, and all these organizations that protect human rights. That would be my challenge to all of us.
Thank you.

Get into the Government and Make It Sustainable

Senator
National Coordinator of the Albinism Society of Kenya

Isaac Mwaura

PROFILE Mr. Isaac Mwaura is the first member of Kenya's Parliament living with albinism. He co-founded Albinism Society of Kenya to champion the rights of persons living with albinism and disability in general in 2006.
As a senior public official who influences public policy toward improving the lives of the marginalized and the Kenyan people, he works for human rights, disability, and development in Kenya. His range of experience includes finance, management, project planning, human rights-based approach, advocacy, gender, public relations, communication, and disability mainstreaming.

My name is Isaac Mwaura. I am the first person with albinism to be a member of parliament and a senator in Kenya. It has been my dream since I was small that one day I would be a member of parliament. When I told my parents, they said, "You cannot be a member of parliament! How could you be a member of parliament?"

They did not say that because they hated me. It's because they had gone through a lot. So, they never anticipated that their child, who was born different, would end up being someone important.

In fact, my own mother was a casual laborer at the parliament. How could the son of a casual laborer become an equivalent of the master? As Mumbi has said, the majority of us in Kenya have grown up with a single mother, because most men run away when they get a child with albinism. This has always been the way. So, there are issues of masculinity, issues of gender that affect all of us.

Now, we started the Albinism Society of Kenya (ASK) in the year 2006, and we came up with the motto, "Don't just stare, ASK." Don't just stare at me, ask me about myself.

The aim is to ensure social inclusion of persons with albinism and to seek better care. We started in 2006 and we are now 12 years old.

Our vision is to make sure that society is free of prejudice and discrimination, so that persons with albinism can enjoy their full rights just like any other person.

Our society has a number of objectives. The first one is to provide sunscreen lotion. You'll be surprised to know that I actually used my first sunscreen when I was at university. Because it is 2,000 shillings a day, about $20, when people live on less than $1 a day, they cannot afford that.

Issues of positive self-image. As Justice Mumbi has just said, about a feature that was done on her, she may not remember, but it was in 1998. My mother brought the newspaper to me that evening, I was so happy to see a very beautiful young lady with albinism who was a lawyer. It is actually true. The media is very, very powerful with regards to how it changes people's perspectives.

Then prescription glasses because of our low vision,

ALBINISM SOCIETY OF KENYA

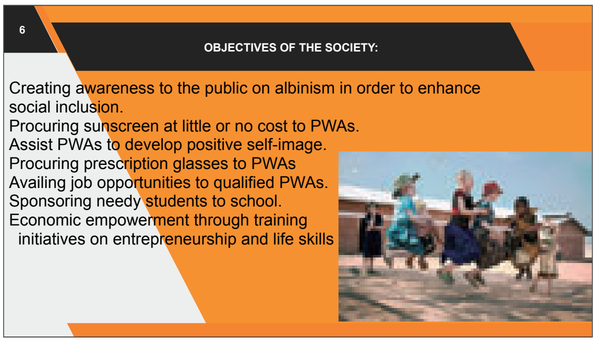
Don't Just stare, ASK

© Albinism Society of Kenya

We started in June 2006

We are now 12 years Old

© Albinism Society of Kenya



OBJECTIVES OF THE SOCIETY:

Creating awareness to the public on albinism in order to enhance social inclusion.
Procuring sunscreen at little or no cost to PWAs.
Assist PWAs to develop positive self-image.
Procuring prescription glasses to PWAs
Availing job opportunities to qualified PWAs.
Sponsoring needy students to school.
Economic empowerment through training initiatives on entrepreneurship and life skills

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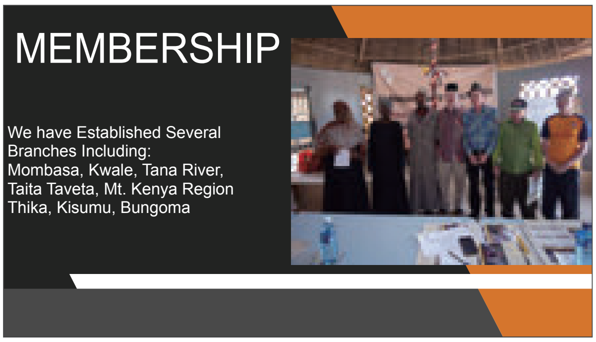


MEMBERSHIP

We have Established Several Branches Including:
Mombasa, Kwale, Tana River,
Taita Taveta, Mt. Kenya Region
Thika, Kisumu, Bungoma

© Albinism Society of Kenya

job opportunities and of course ensuring that we sponsor needy kids and economic empowerment.

The Albinism Society of Kenya has members across the country, in places like Mombasa. The photo you see here is a group of some of us in Tana River county.

There are various challenges. Low self-esteem. Low level of education. High risk of unemployment. High occurrence of single motherhood, and this is a vicious cycle where you have single mothers who bring up children with albinism. If the children happen to be girls they also end up being single mothers.

These are serious challenges that we need to address, because it has an impact even in terms of income of the family, household and all of that. Of course, Kenya is big. You cannot secure the whole country, there's still a lot of work to be done.

Education, Eyeglasses, and Sunscreen

How do we then intervene on these programs? How do we make sure that we work with people to make a difference?

The first one, as Horace Mann, one of the American Congressmen of the 1800s, said, education is the great equalizer, you've got to educate people. We have a program in Swahili which is called *Imarisha masomo*, you can see in that photo some children receiving checks to go to school.

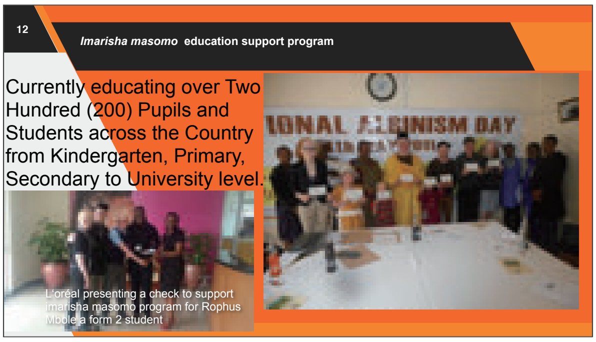
This is a very important thing. In fact, these are flagship programs and we collaborated with individuals and companies to do them. Before I forget, this is a guard. If you can see that photo, that gentleman there is a guard, he has educated with young kids with albinism. One of them just finished his exams. It's not about money. It's about what you are able and willing to do.

In terms of access to university education, we were able to lobby for affirmative action, to ensure that persons with albinism get into a university in a lower grade and you can see some gentlemen there who are able to receive an education.

The other thing is about provision of prescription glasses and eye care services. These are very, very critical because a pair of glasses costs about $100. And of course, many people would not be able to afford them.

Then, it's sunscreen lotion you can see here, us sending off sunscreen lotion to various parts of the country so that our people can get it free. There is no cost in that regard.

Then there is the issue of skin cancer. One issue you noted about skin cancer is that it affects men more than women. You may ask yourself a question why? Because these are people who go out to make a living in the sun and men don't tend to take care of

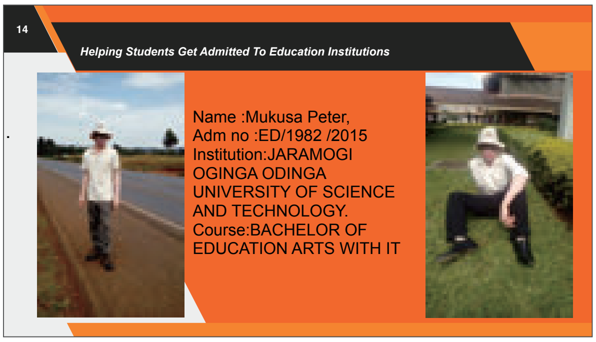


Imarisha masomo education support program

Currently educating over Two Hundred (200) Pupils and Students across the Country from Kindergarten, Primary, Secondary to University level.

L'oréal presenting a check to support imarisha masomo program for Rophus Mbole a form 2 student

© Albinism Society of Kenya



Helping Students Get Admitted To Education Institutions

Name :Mukusa Peter,
Adm no :ED/1982 /2015
Institution:JARAMOGI OGINGA ODINGA UNIVERSITY OF SCIENCE AND TECHNOLOGY.
Course:BACHELOR OF EDUCATION ARTS WITH IT

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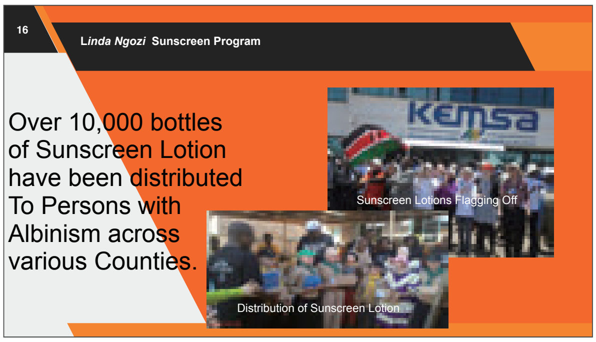


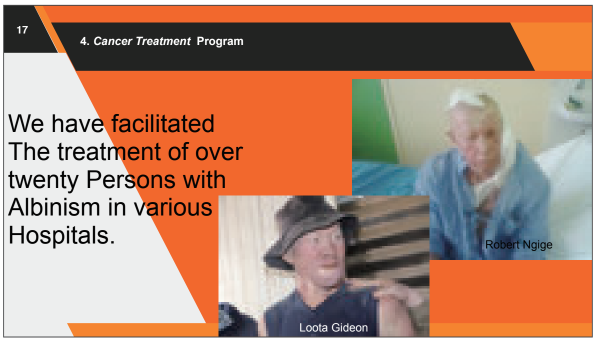
***Linda Ngozi* Sunscreen Program**

Over 10,000 bottles of Sunscreen Lotion have been distributed To Persons with Albinism across various Counties.

Sunscreen Lotions Flagging Off

Distribution of Sunscreen Lotion

© Albinism Society of Kenya



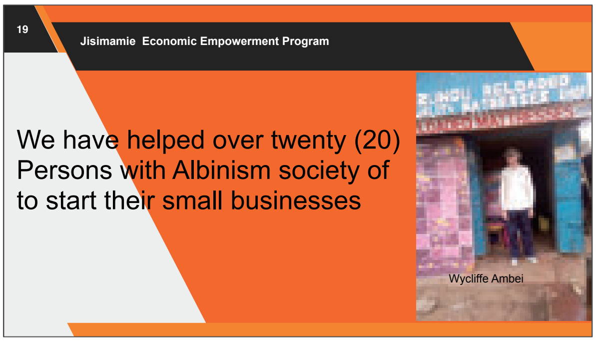
4. *Cancer Treatment* Program

We have facilitated The treatment of over twenty Persons with Albinism in various Hospitals.

Robert Ngige

Loota Gideon

© Albinism Society of Kenya

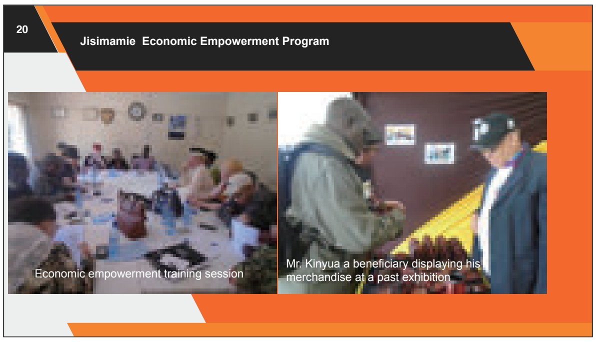


Jisimamie Economic Empowerment Program

We have helped over twenty (20) Persons with Albinism society of to start their small businesses

Wycliffe Ambei

© Albinism Society of Kenya



Jisimamie Economic Empowerment Program

Economic empowerment training session

Mr. Kinyua a beneficiary displaying his merchandise at a past exhibition

© Albinism Society of Kenya

themselves as well as women.

You can see those two gentlemen there, they require medical treatment. Before we get skin cancer, we do screening. This is now on an ongoing basis.

Then the economic empowerment program where you give small grants to persons with albinism to start a business. This gentleman here started a small business in a slum in Nairobi with us. He now has two shops, selling mattresses and all of that. Also he is polygamous, he has two wives, just to demonstrate that men with albinism are equally capable.

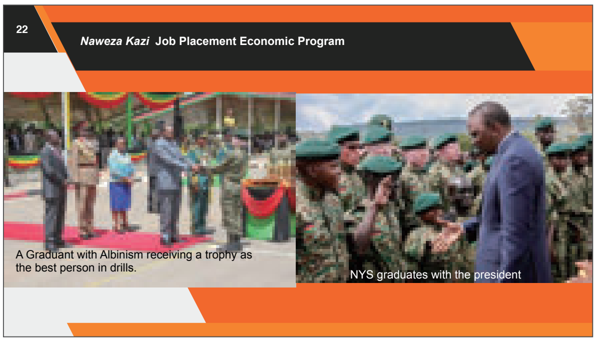
Anyway, then we of course train persons with albinism to do entrepreneurial work, that's one of the workshops and that's one of the exhibitions where people are showing their work.

Then we also try to place persons with albinism in various companies for jobs, we have partnerships, with the bank and other businesses, and our numbers are increasing.

