

SPEAKERS AND KEY PARTICIPANTS



YOHEI SASAKAWA
Chairman, The Nippon Foundation

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. He is the initiator of this conference.



YASUO YABUKI
Assistant Professor, Rikkyo University/Japanese Albinism Network (JAN)

Dr. Yabuki is an assistant professor at Rikkyo University, Tokyo, Japan since 2016. Ph.D. in sociology.

He also works as an operational staff member of the Japanese Albinism Network to support people with albinism in Japan, and to promote proper understanding of albinism. He published a book "*Watashi ga Arubino ni tsuite Shirabe Kangaete Kaita Hon*" in October 2017, presenting his research on albinism. He won "The Japan Sociological Society 17th Incentive Award" in September 2018.



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

Ms. I.K. 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.



MARIAMU STAFORD

Entrepreneur

Ms. Staford is an entrepreneur engaged in 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. 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 USA and joined Under The Same Sun Education Programme. She graduated with an Advanced Certificate in Knitting from Imani Vocational Training Centre in Moshi, Tanzania. She knits sweaters and scarfs as a business.



VICKY NTETEMA

Journalist;

Former Director General, Under The Same Sun (UTSS)

Ms. 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 Byelorussian 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.



BONFACE MASSAH

Executive Director, Association of Persons with Albinism of Malawi

As former president of the Association of Persons with Albinism in Malawi (APAM) from 2009 to 2016, Mr. Massah contributed to building a foundation of the Malawi's first association for persons with albinism.

In 2016, he launched the national secretariat office for the APAM and became National Director.

Mr. Massah is one of the Africa's notable youth experts on rights of persons with albinism and social inclusion. His work with communities and policy makers has helped to develop inclusive community-based programs and policies that are promoting rights of persons with disabilities in Malawi and Africa. He has worked on a research in demystifying stereotypes about persons with albinism. He has also contributed to developing innovative strategies and policy ideas to respond to the educational, health and social needs of persons with albinism.



DJAFFAR MOUSSA-ELKADHUM

Country Representative and Head of Office, UNESCO Mozambique

Mr. Moussa-Elkadhum is an Economist and Demographer with more than 25 years of professional experience in development mainly at the United Nations Educational, Scientific and Cultural Organization (UNESCO). He is currently the Representative and Head of the Office in Mozambique. 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 a member of several scientific and professional associations, in particular the International Union for the Scientific Studies of Population (IUSSP) and the Union for Studies of the African Population (UAPS).



WILIAMO TOMAS

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

Having initiated various projects including support for children at risk and vulnerable persons, Mr. Tomas founded an 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.



PETER ASH

Founder and CEO, Under The Same (UTSS)

Mr. Ash founded an international faith-based NGO with offices in Vancouver, Canada and Dar es Salaam, Tanzania, and now serves as CEO. He holds an undergraduate degree in Theology and a graduate degree in Psychology. His background includes ten years of work in church ministry followed by twenty years in business leadership. His current passion, via advocacy and education, is to see the day 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.



JAKE EPELLE
Founder and CEO, The Albino Foundation

Mr. Epelle works to empower persons with albinism and educate society on albinism-related issues in Nigeria and 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.



NOMOSANTO MAZIBUKO
**Head, Albinism Society of South Africa/
Head, Regional Forum on Albinism in Africa**

Ms. Mazibuko, an educator, has worked for the Department of Education for a period that spreads over three decades. She 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 by declaring June 13 as International Albinism Day. Her passion for disability rights resulted in being appointed a member of the Presidential Working Committee, the National Disability Policy review panel as well as several boards and initiatives in support of social justice.



MUMBI NGUGI
Judge of the High Court of Kenya

Ms. Ngugi is a Judge of the High Court of Kenya currently serving as the Presiding Judge, High Court of Kenya at Kericho. She 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. She holds a Bachelor of Laws Degree from the University of Nairobi and Master of Laws from the London School of Economics. 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.



ISAAC MWAURA
**Member of the Senate/
National Coordinator of the Albinism Society of Kenya**

Mr. 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.



DAISUKE ITO
**Project Officer, Japan International Cooperation Agency (JICA)/
Japanese Albinism Network (JAN)**

Mr. Ito is a Project Officer at JICA (International Cooperation Agency) Financial Cooperation Implementation Department, Grant Aid Project Management Division, Electric Power and Port Unit.

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.



ICHIRO KABASAWA
Executive Director, The Nippon Foundation

As Executive Director, Mr. Kabasawa oversees international projects that The Nippon Foundation conducts in various countries.

Prior to joining The Nippon Foundation in 2017, He worked for over 20 years as a journalist at Japan's public broadcaster, NHK. He started his NHK career in Okinawa, where he covered national security issues, and later was assigned to Bangkok for three years. He was a correspondent with NHK's Washington Bureau from 2010, and returned to Tokyo in 2014 as a senior editor in NHK's international news section.

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.



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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.



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 prizes 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 OHCHR, UNESCO and UNICEF to name only the most important renown organizations of the UN and has been featured in Geo magazine, National Geographic, UNICEF book to name a few.

She endeavors to avoid miserabilism and her work is associated with projects that promote tolerance and dignity.



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