There are other things that we have done very innovatively. People with albinism are seen to be weak. But we work with the National Youth Service. It's a new national service program, where we have had persons with albinism admitted so that they can be given paramilitary training. That means they can now work in the security sector. And you can see them looking like the police or the army. That's the president of the republic of Kenya.

The gentleman you can see there was the best in the year in 2016 in drills over 10,000 graduates and he is a guy with albinism. We took him into the program. Just changing perceptions, because before people never used to think we could do it.

And of course, we give a lot of internships, mentorship programs within our organization. Then we channel these people.

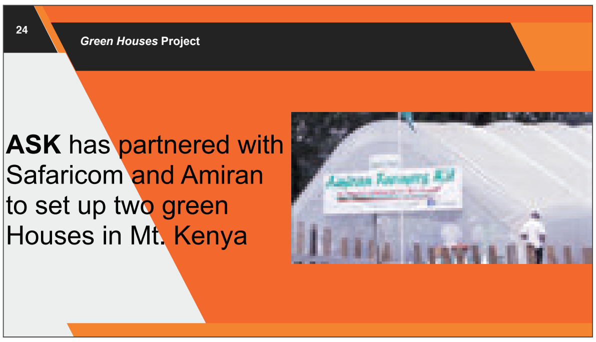


***Naweza Kazi* Job Placement Economic Program**

A Graduant with Albinism receiving a trophy as the best person in drills.

NYS graduates with the president

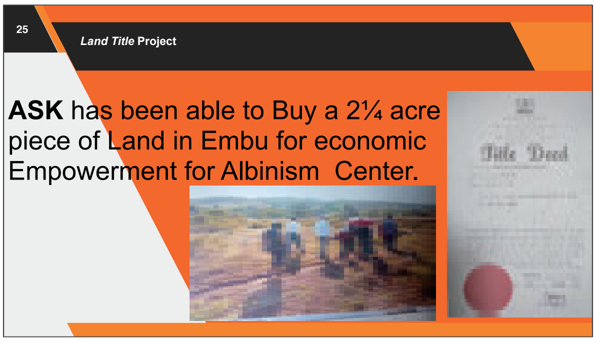
© Albinism Society of Kenya



Green Houses Project

ASK has partnered with Safaricom and Amiran to set up two green Houses in Mt. Kenya

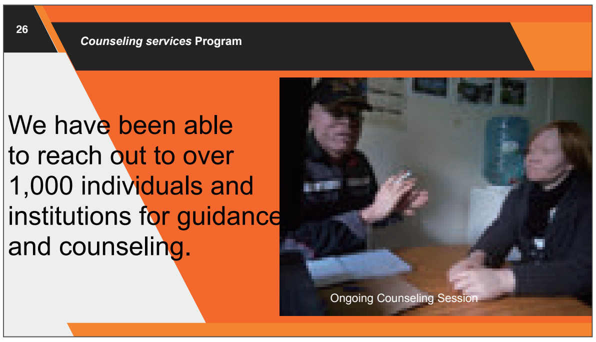
© Albinism Society of Kenya



Land Title Project

ASK has been able to Buy a 2¼ acre piece of Land in Embu for economic Empowerment for Albinism Center.

© Albinism Society of Kenya



Counseling services Program

We have been able to reach out to over 1,000 individuals and institutions for guidance and counseling.

Ongoing Counseling Session

© Albinism Society of Kenya

We are also involved in agriculture through a greenhouse project where persons with albinism are able to plant cabbages, tomatoes or whatever here.

We have a piece of land as you can see there. We hope to build this into a big project.

We also do counseling services. We visit people in their homes and just try to create awareness.

We have also been trying to rescue persons with albinism who are being trafficked. In 2009, just as Mumbi said, there was one of us kidnapped in Tanzania, but he was rescued in Botswana. Gabriel Kinyanjui and Bianca Chacha, two little kids who were almost killed, we rescued them.

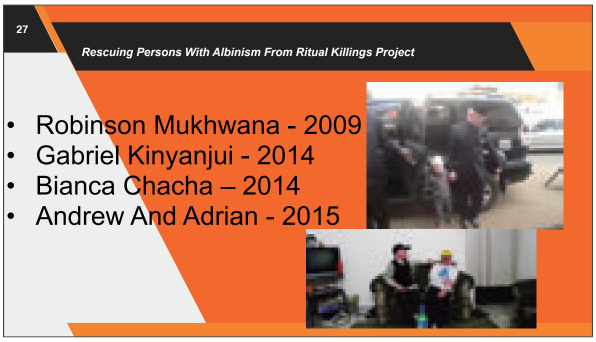
Then the twins with albinism. Also we were able to rescue them. A man who was HIV positive approached the mother of the twins and asked about collaborating to kill the twins so that both of them could be healed of HIV/AIDS. Those are the twins as you can see there.

The stories you are hearing here, they are not just stories. If you look at the first photos on the left, those are the twins. Then the other two are Gabriel and Bianca. They are children that lived with me, but now they are in school and we are happy that they are going on with their lives.

These ritual killings are not just found in Tanzania and Malawi. This is Kenya in 2016, where we lost one of us, Enock Jamenya. He was attacked with machetes and of course he eventually died. So, they are very serious issues.

We do a lot of advocacy. We do a lot of press conferences with the media. That's one of them in places far away from the capital of Kenya.

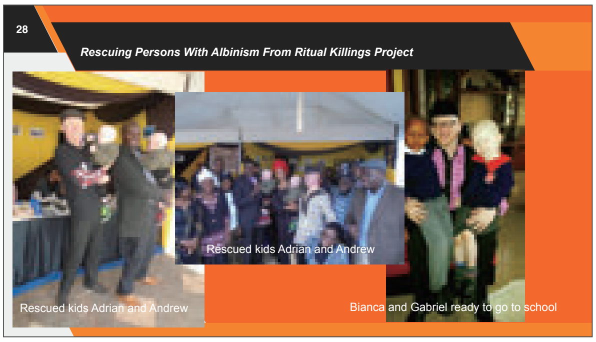
We have also made several petitions. You can see us doing street protests down there, and myself in the farthest photo there in parliament trying to argue for the



Rescuing Persons With Albinism From Ritual Killings Project

- Robinson Mukhwana - 2009
- Gabriel Kinyanjui - 2014
- Bianca Chacha – 2014
- Andrew And Adrian - 2015

© Albinism Society of Kenya



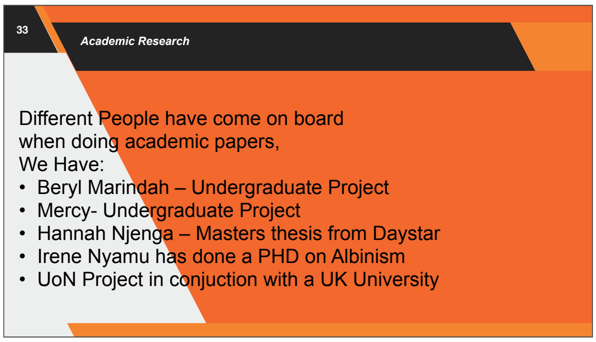
Rescuing Persons With Albinism From Ritual Killings Project

Rescued kids Adrian and Andrew

Rescued kids Adrian and Andrew

Bianca and Gabriel ready to go to school

© Albinism Society of Kenya



Academic Research

Different People have come on board
when doing academic papers,
We Have:
- Beryl Marindah – Undergraduate Project
- Mercy- Undergraduate Project
- Hannah Njenga – Masters thesis from Daystar
- Irene Nyamu has done a PHD on Albinism
- UoN Project in conjuction with a UK University

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Nisikilize - *Policy and Legislature Advocacy* Program

Presenting a petition to Hon. Eugene Ludovic Wamalwa on the plight of PWAs. Lobbying and advocacy

Members of Albinism Society of Kenya Protest ritual killings of their colleagues outside the office of the President

Presenting a bill in parliament on persons with albinsm

Legislative advocacy

© Albinism Society of Kenya

Nisikilize - *Policy and Legislature Advocacy* Program

We have been Lobbying
For Proper Laws in court
And also doing
Demonstrations so that our
Voice can be heard.

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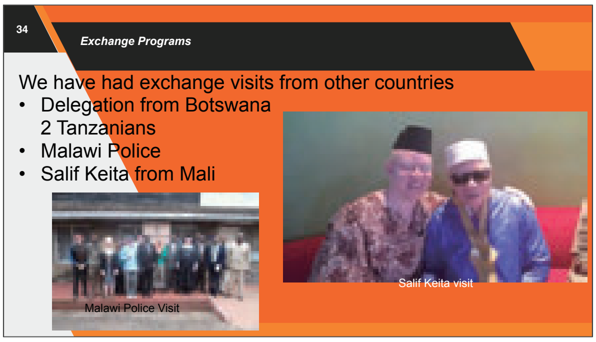


Exchange Programs

We have had exchange visits from other countries
- Delegation from Botswana
  2 Tanzanians
- Malawi Police
- Salif Keita from Mali

Malawi Police Visit

Salif Keita visit

© Albinism Society of Kenya

kids of our people. These are some of the things we do.

We also ensure that we do awareness raising. Awareness raising is critical, because you have to change people's mindset. This is one of the sessions that we have been able to do.

We also encourage academic research. These are some of the publications from undergraduates to PhD level where we have had people come to work with us so that we can document our stories. One of the things that we realize is that when you don't do so, you don't get to know what is happening in terms of the academia, then you have no backup.

We've had people coming to learn from us, from Malawi, from Tanzania and elsewhere because Kenya has been said to be a best practice country with regard to the inclusion of persons with albinism.

We also have role models. You can see our beautiful sisters there, Grace, Mumbi the Justice.

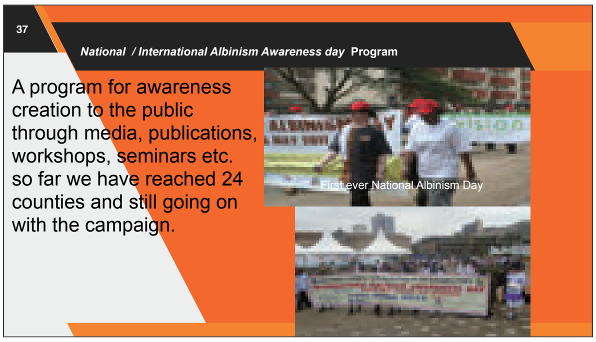
In last year's primary school exam, the best candidate in the whole country was a little girl with albinism. We are really making progress. This could not have been imagined before. We have people who have worked with us, now they are politicians or representatives at a lower level, that's one of them.

Of course, International Albinism Awareness Day (IAAD) is critical for us, but we did not start with the IAAD, we only started celebrating National Albinism Awareness Day in 2011. We were able to be part of the countries that lobbied at the UN to make it an international day. So we were really ahead in this regard. Kenya really does have various celebrations, not just one.

We've done film documentaries, with award-winning Hollywood actress Lupita Nyong'o, called "In My Genes" which really shows the various aspects of our lives. And in this movie, I actually featured as an aspiring politician, so as you can see, dreams come true because I actually became one!

Finally, we are looking at the arts. You cannot just have awareness raising where you take people to a classroom and you start telling them "Someone tell me what albinism is. Albinism is a genetic condition...," People don't understand, you have to use something that will appeal to them.

In 2016, we came up with something new. We used



***National / International Albinism Awareness day* Program**

A program for awareness
creation to the public
through media, publications,
workshops, seminars etc.
so far we have reached 24
counties and still going on
with the campaign.

First ever National Albinism Day

© Albinism Society of Kenya

8. First Ever *Mr & Miss Albinism Kenya*

It's a campaign that aims at promoting awareness of PWAs in the society essentially to stop vices like discrimination and stigmatization. Secondly, to raise Funds for ASK's Programs

© Albinism Society of Kenya

Help Us Put A Smile On The Face Of A Child Who Is Different!!!............

© Albinism Society of Kenya

beauty and talent to speak to the hearts and minds of persons with albinism. So, the first ever Mr. and Miss Albinism in Kenya was held. It was hugely successful. We could see the confidence of the people changed, and we were able to make a lot of partnerships.

On November 30, this year, we are taking it much higher. We are going to have our first ever Mr. and Miss Albinism in east Africa. Three countries are participating, this Saturday we'll have Uganda and Tanzania do the auditions, Kenya has already done so. Then we'll have the grand finale and the whole year's projects afterwards, just to create awareness and to show that we are not just people to be pitied, we are beautiful, because people find it very hard to have the words beautiful and handsome associated with albinism. We are seen as people who need pity.

Making it Sustainable

Now ladies and gentlemen, the charity and a lot of the work that we do as the Albinism Society of Kenya is not sustainable. That is a reason why I joined politics, because as the first Ghanaian President, Kwame Nkrumah said, "Seek ye first the political kingdom and all else shall be added unto you."

Nelson Mandela added by saying, "If you climb one hill, you realize there are several others to climb." Now, we have sought the political kingdom, went into parliament and because we realized as a society we couldn't just rely on donations here and there.

Persons with albinism are not owned by the organization of people with albinism. They belong to the government of Kenya. They are citizens. So, we were able to work very hard, all of us collectively.

We have a program now conducted by our government. The only well-structured government program, I think in the whole of Africa if not the whole world, on people with albinism, where the government provides money every year for free provision of sunscreen lotion, eye care services, awareness raising, treatment of skin cancer.

So, it is there and I.K. can speak more about it, because she just reviewed our country. We really want to have countries come and work with us. What we are learning though is that we can do so much with so little. In contrast, the government has their way of doing things, and does so little with so much. So the work of civil society must continue. We must continue to do what we need to do because we give an idea of what needs to be done.

There is a serious need to ensure that we have role models in society because it changes perceptions. Now in Kenya people walk around and they are asked, "Is Mwaura your brother?" As long as you have albinism, my name has in fact become the second name of people with albinism, because people can now make positive associations with albinism. I don't see that when I go to other countries. It actually pays to have persons with albinism in decision making. Representation actually counts.

Then finally it's good to have legislation. But African governments are very well known for having a lot of policies and legislations and they do not get implemented. Somebody asked, "You have your laws, so what? "

The issue is not about policies. It's about implementation and bringing life to society. It is critical to build the capacity of organizations of people with albinism working with government, because leadership almost invariably has the capacity to transform society. We have a lot of potential. We need to partner together so that we can make a difference. What is the purpose? That this whole issue, stigma and discrimination shall become history in our lifetime. Thank you very much.

Moderator **Thank you very much. Now, let's move to the Q&A session. I see a gentleman with a question already.**

Q&A 5

Moderated by Mr Djaffar Moussa-Elkadhum, Country Representative and Head of Office Mozambique UNESCO

Audience: Mr. Ryoichiro Saito My name is Ryoichiro Saito, from the Africa Japan Forum, a supporting organization of today's conference. This is my request, if I may, to the organizer that we would like to have today's presentation available to us, because what were discussed today have not been available in Japan. Let us also know if any books by today's speakers are available. Thank you.

Correct Diagnosis at the Outset

Audience: Dr. Takuma Ishii My name is Takuma Ishii, a pediatrician and a geneticist. I am one of the authors of a book on albinism published in Japan. PWA in Japan also face problems in societal participation when they are not educated like everybody else. While listening to all the discussions, I have been recalling similar problems here in Japan.

Anyway, it seems to me that I am the only physician attending this conference, perhaps because today is a weekday, and also because not many physicians pay much attention to albinism in Japan. PWA, in fact, are likely to be left alone throughout their lifetime after the first diagnosis is given.

However, I want to stress the importance of correct diagnosis at the outset. If a wrong diagnosis is made, this is where the complications, including the issues related to stigma, start. For several years, I have participated in a gathering of Hermansky-Pudlak Syndrome (HPS) that takes place in the U.S. Patients with HPS have bleeding and a lung condition accompanying their albinism, thus an accurate early diagnosis is crucial for these patients. There are few other diseases which are similar to albinism and need immediate attention. I want to also stress the importance of following up on PWA. In this regard, education of physicians is of paramount importance.

In countries where the government issues medical licenses, the facts about albinism must be appropriately taught before a license is given, and I think Japan can contribute in this regard by providing the necessary teaching. However, this topic has not come up during the morning session. I would like to know, if possible, what is going on in other countries.

Inclusive Education

Mr. Jake Epelle I have a question for Mr. Isaac Mwaura and the judge. I also have some reflections. Honorable justice, you did say that children with albinism are integrated into a school for the blind. I don't know if that's correct, and if that's correct, I strongly differ from that point of view. I don't think it's the best practice, knowing fully well that even the concept of a school for the blind is one of isolation. If you look at the principles of inclusive education, it negates this principle.

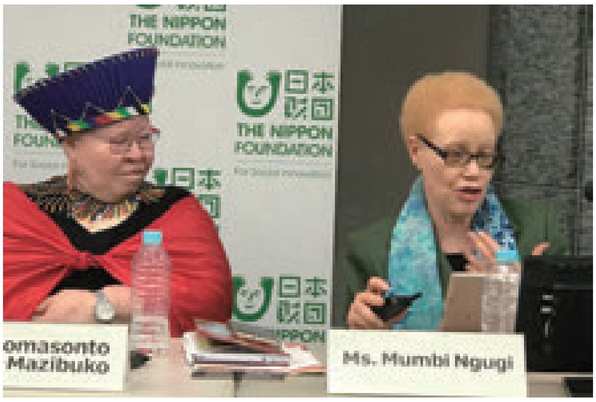
Isaac, you did say that your organization in Kenya was helping persons with albinism with lower grades to be admitted to schools. Do you think that is advantageous? For instance, in my own organization, I don't encourage that, I would rather ask students to go and repeat, compete like every other person, and then gain admission. I need your thoughts on that.

Finally, Isaac you said that you are more or less critical of policy because you feel that there are too many policies and no implementation. My question to you is, "Is it not better to have policies and start struggling to implement them than have no policy at all?" Thank you.

Moderator **Thank you very much. I will ask our two last presenters to answer the questions.**

Justice Mumbi Ngugi Thank you very much. Speaking first to the question from the pediatrician. I totally agree with the importance of having medical doctors and nurses properly educated about diagnosing children with albinism. Like I said, a part of the problem for mothers is that the nurses and doctors who attend to them in hospitals usually haven't come across or interacted with a child with albinism themselves.

I remember one woman told me that she rejected her child, because when the child was born, all the nurses and doctors crowded around the child and



started to say strange things like "I've never seen an albino," "What does an albino look like?" and the mother began to think that she had given birth to an animal or something.

Even basic information, basic knowledge for doctors about how to treat a mother who has given birth to a child with albinism and to teach her at the outset how to take care of the child is critical.

Live with Everybody Else

That was one of the important points I wanted to make, that these interactions, the information sharing with hospitals, at antenatal and postnatal clinics must be there. People must know that we carry the gene of albinism that makes it possible for you as a dark African or Japanese person with dark hair to have a child with albinism.

The other question is from Jake about education. I think we are on exactly the same page. I believe children with albinism should be taken to regular schools with all the other children, because you need to interact with everybody else. You belong to this society, there is no special society for children with albinism only.

Having said that, the only comment that I made is this: If the choice is special education or no education at all, then I will be the first one to take a child with albinism to that special school. At least they get some education. In areas where parents are not taking their children to school, I would tell them to take their child to the schools for the visually impaired run by sisters, because if you don't do that, your child wouldn't get an education at all.

But having interacted a lot with people from schools for children with visual disabilities, and other children who haven't gone to those schools or are going to integrated institutions, I believe the best thing you can do for a person who is different from others is to make them live from a very early age with everybody else.

You will be called names. I have been called names. I went to a school near my neighborhood. I couldn't walk home without children following me, insulting me. But after a while, they got used to me, they didn't bother with me anymore. If anybody insulted me, it would have been a stranger, because my community and my society was used to me and when I did well in school, people began to be proud of me. You know that is our daughter now.

That is what we must do, let children with albinism interact with everybody, be accepted. Belong. Because they belong. That I think is the short or rather long answer to that question.

Moderator **Senator?**

Affirmative Action

Mr. Isaac Mwaura Thank you. Yes, I agree when you have people who are starting to run, one of them starts with ten steps ahead and the other one starts with even one step behind the starting line, you've got to have what we call affirmative action to ensure that you restore parity for these people. When it comes to qualifications in school, for example for university, if you are admitting every other person, say with a grade of B, then with persons with albinism, other persons with disabilities, with girls, you can lower the grade one step lower, so that you are able to give them opportunities, noting the challenges they have gone through so that they can even be at the level they should be at. In fact, it's very difficult for them to even reach that level. I don't buy the idea where you tell them to repeat. That's a bit punitive.

If someone is qualified, well and good, but this does

not mean that everybody should excel in school. Even amongst persons with albinism there are those who are bright, there are those who are not so bright. But it's good to give affirmative action to people, with all the challenges of having a squint, looking at the blackboard and see nothing even though the lecturer or the teacher is writing.

Policy vs Implementation

The other issue is about policies versus implementation. Personally, I stand by the fact that I'd rather have a working program than some piece of paper written somewhere on some shelf. I mean it doesn't help. You'd just be gratifying yourself by saying you have a policy but in actual sense it's not put into practice.

This is why I'm advocating, budget, budget, budget. Let government set a specific targeted program budget for use to help persons with albinism, then the papers can follow. Right now in Kenya, we have a law that we are amending to outlaw ritual killings, we have a law in East Africa at the community level, we are thinking of coming up with policy guidelines.

We will have domestication of a national action plan or the regional action plan, we already started talking around the same. They will follow, whichever way it works. If it works for you to have a policy, well and good. If it works for you to start with actual programs, well and good. But I think eventually what matters is whether you are reaching the child with albinism in a far flung village who may not even know why they have been born the way they are.

Why does it help to locate albinism under the umbrella of disability? Because already disability has been accepted for a long time and indeed, we are persons with disabilities.

The only thing is that we have the "intersectionality," as I.K. put it, of color. So, you combine both. You get the best out of both worlds. But do not be put down by what I call the individual relational model where you compare different types of impairment between, say, a wheelchair user and a person with albinism. You are comparing the incomparable, because disability is not impairment. Impairment is any form of bodily loss of function that can be the result of injury, illness or congenital condition. But disability, just like gender, is a social construct that results from the interaction between persons with various forms of impairments on the one hand and barriers, especially environment and attitudinal barriers.

So, disability can be deconstructed. Impairment may relate solely to one's capacities, while disability is more of a political matter.

Importance of Networking

Finally, we need to network. To give an example, I was very happy to hear from my friend Junko from Japan. She tells me that she follows me on Facebook. This is just one example of networking that may have positive implications for the global community of persons with albinism.

Let us stay in contact with the Japanese albinism network, we have loved to see you here, you are really beautiful people, we have now social media and all of that. It's agonizing to hear that you are being told to color your hair to be accepted. It's the same thing that we feel. We need to be white and speak English with no accent, yet we are Africans. We feel the same challenges of being neither one thing nor the other. You are too white but not white enough, black but not black enough, disabled but not disabled enough. We suffer that kind of in-betweenness.

When you suffer that in-betweenness, you may feel lost. But our battle is not going to be won in conversations like this. You must take it to where it belongs. When I ran for the parliament office, I was even physically attacked, I had to have stitches in my ear following an attack, because people thought I was becoming too big for my boots, and because I wanted power for my people.

Let's go and fight and claim our rights. We are human beings, just like any other. Thank you very much.

Moderator **Thank you very much for these very passionate debates.**

Session 3

Promoting Involvement, Building Sustainability

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Overview: Albinism in Japan

PROFILE Dr. Yasuo Yabuki works as an operational member of the Japanese Albinism Network (JAN) to support people with albinism in Japan and promote proper understanding of albinism. He published "The Book I wrote after Researching and Thinking About Albinism" (in Japanese only) in October 2017, which presents his research on albinism. He won The Japan Sociological Society 17th Incentive Award in September 2018.

Assistant Professor, Rikkyo University
Member, Japanese Albinism Network (JAN)
Yasuo Yabuki

Hello, everyone. Let me first introduce myself. My name is Yasuo Yabuki and I teach at Rikkyo University. For some time now, I have been researching the history and life of persons with albinism from the perspective of sociology and the disability studies.

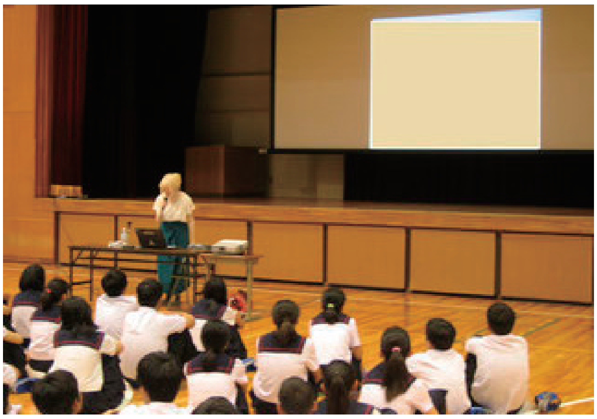
My research has focused on identifying the kinds of problems persons with albinism encounter and the ways in which they deal with them, based on surveys with people with albinism in Japan.

I have also been involved in self-help activities. There are two organizations in Japan. One is the Japanese Albinism Network (JAN), where I am also involved in an operational capacity. JAN is active in Tokyo and the surrounding area. The other is the "*Albino Donatsu no Kai* (the Doughnut Group)," active mainly in Kansai region. Both organizations provide peer and family support, information sharing on albinism, conduct awareness-raising and educational

■ The cover of Dr. Yabuki's book.
Ichiho Kasuya×Seikatsu Shoin ©2017

■ Christmas get-together of the Doughnut Group.
Photo ©: The Doughnut Group

■ Human rights seminar at a municipal level. Photo ©: The Doughnut Group



■ Explaining about albinism to students. Photo ©: The Doughnut Group activities to promote understanding of albinism in Japanese society.

We intend to network with professionals in areas such as healthcare and education in the coming future.

The photos show our activities at the iPad and visual aid workshop. We also held workshops on UV protection with the cooperation of the cosmetic product maker FANCL, with a dermatologist giving a lecture on the latest medical information.

Photo © Japan Albinism Network

Photo © Japan Albinism Network

Albinism and Leprosy

Today, I am delighted to attend this conference. As Chairman Sasakawa noted in his opening speech, The Nippon Foundation has been firmly committed to eliminating social discrimination against leprosy. We hope that the achievements and experiences of the foundation will serve to solve problems concerning albinism in African countries. Asked about ways to eliminate discrimination on leprosy, JAN, in fact, has given opinion, as a patient group other than leprosy, in a meeting organized by the Ministry of Health, Labor and Welfare. The meeting was intended to review how best to prevent recurrence of problems associated with leprosy.
Although the problems faced by persons with leprosy and those with albinism differ, we hope we can help each other and create a condition that brings benefit to both parties.

Let me now give a brief summary on the status of albinism in Japan as well as a few other developed countries.

In Great Britain, the United States and Japan

Researches in Great Britain and the United States suggest that no significant attention has been paid on albinism by the medical field, largely because the symptoms are stable, and PWA can live relatively normal lives without special care. One research that I found described albinism as "one of the most visible and characteristic conditions on earth," yet "a minority" that has been "rendered socially and culturally invisible."

Social ignorance and inadequate understanding give rise to problems. Let me introduce an example from the Great Britain. Though PWA are susceptible to UV rays, it is highly unlikely in countries like UK to develop life-threatening disease as a result. In legal cases where PWA insisted paying higher insurance premium as unreasonable because it was based on a supposedly higher incidence of skin cancer, insurance companies were found to be unfair.

With regard to visual impairments, a certain degree of technical and institutional assistance is available in Western countries. Accordingly, various disadvantages subject to PWA are due more to a lack of understanding by people around them than material shortages and system deficiencies.

In my book, I described in detail about similar situations in Japan. When PWA sought advice to improve their conditions coming from low vision, they were simply dismissed by response such as "You're not even wearing glasses," and therefore unable to receive necessary information. There have also been cases where they were denied of employment in the food industry for "sanitary reasons" because they were mistakenly believed to have dyed their hair too bright.

Doctors and teachers are no exception. They often lack correct knowledge and accurate information and are therefore unable to provide appropriate information to families. As a consequence, too often, PWA learn when and how to take precautionary measures only through their personal experiences. For instance, they avoid hours of outdoor activities only after they develop terrible sunburn themselves. I have also heard of cases where their vision were deteriorated at school and at work, because they were not provided with accurate information.

This can sometimes result in excessive anxiety. I know one family that took ultra extraordinary precautionary measures for their child with albinism. They were too worried about negative impact of UV rays, they closed all the curtains at home and the child was totally banned to go outdoors during the day.

I myself have also shocked such people by wearing short-sleeved T-shirt. There is a ton of misinformation on albinism on the internet; PWA have red eyes, magical powers, and so on. These are typical stereotypes in overseas as well. In Japan, PWA are also believed to be frail, sickly and short-lived.

Because not many doctors have accurate knowledge on albinism, I have heard of cases where doctors tell parents of a baby with albinism, "This child will not make it until twenty years of age," or even "ten years" in some cases. Parents, unfortunately, are often easily swayed by baseless comments from doctors. Some doctors are reported to dismiss claims from PWA, comparing albinism with other more serious diseases and say things like "There are people with more serious hardships. Your condition is nothing to complain about."

Current programs and technologies useful to PWA are not well known to medical and educational professionals, nor government employees. As such, they are often not available to PWA, and they suffer needlessly as a result. I think this is one of the characteristics of our situations in Japan.

PWA are often left isolated, not understood by friends and families. Since around the year 2000, online communities have emerged in Japan, allowing PWA to interact with each other. But prior to that, many PWA were left alone without relevant information. That, unfortunately, is still the case for some PWA today.

■ At a get-together meeting of JAN. Photo © Japan Albinism Network

Japan: Society Intolerant to Diversity

I would now like to talk about issues which I believe are unique to Japan. Despite ongoing globalism, Japan, I think, is a society extremely intolerant to people who were born with different looks. Foreign nationals and foreign born may share the same view.

In particular, what I call "black-hair norm" is very strong in Japan. Taking an example of job interviews, I have heard of cases where PWA are requested to dye their hair black, and when they refuse, saying this is their natural hair color, they are not hired. This happens mostly in service industry, but also in the field of welfare.

Worried about being bullied at school, parents of kids with albinism sometimes dye their hair black before they begin schooling.

While it is embarrassing to describe intolerance as "culture" unique to Japan, rigid school rules exist. Being different from others at school is not allowed, and force every other person to be the same.

Only recently, students with naturally brown hair were forced to dye their hair black, due to school rules. Dubbed as "black school rules," this incident attracted quite a lot of attention. PWA, in this regard, may not be the only one suffering from intolerance against light hair color.

Examples of unreasonable school rules can be found in clothing, too. But I must admit many such rules exist regarding hair styles and hair colors. Students not born with black hair are sometimes forced to dye their hair black, and in some cases where they are allowed to keep their natural color, they are demanded of a photograph from an infant age or "*jige shomeisho* (natural hair certification document)."

Rigid school rules also exist in the ban on; applying sunscreen at school; wearing hats and sunglasses during outdoor activities and going to and from school; wearing clothes other than school uniform, and more. In a case where the school rule prohibited sunscreen lotion, a student with albinism was allowed to put it on only after being suffered from severe sunburn, and with a condition that the lotion must be applied in a school infirmary with a presence of the school nurse, in secrecy from other students.

While today's conference focus on Africa, I have to stress that misconception and misunderstanding are deeply rooted in our society. It leads to human rights violation, and PWA are forced to suffer as a result. The problem is cross-cutting on the globe, regardless of national boundaries.

Japan: Missing the Real Issue

Another problem unique to Japan, I believe, is "*Moe*" culture towards characters with albinism in anime and manga. Looks of characters with albinism, typically, are regarded highly. They often evoke love and sexual desire, and are commercially consumed. This positive evaluation on appearances of PWA came from attraction to physical aesthetics of Caucasians that I believe is widespread in Japan.

Talking about identity politics among PWA, emphasizing beauty can work positively in terms of: empowering themselves; raising public awareness; and creating role models in their community.

However, when such stress on "beauty" of PWA is made by non-PWA, it can obscure and hide the reality where PWA are subject to discrimination. In one of the cases that I heard, when PWA shared their problems and issues, they were met with a response, "But you are beautiful." In this case, a positive evaluation on how PWA looks deprive PWA of raising their real issues, and prevent them from discussing experiences of pain and hardships.

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Toward an Inclusive Society

Project Officer, Japan International Cooperation Agency (JICA);
Japanese Albinism Network (JAN)

Daisuke Ito

PROFILE Mr. Daisuke Ito is a Project Officer at JICA (International Cooperation Agency).
He was Born in Mie Prefecture in 1992. He earned a Master's degree in Science from Tokyo Metropolitan University. During his Master's program in 2015, he studied at Umea University in Sweden. After completing his Master's program, he worked for the Albino Peacemaker, an NGO in Tanzania as an intern. Mr. Ito joined JICA in 2017, and was assigned to the JICA's Jordan Office until recently.

I'm so happy to be able to speak to you here today. I would like to thank Mr. Sasakawa, and Ms. Kyoko Itoh, my friend who organized this conference and who invited me here today.

I have been inspired by everyone's speeches about their efforts in tackling the problems that persons with albinism in the world face, protecting their lives and human rights, and how everyone is striving to make this world a better place.

Nobody thought I was Japanese.
It was very saddening to have to explain.

I haven't accomplished anything compared to all the other speakers, and I am still being supported by a lot of people.

Today, I would like to share my experiences in Tanzania and thereafter, how those experiences have made me realize that the problems that persons with albinism face today are not something that should be considered on an individual level, but rather on a societal level.

But before that, let me briefly share with you what it was like growing up as a person with albinism in Japan.

Being Different Annoyed Me

To be honest, I didn't have any interest in albinism when I was younger. Needless to say, opening up about my past problems and trauma, getting my voice heard, giving a speech in front of an audience were all out of the question. I had a strong sense of inferiority being a person with albinism.

What annoyed me the most at the time was the fact that I was different from other Japanese people. I looked different. And it was frustrating putting on sunscreen, wearing sunglasses and long-sleeved shirts and pants even on a hot summer day. I was always the last to leave the classroom at recess because it took me so long to prepare just to go outside. My visual impairment did not allow me to share the excitement that my classmates had of changing seats because I always had to sit right in front of the blackboard.

Nobody thought I was Japanese. Whenever I meet new people they would ask me, "Where are you from?" "Where are your parents from?" "Is your hair dyed?" My parents are of course from Japan. The first time I went abroad was when I was 18. I didn't like it when people asked me these questions. It was very saddening to have to explain that I was born and raised in Japan as a Japanese citizen, just like them. There weren't many people who were familiar with albinism back then.

Mother's Words Changed My Life

And as I grew up like that, one day when I was 18 years old my mother said something that changed the course of my life. My mother and I were reading the newspaper together and she all of a sudden said,

世界発
2012

白い肌 偏見と闘う

先天性「アルビノ」アフリカで虐殺も

「私の個性」世界的モデルに

「呪いだ」はびこる

■ Newspaper article on the issues of albinism in Africa (December 18, 2012 Asahi Shimbun).

"Daisuke, you are so lucky."

The article was about people with albinism in Africa. It was very shocking to me to know that some people's lives are under threat just because they have albinism.

Because of stigma, persons with albinism are being attacked and their body parts are sold for witchcraft ceremonies.

> I couldn't help but take it personally.

Because of their hair and skin color, some parents abandon them.

More than 90% of people with albinism in Africa are said to die by the age of thirty.

It was really hard for me to accept and believe what I was reading. I think my mother said what she said because she thought we were in a much better situation compared to the people mentioned in the article. But to me, I couldn't help but take it personally.

I didn't choose to be born with albinism. Nor did I choose to be born and raised in Japan. Likewise, people with albinism in Africa didn't choose to be so either.

Five years later in 2016, I joined "Albino Peacemaker" as an intern. It's a support group for persons with albinism in Tanzania.

What I Received in Tanzania

I lived in a dorm of a special school for children with albinism and low vision or blindness in Musoma, Tanzania. I organized their summer school, safari tour and film festival.

It was not easy to get used to the Tanzanian life and working there, but despite that I was so happy to be with many people with the same condition as me. It was very heartwarming.

I made friends with albinism for the first time in my life.

The elder students gave me a lot of useful advice and they cheered me up at difficult times.

Hearing the story of one of my new friends, Sr. Martha, encouraged me to keep doing what I was doing. Being a person with albinism herself, she has been helping and supporting children with albinism and their families for over 20 years. I was inspired by her love and passion.

Living together, I could share with them what I had

■ Dealing with albinism is no longer a personal issue, they are societal challenges we all face.

■ Days spent in Tanzania, filled with a lot of heart-warming experiences.

gone through and the challenges I had faced. We had a lot in common, but at the same time I was also keenly aware that being a person with albinism in Japan and being a person with albinism in Africa are not the same.

And I felt helpless because I didn't have any financial or political power to solve their life-threatening situation.

Right before leaving Tanzania, I talked to Sr. Martha and other staff members about how I felt. Upon hearing what I had to say, Sr. Martha said, "We would like you to contribute to society in your home country first. Your effort will inspire the next generation of children with albinism in both Tanzania and Japan. Just like how other persons with albinism have worked hard in their own countries changing the society for the better, we want to change our country, too. I want you to support us."

> "We would like you to
> contribute to society
> in your home country first."

■ With Sister Martha.

My experiences in Tanzania and the words that I received from them are what support me today.

Shortly after coming back to Japan from Tanzania, I graduated from graduate school and started working for the Japan International Cooperation Agency (JICA) to put to practice what Sr. Martha had told me. It's an organization that carries out financial assistance to developing countries in the form of Official Development Assistance (ODA).

I also started co-running the "Japanese Albinism Network" with Dr. Yabuki, who delivered a speech this morning, and others including people who are persons with albinism to support people with albinism and their families.

I'm currently taking part in an infrastructure development project led by JICA in developing countries in regions such as Africa as a government official.

Last year, I was dispatched to Jordan to join a project which supported Syrian refugees who had been disabled in the civil war.

■ With persons with albinism from Tanzania and Malawi who came to Tokyo to participate in a JICA project.

■ Listening to the stories of parents who have children with albinism and giving them advice is a part of my work at Japanese Albinism Network.

The other day, I met some people with albinism at JICA Headquarters in Tokyo. They came from Tanzania and Malawi to participate in a technical assistance project.

Meeting them as part of my work was one of the happiest things that have happened to me since I started working for JICA.

I have also had many opportunities to talk about my experiences in Tanzania at junior high schools, universities and at the Ministry of Education.

As part of what I do for the Japanese Albinism Network, I often listen to children with albinism and their parents talk about their problems. Most of the problems are the same problems that I had when I was younger. They also mention problems that are common among persons with albinism in Africa regarding health and education.

On the one hand, I feel relieved to know that I am not alone. But on the other hand, finding that children and parents today are experiencing the same difficulties my parents and I experienced ten years ago worries me. Has the world gotten any better for persons with albinism?

Making This World a Better Place

To solve this problem on a fundamental level and to ensure that our next generation can live safely and happily, I believe that we should not only help and support persons with albinism and their families but also take further action to change how society views albinism.

This is obviously easier said than done. And it cannot be done by just one group or organization. It is very important that we all work together. This conference is another step towards this direction.

I have learned a lot today. I feel the world is gradually changing. I am full of hope knowing that there are many who are working hard all over the world to raise profile of the struggles of persons with albinism and to get others to join us in making this world a better place.

Ten years ago, I used to see all the problems concerning my albinism as personal problems. How I look, stigma, visual impairment, sunburn, etc. However, I now see all these as social challenges for people with albinism in Japan, Tanzania and other countries in the world.

I believe that by tackling these issues, we can create a positive ripple effect on other social issues such as human rights, discrimination, education, and healthcare.

I am determined to keep striving with my family, organization and all of you here today.

Thank you.

The Sky's the Limit

PROFILE Known as the world's first fashion model with albinism, Hong Kong-born Ms. Connie Chiu is also making a name for herself as a jazz vocalist. Her very first international fashion show was for the French designer Jean Paul Gaultier, and she has worked for brands such as Diesel, Bulgari and Rover. Images of Connie have been published in Vogue, Vanity Fair, and the Sunday Times. As a jazz singer, Connie performs at major events and festivals such as Ealing Jazz Festival. Her debut EP "My Huckleberry Songs" released in 2015 features songs such as "Moon River." She is a Champion in the United Nations Human Rights Office's Albinism Awareness Campaign, sharing her story and supporting the rights of individuals with albinism.

Jazz Singer and Fashion Model

Connie Chiu

This is my first presentation ever, so be patient with me. I'm going to share a little bit about myself, about my experiences, as a person with albinism working in music and also in fashion. I have a catch phrase: The Sky's the Limit. I'm a little bit of a dreamer. But I think sometimes it helps to dream big.

Born as a White Chinese Girl

I was born in Hong Kong, my family is Chinese and I'm Chinese. I was the only child in the family born with albinism. The only thing the doctor said to my parents was "Your baby lacks pigment." I was born in the pre-internet time. My parents couldn't google "albinism" and it was very hard for them to find any information at all about it. It was difficult in school, I couldn't see the blackboard, I think a lot of people with albinism, people who are partially sighted can relate to that.

And my family thought, "Perhaps we should emigrate to Sweden, to Scandinavia." Because in Hong Kong, Connie was stared at because she was a white Chinese girl, but surely in Scandinavia, everybody is blond, so she would fit in so much better. That plan didn't quite work out. Because in Sweden, I'm still a white Chinese girl.

But there was a difference, because the Swedish school gave me support straight away. They helped me with equipment such as magnifying glasses, and a monocular so I could see the blackboard.

They also arranged for me to see an eye specialist. I was only eight, and I didn't understand much Swedish at that point, and someone had to translate what the eye specialist told me. He said, "Because of your albinism, and because of your eyesight, everything is going to be so much more difficult for you." "*Everything* is going to be so much more difficult," he repeated, "compared to your siblings, compared to your classmates." And as an eight-year old, I did feel a bit sad and a little upset about it. Life has just started. And here is someone telling me, everything is going to be difficult.

But then it just took me a few moments, and I thought to myself. "Really? That's what you think? We'll see about that." So very early on, I was a bit crazy. I'm obviously a bit rebellious. I don't know where it came from. But I think that attitude has helped me.

■ A monocular to magnify the images.

Go for What You Love

Let's talk about how I got into modeling. Well, this "crazy person" was invited to model for my big sister's fashion show. It was a college fashion show, because my sister was studying fashion design. I really enjoyed it. The feedback was really good, and I thought "I want to do more!" I really like French designer Jean-Paul Gaultier. I thought, "I send him a photo of myself. And let's see what happens. I'm not going to write a long letter. What's the point, you know." I wrote my name and phone number on the back of my photo and sent it to him.

A few months later, his office got in touch, they wanted me to do his fashion show, an haute couture show in Paris. So that was the second fashion show I did in my life. I continued to take on more modeling assignments, I did pop videos, TV commercials, a lot of jobs. So, I started out in modeling without knowing anyone, I just took a chance. This "crazy person" took a chance.

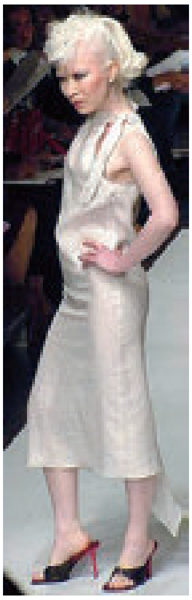
And how did I get into jazz singing? Well, in the same way. I always liked singing, and I used to listen to records from my dad's record collection. And he had records by artists like Nat King Cole, Acker Bilk, he is a British artist, and the Glenn Miller Big Band. I was about five, and I was listening to jazz. I didn't know it was jazz, I just loved it. So that's how my love for music started. I was actually teased for my singing when I was little because I used to sing with a very deep chesty voice, if you imagine a little girl with that voice. I guess it was quite funny.

I joined the school choir for a few years, but it took a quite some time, before I had the courage to say that I wanted to do solo singing. I took some classes, and I did some courses. And a pianist, playing for us in one of the courses in London, he was very talented. And he's got a lot of experience and had done a lot of gigs. He said, "You should do gigs." I thought, "Okay, yeah, why not?"

I started to do gigs and now I do my own gigs. I do gigs for major events, for dinners, for festivals, and I'm very happy to say that I have managed to release a debut EP all by myself. It's all my own handiwork. It's been really hard work but if you're willing to work for it, I guess it can happen.

Practical Problems and People's Attitudes

Let's talk about practical problems and attitudes when you are a person with albinism and you are working in music, and also in fashion. Light comes to mind. Bright light is quite difficult for us. But luckily, I remember the first show in Paris that I did for Jean-Paul Gaultier, I had light protective lenses on me. Jean-Paul Gaultier and his team were quite happy for me to wear them.


Design: Margie Tsai
Photo: Cynthia Nellis
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But on the other hand, about 20 years later, I was invited to do a video interview, commissioned by a major fashion magazine. I went to the set. They wanted me to talk about albinism. The light was very bright, I tried to negotiate to turn the light down, and I said to them I have light protective lenses that I could wear, but they did not want to know. They said no, no, no, it's fine, let's just get started. It was very weird for me. It was as if we were in two different dimensions. They just couldn't hear me.

I ended up standing in front of the camera, in very bright light, talked about albinism, talked about how light-sensitive my eyesight was, squinting in the light. It was quite ironic. A difficult situation, but I decided that I could actually take control of what I wanted to say in the interview. I couldn't control the light, and I just had to suffer through that. I thought that was the opportunity to share, to reach a lot of people, to share my experience. I stood there for one hour in very bright light and answered all kind of questions.

I think attitude is so important, you know what sort of attitude people have. Jean-Paul Gaultier was fine with lenses and 20 years later, we moved on so much in medical sciences, but no, if you have the wrong attitude, nothing is going to help.

Pros and Cons of Being Partially Sighted

Let's talk about being partially sighted, and not being able to see properly. When I stand on stage and sing, I can see the front row quite well, but the rest is, let me describe it as an Instagram filter. When you put a soft filter on, and everything is slightly blurry. It's for better or for worse, because for better, you are slightly less nervous when you can't see people making faces at you. I can see you are here, but over there, yes, I think you are blond, I think you have dark hair, but that's about it. Sorry. That maybe the good thing about it. You can be less nervous. But on the other hand, as a singer, you can't really work with the audience in the same way if you can't see their faces and expressions. You just have to live with that.

Daydreaming in Modeling and Singing

So why modeling and why music? Well I think those two fields have things in common that I really like. For example, teamwork. When you do a photo shoot, it's a makeup artist, stylist, hair stylist, photographer, and me. You all have to work together to create something. And a lot of times, it's very hard to put in words exactly what you want to do. So it's like reading each other's minds.

And music, it's the same thing. Today, we had a very small team for a lunchtime concert, it was just me and the pianist. But it's still teamwork, you still have to figure things out, and try to work together, and I think another good thing about modeling and music is that I get to daydream, because I always want to convey something in my work. I want to tell a story. I want to take you to a different place.

Dealing with People's Attitude

But there is more about people's attitudes I would like to focus on a little more. When I started modeling, a man who was studying acting said to me, "I can understand why people want to work with you. You know why a makeup artist wants to work with you? Because you are like a piece of white paper."

I thought that was quite insulting. Would you say something like that to a black model? Here people like to work with you because you are...? So, I think sometimes, people don't even think about it. Perhaps they feel the need to objectify you just because you look different. And maybe they want to diminish your achievement a little bit as well just to make them feel slightly better. I think sometimes you just have to be aware of those attitudes from people.

But it's not easy in music either, I can tell you that. I

remember once I was talking with the host of a venue where I was going to have a gig, and the host turned to me and said, "Do you think people come to your gig for your music?" I was quite speechless at first. Yes, live music. Why else would they come?

But then I realized he meant me, and the way I looked, that maybe people come to my gig to just look at me to have a good stare, like a curiosity act. I think the horrible phrase that people used to use, was freak show. So I was quiet, but you have to react. You cannot just back down, so I said to him, "Well I don't think so because I have to keep people's attention for 40 minutes, for 90 minutes. Can you stare at me that long?"

So that's another way that you have to deal with people's attitudes. But of course, then I have my attitude, you know, how I cope with things.

I told you about the eye specialist before. Sometimes in music I do get negative responses from singers and from instrumentalists. Because one of my first ever gigs, right after I finished performing, a singer came up to me and started to shout at me, she was quite unpleasant. And other singers they just shouted at me, pointed me in the face and said "I hate you because you are nice to me," "I hate you because you helped me," "I hate you because you had a chance to record a CD and I don't." So how do you react to that? Hide under the duvet forever?

Oh no, not me. I thought to myself why are these people being so aggressive, and so hateful? When I got the Ealing Jazz Festival gig, a sax player said, "How come you got the gig?" It's very hard to say if people behave like that because of my albinism, because I'm a woman, or because I'm Chinese.

I just don't know. Maybe they don't know themselves. But I just have to deal with it, and the way I deal with it, I think about the situation and I think, "Why are they so aggressive? Why are they so hateful? Actually, I must be doing something right." They must feel like they wanted to discourage me somehow. They must feel slightly frightened by me, little me. So I think you do have to pick your battles in life, but you also have to use your brain, and think about what people want from you, and what you want from the situation.

Learn to Trust Yourself

Right, so let me finish off by talking about what I would say to a young person with albinism. Some people call me a role model. I don't want to call myself a role model, because I think that a role model is someone that you pick. It's not for me to say I'm a role model.

But I would definitely say to people, don't believe in everything people say to you. People want to say, be this, you can't do this, you can't do that. I remember a makeup artist I used to work with, I only worked with her once, she said to me, "Don't you ever dare to put mascara on your lashes." I think for her, my white lashes are like a part of my identity, and in her mind, if I put mascara on my lashes, I'm denying myself, my true identity.

But I look at it in a different way, because it's my lashes. I can do whatever I want with them. You know everybody else is, so why can't I? So, don't believe in what people say to you. But also, I would definitely say that you have to trust yourself. You have to learn to trust yourself. Because you are the best person to know when to push yourself; to try to find out where your limits are; to find out what your potential is.

So, we all have different dreams. You may want to be an astronaut, you may want to be a doctor, the best mom in the world. Yes, why not? Or maybe you want to be a shoe designer, yes that would be great too.

It's not going to be easy, but definitely dream big. The sky's the limit. Just a message from a dreamer. Thank you very much.

Q&A 6

Moderated by Ms. Ikponwosa Ero, UN Independent Expert on the enjoyment of human rights by persons with albinism

Moderator **We now have roughly about 30 minutes for discussion and questions to our panelists. You can ask questions about anything that has happened today, because this is the time to dream, as our speakers have spoken about dreaming, and about acting on their dreams. The floor is open to questions not only for panelists but also for the whole conference.**

Any Support Available from JICA?

Mr. Isaac Mwaura Thank you, I couldn't resist being the first one. Thank you very much, Daisuke Ito and wonderful Connie. Daisuke, one question for you. You are now working with JICA. JICA is very, very powerful in terms of development cooperation. And if you look at Article 32 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), it calls upon state parties to collaborate either bilaterally or multilaterally with regards to development cooperation.

As a young person with albinism, what is your vision? You may be one part of the whole organization, but what is your vision with regards to ensuring the issues of albinism as part of JICA's development cooperation?

And Connie, first I really want to thank you very much, and yes indeed you are a role model. And I'm very privileged that I have met you today. Because I've been talking about you as one of the role models when we talk about albinism in Kenya, I'm very happy. You have spoken very powerfully, and you've inspired a lot of us. In fact, I was speaking with Patricia, Ms. Nomasonto, our mother, and Peter, big brother, we are all connected with you. Because the things you were saying really connect with us. Your eyes were crying in front of that camera, you clearly couldn't see who was interviewing you, yet you were supposed to be focused. We go through those things. But there's something I want to ask about just to elaborate further.

That issue, when you excel, when you stand out, people throw albinism at you. That issue about people's feeling. When you help others, it's not adequate because you have albinism. They don't like the fact that it is you who is helping them, it's less valuable, that kind of thing. This is something we face all the time. When you don't work hard enough, it's attributed to albinism. When you work hard and excel, it is attributed to albinism. It's like you don't deserve the things you deserve. Kindly explain how you interpret it in your own terms. Thank you.

Moderator **Thank you, Isaac.**

Mr. Jake Eppel Excellent. Ms. Chiu, if you say this is your first presentation, well done! I told you privately that my wife follows you and you are one of my wife's icons, you know but the thing is, I want you to use your platform, especially your musical platform. You're better than Celine Dion, right? You know, you have a huge platform, very good personality. Please

use it to advocate for albinism on the global level. You know that is just my appeal to you. And for my brother, less collectively, at the end of this conference, please come up with a resolution. A powerful personality like Mr. Sasakawa can attend, whom you will take to your organization.

Two things that the ambassador in Nigeria said when I went to the media on behalf of this conference. One, you are going to meet Mr. Sasakawa of The Nippon Foundation. And two, somebody from JICA will be there. He said these two organizations can fund everything for albinism in Africa. So let's pass a resolution that you can take to your organization. I said one of the things that was said in this conference was that JICA should fund the African Albinism project. You know, not like a command, but an appeal. Thank you.

Moderator **Thank you. Was there another question? Okay, so we are going to take a pause and allow panelists to respond, then we will take a new set of questions.**

Mr. Daisuke Ito Thank you for your question.
It has been two years since I started working at JICA. JICA is a very large organization, and I feel that the organization has financial as well as political strength. Nevertheless, I feel that it would be extremely difficult for me to be able to apply JICA's capability immediately to my efforts on albinism, though I regard it my life's work.

One point is, people with albinism are very few. albinism are very few. The reality is that when I talk about albinism issues with my colleagues, they suggest rather than focusing too much on such issues, we should consider what kind of infrastructure to put in place to combat poverty in Africa as a whole, and this is the direction in which the conversation is proceeding. This is a matter of considerable concern for me and I feel frustrated about it.

After living in Tanzania, I feel that all of the problems of development and poverty in Africa could be could be found in the life of a person with albinism. That they are too poor to buy sunscreen; that they go through poor education system; that they cannot get jobs with decent salaries and; that they die young because they work outdoors at low wages. The problems of poverty in Africa are reflected in the lives of persons with albinism.

How we can make international and development organizations aware of these problems is a matter of great concern. Here today, with people representing organizations from countries all over the world, I would like to ask everyone's opinion afterwards on how we, as a group gathered here today, can make an appeal to large international organizations, and what kind of message we can convey to them.

From my personal standpoint, I was able to realize my dream of meeting Ms. Ero at today's conference, As a person working for JICA, my dream is to take on a development project for people with albinism. To realize this dream, and also to become a personnel who could make the best use of many of JICA's strength, I will continue to do my best in whatever work I do for JICA. Thank you for your attention.

Find Your Tribe

Moderator **Thank you so much, Daisuke. Connie, you have the floor.**

Ms. Connie Chiu I think you are talking about being scrutinized, being judged, as an individual because of albinism, you can't do anything right. I think it is very hard for other people to understand people who haven't got albinism that this is so natural to me. When I wake up in the morning, I don't think "Oh,

I've got albinism." The first thing I think about is like, "I'm going to have breakfast." I think it's very hard for people to understand, and to see you as a person, as an individual.

You also talked about the example of the singer who said she hated me because I helped her—I was nice to her. I think there's also almost the expectation that you need to be inferior to me. That's an attitude they are not even aware of. Perhaps that's why it's difficult for them when a person with albinism achieves something.

But who cares? That's all I have to say. This is what I want to do, and I'm just going to do it. Although I have been being very negative now, of course in music, I meet wonderful people, too. Like the pianist today, Elia Gaitau, we worked so well together. I have a band in London that I work well with.

I think eventually, you will find people. You will find your tribe. That's how I see it. people who can see you for who you are. There are always people who will try to put you down for whatever reason, you know, because you are a woman, because you are at a certain age, because of your sexuality. You just have to understand where people are coming from.

And you have to decide, this is what they want from me. Do I want to give it to them? You have to decide what you want from this situation or from this relationship. I think most of you have to think about yourself as a person, with exactly the same rights as other people.

Concentration of PWA in Tanzania

Audience: Dr. Takuma Ishii I have seen a report in Japan that people with albinism are concentrated in a particular area of Tanzania. However, I do not quite understand the reason for this in terms of genetics.

There is a theory that there were many people with albinism who took refuge in that place. However, I am not convinced that people with albinism increased solely due to this reason.

Many people with albinism, as many as 200 families, congregated in this place in Dar es Salaam, and that people with albinism from all over Tanzania went there. Personally, I find it very difficult to believe. How in the world could all those people become concentrated in one location without notable communication network or anything? I wondered if something like that really took place.

I might be able to agree with this theory if people of a totally different race lived there, and if the ratio of albinism were particularly high among those people. Or maybe the situation is plausible in the case of inbreeding, or if consanguineous marriage were extremely high in this area. I would like to ask Mr. Daisuke Ito who has been to Tanzania or any persons from Tanzania, about the correct information.

Moderator **Thank you, Dr. Ishii. Any more questions or comments?**

International Organization for PWA

Mr. Bonface Massah I was just thinking about the network of albinism in Japan. It's very coordinated.

We haven't had a really visible organization that really helps us, maintains us and also gets us connected. If you look at people who are blind, there has been the world unit for the blind. It is the same if you look those who are deaf or those who have physical disabilities.

But for albinism, why can't we make such an organization? Most of us are struggling in a civil society. We really need to set up this kind of a world body that addresses issues, controls sources, channels to the right organizations, conducts monitoring, implementation and empowerment of the classified organizations.

I was looking at this platform as an opportunity. The Nippon Foundation, the UN and different partners who are here may start thinking around what we can do. I know there are a lot of issues around Africa. But I want to see something really working, like what the disability sector is doing to ensure consistency. This issue is really championed by people both at the global and national level. Thank you.

Moderator **Thanks, wow, there are more hands. Yes, please.**

How to Share the Best Practices

Mr. Djaffar Moussa-Elkadhum Thank you very much. I wanted to relate experiences of Daisuke with the one of Peter. Privileged in a sense, the difficulties of persons with albinism in societies such as in Canada and Japan, are not similar to those in Africa.

My question is how can we mobilize youth from developed countries to have experience in Africa? How can we support civil societies in those countries, sharing our experiences for their learning and further engagement?

Moderator **Thank you very much, Moussa, because it's an open discussion, we can have some responses from the floor. The first question was by Dr. Ishii, who wanted to know the concentration of the persons with albinism in Tanzania. Are there areas that have higher concentration or are there races with higher concentration? What is this issue about consanguineous or intermarriages and the relationship with albinism? Can I call Vicky to respond? Could you very briefly, explain? Thank you.**

Ms. Vicky Ntetema Thank you very much. There is no place where more than 200 people have gone to live together. We are not aware of that [Ms. Ero: Ukerewe island? Maybe he was talking about the island of Ukerewe?] That is the report that we have been hearing from foreign journalists who go to Ukerewe. But we know people in Ukerewe in the education program are running away, because it's not safe for them, including the chairperson of the Tanzania Albinism society in Mwanza. He lives in Mwanza although his home is in Ukerewe. So, I don't know how that story started. But definitely, there are not 200 people who have gone there to live in peace.

Another thing is about intermarriage. Yes, we have an area in Lushoto. Lushoto is in northeastern Tanzania, in the Tanga region, where cousins marry cousins. Distant cousins would marry also. That is why, in one village, you have quite a lot of persons with albinism, I don't know the number right now, but it's something that you can get later. I think those are the two things. Was there another question?

Moderator **Yes, about race, but I can answer that if you want. In terms of race, North America and Europe have reported estimates of one in 17,000 persons with albinism, Fiji and the Pacific Islands, have reported estimates of one in 700, one of the highest in the world, in Panama and among Aboriginal groups in Panama, one in 125. That's the highest we have recorded. In the Africa region, the World Health Organization did a study in 2006, and it was one in 5,000 to one in 15,000 with many tribes having one in 1,500. So it really varies. Thank you.**

And the other questions? One of them was concerning whether we could have a world body on persons with albinism? It was more like a comment, if somebody wanted to address that. You're welcome. Peter?

Past Attempt: World Albinism Alliance

Mr. Peter Ash I'd like to address this question about a world body for albinism for couple of reasons. One year ago, I was a member of, I am still a member of, National Organization for Albinism and Hypopigmentation (NOAH).

I have been very involved in NOAH off and on since the 1980s. I was at the conference in Chicago in the late 1980. There was an attempt to create, in fact, we did create, the World Albinism Alliance, the WAA, and I was one of the founding members of it. My brother Paul and I are executives. I created a logo for it, with a lot of enthusiasm from a small group of people, and we tried to get it off the ground. Frankly, there was just very little volunteer dedication. Most albinism groups around the world are volunteer-driven, including NOAH. There was no staff members, there was no funding for it. You know, we did our best to get other groups involved. Some groups had the enthusiasm but didn't have the resources. Some groups have the resources but don't have the enthusiasm.

After a few years, it was fizzled out due to lack of commitment. I just said, well I can't run this thing on my own. At that time, I was very busy with my education, and business and other endeavors I was engaged in. So I kind of put it aside.

Moving forward, in 2008, I started Under The Same Sun. My attention at that time was on the crisis of people with albinism in Tanzania. But de-facto in a very indirect sense, Under The Same Sun ended up filling some of that void. We started with Tanzania but we were Pan-African. We organized the Pan-African Albinism Conference. It was held in Tanzania, but we had people from other countries and from around the world with albinism. So, it wasn't just Africa, though it was billed as a Pan-African conference.

And Under The Same Sun gets emails all the time from all over the world, not just Africa, but people with albinism with issues of discrimination. We get emails from China, and countless other countries. So, I like the idea of a World Albinism group.

Here's the challenge. As I discovered in the 1980s, people who have some of the interest have limited resources, people who have resources have limited interest. To be really frank, most Western groups don't really care. I'm Western. So I'm free to put myself down. I get very little enthusiasm from most Canadian, American and European albinism communities about this issue.

So, I decided I wasn't going to wait anymore, because I care. The issue is I'm not trying to be negative. I'm trying to be realistic to explain why it's been a hard time. We can go and wave the flag and get a group going, but the people who really have that dedication are the colleagues here in this room from Africa, because they view this as a life-and-death issue. To many people in the Western context, either they don't want to talk about albinism, or if they do, it would perhaps be on hard-to-deal-with challenges in schools, because of low vision and so on. So it's a very select group that are significantly motivated, to put that kind of time and energy into running such an organization. So if I talk about the kind of challenges around it, I'm behind it.

Talking about having another Pan-African Albinism Conference, when we had one in Tanzania, there were people from a large number of countries. Most of them were African, but a few were non-African countries. We had a few hundred people there. That was a big success. We have been looking to have another one for a couple of years. We haven't set the date yet. And maybe next Pan-African conference, we can somehow expand internationally. And we will be free to invite others to attend. How many would attend, it's hard to say, since we are taking an advance. We are considering, but it all depends on the level of interest of the participants.

Moderator **Thank you, Peter. There was a final comment from Moussa about how to mobilize sharing best practices but I think this has somehow addressed a little bit of the question. Okay thank you Moussa. We will take a final round of questions.**

Ms. Nomasonto Mazibuko Thank you very much to the panelists. To me, as a founder, I feel very, very empowered and excited to see young people coming together. Because usually, there is a generation gap, and you always feel, and you sit and don't give a chance to young people. But I'm very inspired, as I said in my speech, I see many smiles on our faces this morning and today.

And to you, Connie, thank you very much. As an activist on women's issues, I feel very, excited. And the social media, you don't know how much you are a role model in social media. Congratulations my dear sister. And welcome to the big world.

To you, Mr. Ito, JICA has an organization in South Africa that talks specifically about disability for independent living. To me, this morning, again, it means becoming together. As persons with albinism, through JICA to say we were the last, can we be the first to come in? So congratulations to you. And to me, with my brothers and sisters, as an older person, I feel so empowered that I can give way, and feel I will have the best sleep tonight because I know they are on our side.

Just one more question, Connie. As a person with albinism, in Africa, I feel very much looked at as a black person who is white. How do you take the challenge of being white and in the white situation and still feel different?

Moderator **Thanks, Nomosanto, can we just take two more questions?**

About Self Confidence

Audience: Ms. Yuka Kanbara My name is Yuka Kanbara and I am from the Japanese Albinism Network. I have been listening to everyone talk since this morning, and all your remarks made me think of every one of you as my role model.

My question is personal and based on my own experience. I have never experienced bullying in school and I studied in regular classes. So unlike the situations in Africa, I never experienced discrimination or persecution as a victim.

Nevertheless, even now I am completely lacking self-confidence. Listening to all of you speak today. I cannot help admiring how strong you are and exemplary to me, because, somehow, even attending the same class with others, I cannot help but feel a little out of place, and I always have contradictory feelings—I want to be normal just like everyone else, at the same time I wonder why being different is not acceptable.

Even now, these contradictory feelings hang over me. If the feelings were gone, perhaps I could become more easygoing and more forthright in the way I live. I wonder if there are any methods for gaining confidence. If you have any advice in this regard, I would be very grateful if you could share it with me.

Moderator **Thanks very much, Yuka, for that great question. I think we can go ahead with answering questions. The first one is addressed to Connie. If you can take that question, please.**

■ Ms. Yuka Kanbara asking a question.

Nomosanto from South Africa wanted to know how you handle, on this issue of being a white and Chinese because she commented about being white and black at the same time. How do you handle that?

Ms. Connie Chiu I think it's great to be white and Chinese. To be white and black. And to be white and white. Because the way I see it, I remember, one teacher, who said that we are all worth the same, because we are all individuals, because we are all unique. And that has really stayed with me. And I think that is how I see it, because I know I'm not Caucasian, I know that I have white hair, I know that I'm Chinese, I like all those bits of me.

And I think once you learn to accept and embrace all those different parts of you, that's when you become whole. And that's when whatever people say to you, you know, because you will—I'm trying not to be negative, but there will be people who are not that nice who will try to make you feel bad about yourself. But once you are clear about who you are, and are happy with it, it doesn't matter what people say.

Moderator **Thank you very much, Connie. I see one more question, I'll take it.**

Mr. Isaac Mwaura I try to be modest, not to talk too much. As a politician, I talk a lot sometimes. I just wanted to make a clarification. First, I think I agree with you, Connie. Sometimes, people think if you are a person with albinism, and you move to a predominantly white society, you will be covered. But, it's not true.

I was a student in England. I thought if I went to England, I would be with my fellow white people. But going there, my body type is African, so they look at you. Of course, the skin is not the same. It has been caught by the sun and your body type looks like African, so you're lost.

But somehow, white people associate with you a little bit better in a way. But because you are an African, you are lost sometimes. Because with your fellow African sees you as white-ish. Then, white people also discriminate around their own whiteness. German or French, it's there. So, we need to talk about this inter-racial discrimination, so that you don't get lost in that sense. Every time when I'm around, I always get asked, "Where are you from?" "Are you from the Philippines?" I think people with albinism come from everywhere. People can't quite place you. This of course we also need to highlight.

Secondly, yes, indeed as Peter said, we need to form a world global alliance. I went to the albinism fellowship of the UK when I was a student, expecting I would find a robust organization, but I could only find people who were looking for social welfare benefits. They didn't even allow me to speak about the killings of our people in Africa. So, the West will not help us.

The other day, with Jake, we went to the European disability forum. They complained about the same thing. There is no strong albinism organization even when their members are 160 disability organizations. It is Africa, and it is going to teach the world about albinism. I think we must join hands. Peter, all of us, let's come together. This room is full of powerful people, you know, for the young lady from Japan who feels she has lost her self-esteem, the Japanese Albinism Network. We give you the fire in your belly and you can fight for your rights. So that you will become the Japanese champion on albinism. We in Africa, Peter in Canada and the UTSS, then the whole world can know that albinism is not just something to be a flimsy movement, but a real movement.

Daisuke Ito, kindly allow me to persuade you. Don't wait for numbers for JICA to work on albinism. It will never happen. Because it's not about the numbers. If it's a game of numbers, that's politics, and we'll never win, because we are a minority.

It's about affecting that single life of a person with albinism. JICA has a responsibility to work on this issue. We applaud them for having employed you. We want more of you there. And please argue the case. We will give you the facts, we'll back you up. And tomorrow they should have a big program in Africa and in Asia and everywhere that is going to impact the lives of children with albinism. Finally, nobody will ever accept us until we accept ourselves. We face a lot of hate out there. It is up to us to overcome the hate and claim our rightful place in the society. Thank you very much.

Moderator I want to take answers to Yuka's question on the self-esteem problem, because it is quite important. Yes, Jake.

Mr. Jake Epelle My dear sister that talked about lack of confidence and low self-esteem. You know, should be told, that's one big elephant in the room. Every one of us goes through one form of low self-esteem or the other. And sometimes there are people who had mastered it, you know, life generally, is full of fears. The only person that gets over it is somebody who has mastered the fear. Courage is not absence of fear. Courage is mastery of fear. So be courageous.

Believe in yourself. Sometimes, you are the only person, believe in yourself. Invest in yourself. Stay away from people who discourage you continuously. Don't hang out around with people who talk you down. Don't hang out around with people who feel that you don't want anything. Hang around with people who motivate you. Believe in yourself, take the bull by the horns and get on with your life. Thank you.

Moderator Thanks Jake. There you go, Yuka. Next time we hope you will be on the panel, talking like that. Very good. We have one person who really needs to say something. I'm sorry, quickly. Thank you.

Justice Mumbi Ngugi I also wanted to answer that question from the young lady from Japan. The reason why I wanted to speak about it is because that is something that we all go through. And I tell you, from a personal perspective that one of the best ways of dealing with the issue of self-esteem and self-acceptance is to actually articulate those things. The reason I wanted to do that article in the magazine in the late 1990s was that I realized everybody around me was defining me and describing me, but the time comes that you must define yourself and describe yourself. I like what the young man from JICA said, he was articulate, he was raising this question with his mother and with his parents. We need to raise this question ourselves and answer them.

At some point, you need to come out publicly and say, I have albinism. So what? Those who have a problem really are the general society, because they do not see beyond skin color. If we can stand up in a much darker continent like Africa, we need to stand up all over the world and articulate these things.

And I can tell you from many years of talking about albinism, that it gets easier with speaking about it, with meeting more people, with people beginning to hear you, not just look at you and stare, but beginning to hear what a great woman you are, and you define yourself as the woman that you are. That's what I say to young people with albinism all the time.

Don't let people define you or set your boundaries for you. Define yourself, set your boundaries, but don't even be shy about it, don't be apologetic about it. This is you, and this is what you are. Try as much as possible to define yourself to articulate who you are.

Moderator Thank you very much, Judge Mumbi for that. Now we have comprehensive self-esteem advice.

Ms. Connie Chiu I want to add something quite quickly. I just want to applaud the lady for stepping up, and actually asking the question. I think that's a good step on the way.

And you want to improve your self-esteem. That's great, because some people don't think about that and just try to attack other people. So, I think that's great.

And I want to add that you will find your tribe, I'd like to say tribe, because tribe doesn't mean you look exactly the same. It doesn't mean that you come from the same place. It's something else that connects you. So, your tribe will find you. Stick with your tribe, because they will give you the support and the love and understanding you need.

Will You Take a Pill to Develop Color?

Moderator **Thank you very much for those comments. We have had a wonderful session. I'm sure we have said all we can in the limited time frame.**

But before we close, let's hear final comments from Mr. Ito and Miss Chiu, any final remarks for one or two minutes?

I'd like to ask this question. Some scientists are actually working on a medicine that people with albinism can take which causes them to develop color. It's not safe to use in humans yet. They are for people ten years old and older. Imagine in 20 years' time, this would be possible. If it were possible now, would you take this pill? You wake up tomorrow, and suddenly you look like a normal Japanese or a normal person from Hong Kong. Briefly tell us in your comment if you would, or if you would not and why. Thank you very much.

Ms. Connie Chiu I can go first. If the pill was ready today, at this very minute for me to take, I wouldn't take it. But having said that, I wouldn't judge anyone who would like to take it. I think for me, it's been a long road and I'm still enjoying the journey to just to be myself. And I'm quite happy to be myself. But as I said once again, I wouldn't judge anyone who would like to take the pill, it's up to each person.

I think I did the wrong way to answer the question first. My last remark is, I want to thank you all for listening. I have learnt quite a bit about myself. And I think it's been a wonderful occasion just to share, just to learn. I think we are all going away with a mental goodie bag. So, I just want to thank everyone. Thank you.

Mr. Daisuke Ito Your question is difficult.
Whether I took the pill or not, I do not believe that I myself would change. I believe my relationships with people around me has shaped who I am today: How my parents brought me up; how they spoke to me; and how my siblings treated me. If my appearance changed after taking such a pill and the relationships of the people around me changed, I might end up as a different person. If the relationships were negatively affected by misunderstandings and misconceptions, I believe I would definitely act the same as I do now for the issue of albinism. Thank you for today. This is my final remark.

Moderator **Thank you very much to the panelists. Thank you.**

Mr. Jake Epelle May I, on behalf of the African delegation, express our profound gratitude for your good heart and the compassion in your heart to bring us together, Mr. Sasakawa. Thank you so much sir, you have made a wonderful impact in our lives, you have invested in our future. We will never, ever forget you.

Ms. Yuka Kanbara Although I am not the representative of Japanese Albinism Network, as a person with albinism, I am very grateful to have had an opportunity to learn at this conference today. Although in Japan, we experience no life-threatening problems, learning firsthand about circumstances in Africa, countries like Tanzania or Nigeria, changed our perspective. Although we have many hardships in Japan, I strongly felt that I would really like to learn about what is going on in other parts of the world. I would like to create horizontal connections, and apply what I learn in the course of my everyday life. I am grateful for the valuable opportunity I was afforded today.

Closing

Mr. Ichiro Kabasawa, The Nippon Foundation I know it's been a long day, so I will keep my speech as brief

as possible. I would like to express my sincere gratitude to all of you for sharing your stories and experiences with us. Your stories are very inspiring and I watched your enthusiastic discussion with pleasure. The Nippon Foundation is very happy to be able to provide this kind of platform for you to come together and exchange your views and opinions.

Before I joined The Nippon Foundation, I was a journalist for more than 20 years. From my journalistic point of view, the conference was very good, very comprehensive, holistic. We covered albinism from many different aspects, such as medical, educational, criminal in a sense, disabled, and of course, stigma and discrimination.

This is the first international conference on albinism held in Japan. It's a historic moment and milestone for albinism.

Since we covered this issue from many aspects, I now have much clearer picture of what albinism is and what the issues are. I do not yet have any concrete ideas how we can cooperate, or how we can work together. Hopefully my colleagues have one already.

Please do not forget that since we are having this conference in Tokyo, your voices will be heard not only in Africa, Europe, and America, but also in Asia, and we are looking forward to working with you in the future.

LOVE IS HERE TO STAY

For the Tokyo Albinism Conference

Jazz Performance by CONNIE CHIU

©Connie Chiu

CONNIE CHIU

Jazz singer and model

Known as the world’s first fashion model with albinism, Hong Kong-born Ms. Connie Chiu is also making a name for herself as a jazz vocalist. Her very first international fashion show was for the French designer Jean Paul Gaultier, and she worked for brands such as Diesel, Bulgari and Rover. Images of Connie have been published in Vogue, Vanity Fair, and Sunday Times. As a jazz singer Connie performs at major events and festivals such as Ealing Jazz Festival. Her debut EP ‘My Huckleberry Songs’ released in 2015 features songs such as ‘Moon River’. She is a Champion in United Nations Human Rights Office’s Albinism Awareness Campaign, sharing her story and supporting the rights of individuals with albinism.

Set List

1. Love is Here to Stay
2. Skylark
3. So in Love
4. What a Wonderful World
5. Tea for Two
6. One Note Samba
7. The Christmas Song
8. Don‘t Fence Me In

See page 119 for Connie’s official youtube.

ELIA GAITAU

Pianist

Mr. Gaitau is a wonderful pianist, composer, arranger and educator from Auckland, New Zealand.
He has completed a jazz piano degree from Massey University back in 2003 and has been playing professionally for over 20 years.
He is now based in Japan and is regularly playing in the Tokyo music scene.

LOVE IS HERE TO STAY

For the Tokyo Albinism Conference

Jazz Performance by CONNIE CHIU

WHITE EBONY

PHOTO EXHIBITION

©Felix Schmitt
Edition Lammerhuber

They are frequently sworn at and accused of witchcraft. Some people spit on their own chest when they meet them in the street to ward off bad luck. Others wake them in the middle of the night to avoid running into their spirit-said to float from their body while they sleep and rejoin it when they awake.
Sought out for their supposed powers, persons with albinism in Sub-Saharan Africa are often victims of folk beliefs and superstitions. Their inherited genetic condition, which reduces the amount of pigment in their skin, hair and/or eyes, leads them to suffer from discrimination, stigma and social exclusion. They also run the risk of being brutally attacked and murdered, with their body parts are used as amulets and in the preparation of magic potions alleged to bring good fortune.

The appalling discrimination and violence to which they have been subjected led the United Nations Human Rights Council and General Assembly to adopt resolutions to protect persons with albinism. Since 2015, June 13 has been marked as International Albinism Awareness Day. These photos are a part of a larger project to show that persons with albinism, young and old, are entitled to enjoy life—integrated into society and protected and cared for by their loved ones—just like everyone else.

They have been displayed in various countries around the world, including the Democratic Republic of Congo (DRC), Belgium, Netherlands and France. When they were exhibited at the United Nations in Geneva, Switzerland in 2015, Flavia Pansieri, UN Deputy High Commissioner for Human Rights, said at the time: "While we continue to receive shocking reports of killings and attacks against persons with albinism, these photos send a message of hope and encouragement for all those who work to improve their lives."

Persons with albinism still face many challenges. It is my hope that the Tokyo Albinism Conference will promote awareness of this issue among the Japanese public and generate further momentum for an end to the violence and discrimination, abandonment and exclusion that persons with albinism face.
I thank The Nippon Foundation for this opportunity.

Willocq

© Patricia Willocq

Ma Gloire is five years old. His skin is very white and his eyes are almost red. Ma Gloire finds it hard to keep his eyes open. He instinctively bends his head toward the ground to avoid getting the sun's rays in his sensitive eyes. Ma Gloire socialises well with his group of friends at school and in his neighborhood.

Joëlle, Claude, Kevin and Viktor are reading a book before going to school. Their dad was advised many times to leave his wife, who is supposedly responsible for their children's condition. Instead, he decided to fight to keep his family united and to provide them with a good education.

© Patricia Willocq

© Patricia Willocq

Serge is one of the main actors in the film *War Witch*. According to him, one of the best ways to protect people with albinism worldwide is to advocate for them through fame. He hopes that his local notoriety will help other people with albinism by spreading a message of integration, just as the famous Malian singer, Salif Keita, has done.

© Patricia Willocq

The Franc family have nine children. Three of their daughters have albinism and their parents are very proud of them, calling them "our golden skinned girls!"

Keren is eight years old. She is the youngest of nine children (two of her sisters have albinism) in her house. Her parents are proud of their girls and encourage them to enjoy life despite superstitions against them. Keren and her brother David are very close and love to tell each other secrets.

© Patricia Willocq

Photo Tour

by Patricia Willocq

Photographer profile PATRICIA WILLOCQ

Ms. Willocq is a freelance photographer born in 1980 in what today is the Democratic Republic of Congo. Amongst her assignments around the world, she dedicates time to support the work of associations and NGOs fighting in the field of human rights. The quality of her work has made her win several important prices including the UNICEF Photo of the Year Award 2013 (Honorable Mention) and the Alfred Fried Photography Award 2015 amongst others. Her work has been exhibited by Office of the United Nations High Commissioner for Human Rights (OHCHR), UNESCO and UNICEF to name only the most important renowned organizations of the UN and has been featured in Geo magazine, National Greographic, UNICEF book to name a few. She endeavors to avoid miserabilism and her work is associated with projects that promote tolerance and dignity.

After the Conference

Albinism as a symbol of diversity

Motivated by the Tokyo Albinism Conference, the first entertainment festival organized by persons with albinism, "Albino Fes (Albinism Festival)," was held in Tokyo on June 1st, 2019, commemorating International Albinism Awareness Day (June 13th).

Under the banner of "enjoying albinism," fourteen persons with albinism took to the stage at the Albino Fes, the first festival for and by persons with albinism in Japan, to entertain about seventy guests with musical performances including acoustic sets, gospel music, talk shows, and fashion shows.

The organizer is Ms. Junko "Catherine" Kobayashi. She had participated in the Tokyo Albinism Conference and had been appalled to learn about the events that have transpired in Africa. She was shocked especially by the personal testimony from Mariamu, who was brutally attacked in Tanzania.

After the conference, Catherine felt the strong urge to do something to let Japanese society know about this severe discrimination against persons with albinism, but at the same time, she wanted to do so in a positive way. Even before the conference, she had always wanted to spread a positive image of persons with albinism as she knew many of them who are really attractive.

Catherine met Mr. Miyabi Shimizu and a few others at the Tokyo Albinism Conference who shared her views, and they decided to jointly organize this festival for and by persons with albinism.

When they created the program, they tried to emphasize "enjoyment" aspects rather than focus on negative images of persons who had been persecuted because of their albinism.

In her childhood, Catherine also experienced terrible sunburn and difficulty in reading the black board in a classroom just like other persons with albinism, but she never regarded her life as hard. She is confident that "most things are manageable with neat solutions, and having albinism should not be a reason to give up things I want to do."

At the festival, Catherine wanted to send a message to many parents whose children have albinism: Do not worry about having kids with albinism. And to those with albinism, she wanted to say: You are attractive, you don't have to lose your self-esteem, you just need to be yourself.

The festival also featured a "White Ebony" mini photo exhibition by Patricia Willocq (with support from the photographer and The Nippon Foundation), which caught the attention of many guests.

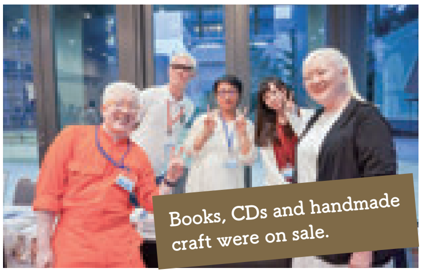
"Albinism as a symbol of diversity." Having had a great time at the festival, Catherine plans to evolve this festival into an annual event.

Junko "Catherine" Kobayashi and Miyabi Shimizu, the organizers of the Albinism Festival.


Miyabi and Catherine, the organizers!


Gospel choir from Osaka posing at the photo exhibition.

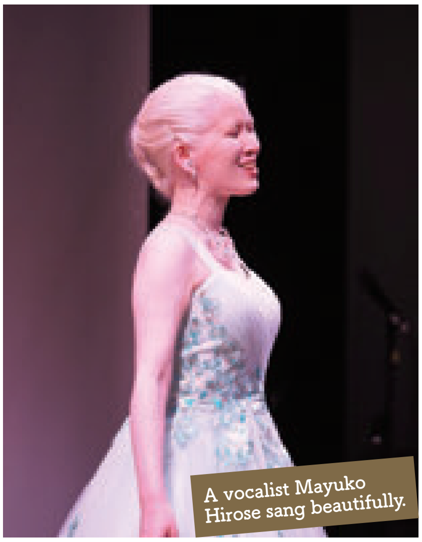

Dressed up on stage.


Books, CDs and handmade craft were on sale.


Singer song writer Megumi Irei.


Staff at the reception having a good time.


Talk show topic: Marrying to a person with albinism.


A vocalist Mayuko Hirose sang beautifully.


The festival choir is made up of 19 people.


Beautiful curtain call.


Catherine looking serious preparing for the photo exhibition.


Performance by Megumi Komatsuzaki.


“Like a real princess”


Kaori Suzuki is a talented dress designer.


Everyone had a great time at the first Albino Fes.

*Platinum Angels
“Let’s enjoy having albinism!” The Theme song of Albino Fes (Albinism Festival).
The song by the Japanese choir is on YouTube (Including Swahili chorus and subtitles).

Afterword

In concluding this report, we would like to offer our deep gratitude to those who attended and contributed to the conference, including many nurses, who kindly sent feedback to us. Their feedback is written below. Though this report has come to an end, the struggle of the persons with albinism continues. And on this note, we dearly hope for the day when persons with albinism all over the world can live peacefully and in happiness.

Feedback from the Nurses

I am grateful for the opportunity I had to participate in the Tokyo Albinism Conference. During the conference, I recalled this boy with albinism in my school who was in the same grade as me. I used to wonder what had happened to him, and presumed that he was inflicted with a disease of some kind. I had forgotten about him as life went on, until today. Today, I was totally struck by the horrific reality in Africa, and thought about how little I know of the world. There are things that people must know, and I feel the strong need to share this reality with the people around me.

I learned about albinism for the first time today. I did not know about PWA who are mistreated because of wrong beliefs and discrimination. I was shocked to know that PWA have their body parts chopped off or are even killed because of witchcraft, which people still believe in in Africa.

I did not know about the horrendous persecution of PWA in Africa, who are wrongly persecuted because of myths and misconceptions. They are one minority group forced to go through atrocities because they are not regarded as normal, and because of the absolute lack of correct knowledge. This is not limited to albinism and I think the same can be said of racism in general. Horrifying.

The conference was particularly informative and valuable.

1. I was able to learn about albinism, and how PWA are treated in Africa. I also found out about the delicate inner feelings of Japanese PWA.
2. I was reminded of the importance of having wide knowledge when we work as a nurse in rural areas, and also reaffirmed the importance of family support.

I not only learned about medical aspects of albinism, but was also provided with an opportunity to listen to the real voices of those affected by albinism, their hardships, the discrimination, the infringement of human rights, and the crimes committed against them. The conference was outstanding in the way it offered an opportunity to bring together PWA, their supporters, and the media, and to think about international cooperation.

I did not know about this genetic condition, albinism, and was deeply shocked to hear about the ongoing persecution in Africa. There are many kinds and levels of disability, be they physical, intellectual, mental or resulting from appearance. And the lives of those with a disability will depend on how society accepts them, and how they accept themselves. Eradicating discrimination through education so that people understand the reality of disability is essential in order to create a society that is safe and secure for everybody, with or without disability. I would like to do what I can to get to know people with albinism, and to realize a society without discrimination. Hearing about the dream to make the ongoing discrimination something of the past deeply touched me.

I was shocked to learn that people are hunted and have their hands and legs mutilated because of their white skin color. Minorities are often disrespected and bullied. Their rights are easily infringed, though they did nothing wrong. This is totally unreasonable and should be properly addressed.

Attending the conference was like watching a documentary on TV. Totally shocking. I could see every step that the PWA had taken before making it to the Tokyo Albinism Conference. I relearned the importance of spreading the right knowledge as well as network building. I sincerely wish for the day when PWA can live fully and safely with all of us in society. Let me also add that I really liked the way the PWA spoke with confidence at the conference. Watching them full of life also made me feel good.

There are many issues going on in the world that I do not know about. This conference reminded me that getting to know them is really important. On a personal note, I plan to get into home nursing, and I would like to think hard about what is truly wanted and necessary, and reflect them in my work as a nurse.

I learned about albinism for the first time in this conference. Several PWA were sitting near me, and I just thought they were very beautiful. I have learned that they are categorized as disabled because of low vision and the risk for skin cancer, but albinism is just one of many kinds of diversity. I was totally struck by Mariamu saying she has never given up and believes in herself. Her smile and her strength. Speaking about the incident right in front of me, I could hardly believe that the murders and human trafficking induced by superstition and witchcraft are still happening today. I wanted to ask her where her unyielding strength came from.

It was a big day for me attending the conference. I was particularly moved by the words of the survivor, Mariamu, and by the efforts of the speakers who sometimes had to risk their lives through their activities.

There was a PWA in my elementary school, but this person was in a different class, and we never talked, and I had only presumed that the condition was due to some disease.

Should there be PWA in my community, their physical, mental and social support will be on my mind. Being a nurse, I shared what I learned in this conference with my colleagues and pediatricians.

I knew about witchcraft and the horrific conditions surrounding PWA in Africa, but I was astonished to learn that the parents and relatives are often the ones helping in the attack, though abuse is taking place in our society as well. As I listened, I wanted to learn more about hate speech and religions in Africa. My seventh-grade daughter said it was important to learn the correct knowledge on albinism and was surprised to hear the horrible crimes committed because of differences in skin color.

Listening to the stories of the PWA taught me the fearful reality that ignorance can bring and the importance of education. I have also witnessed the strength of people who believe in themselves and have a dream, and thought they are beautiful. It was a valuable experience and I would like to share this in my community.

I am grateful that I was able to attend this conference. I could not help asking myself why human rights violations, discrimination and miseries of minorities still continue today, in Japan and in the rest of the world. The tragedy of PWA in Africa, I think, may be just an example of what we human beings have done through centuries since the time of the great civilizations. Hearing the speeches of the PWA firsthand made me realize the importance of understanding the social, mental and physical aspects of disability and speaking out about it. I am a little ashamed of myself, as I could not comment or ask a question at the conference. But would like to act more positively and more proactively.

Press Reports Related to the Tokyo Albinism Conference

Date	Newspapers/Webnews/TV/Publications	Headlines
2018/11/5	Asahi Shimbun	Conference on “albino hunting” to be held in Tokyo on November 9
	Asahi Shimbun Digital	Same as above
	Withnews (News site operated by Asahi Shimbun)	“I could have been killed, too” -The path PWA chose after learning about “albino hunting” (Interview with Mr. Daisuke Ito)
	Yahoo News Japan	Same as above
2018/11/9	TBS	Japan’s first international conference on PWA persecution held
	NHK Web News	Japan’s first international conference on PWA held aiming to eliminate discrimination and misperception
	NHK	*Introduced in evening news program “News Check 11”*
	NHK BS1	*Introduced in news program “International News Report 2018” (kokusai hodo 2018)*
	NHK BS1	*Introduced in news program “Catch! World’s Top News”*
	Kyodo News	Albino persecution, including killings, in Africa discussed in Tokyo
	Shizuoka Shimbun	Same as above
	Kyoto Shimbun	Same as above
2018/11/10	Mainichi Shimbun	“Albino hunting” needs to be addressed
2018/11/12	BLOGOS	Cruel “Albino hunting” continues in Sub-Saharan Africa
2018/11/21	Asahi Shimbun	“People” column:“Ms Mariamu Staford: Fighting against discrimination on PWA”
	Asahi Shimbun Digital	Same as above
2018/12/15	AIYU magazine	The Tokyo Albinism Conference “We also have human rights” Interview with Ms. Ikponwosa Ero
2018/12/18	BLOGOS	Persecution of PWA continues in Africa Press report on cruel reality induces further discrimination?
2018/12/21	Withnews	Her arms cut off because of her skin color -Horrific experience of “albino hunting” Not someone else’s problem. “Darkness of discrimination” also in Japan-
2019/1/1	International Development Journal	The Reality of “albino hunting” exposed
2019/1/16	Abema TIMES	The Suffering of PWA -Denied employment and part time jobs

Related links

About Albinism

- UN Resolutions and Reports on Albinism
- Regional Action Plan on Albinism in Africa (2017-2021)
- albinism.ohchr.org
- Action on Albinism

Connie Chiu Official YouTube

♬ Skylark

♬ The Christmas Song

♬ Don’t Fence Me In

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PEOPLE
WITH ALBINISM:
NOT GHOSTS
BUT HUMAN BEINGS

UNITED NATIONS
HUMAN RIGHTS
SPECIAL PROCEDURES

UNITED NATIONS
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PERSONS WITH ALBINISM