

TOKYO ALBINISM CONFERENCE PROGRAM

ORGANIZED BY THE NIPPON FOUNDATION
NOVEMBER 9, 2018

- 9:00-9:05** Opening
- 9:05-9:10** Remarks by Organizer : Mr. Yohei Sasakawa, Chairman, The Nippon Foundation
- 9:10-9:20** Remarks by Japanese Albinism Network (JAN) "Albinism Issue in Japan"
Dr. Yasuo Yabuki, Assistant Professor, Rikkyo University
- 9:20-9:40** Remarks by UN Independent Expert "Overview of the Issues and Ways Forward"
Ms. Ikponwosa Ero, UN Independent Expert on albinism

Session 1: Realities: Our Experiences (9:40-12:10) Moderator: Hon. Isaac Mwaura

TANZANIA

- 9:40-10:00** "Personal Testimony of Mariamu: My Recent Climb Up to Mt. Kilimanjaro"
Ms. Mariamu Staford, Entrepreneur (small-scale knitting business)
*Interpreter: Ms. Vicky Ntetema (Swahili to English)
- 10:00-10:10** "Reflections on Ten Years Serving Persons with Albinism:
Challenges, Successes and What is Left to be Done"
Ms. Vicky Ntetema, former Director General, Under The Same Sun (UTSS)
- 10:10-10:25** Q&A

MALAWI

- 10:25-10:40** "Successes and Limits of Multiple Interventions by Multiple Stakeholders:
A Case Study of Malawi" Mr. Bonface Massah, Executive Director,
Association of Persons with Albinism of Malawi
- 10:40-10:55** Q&A

MOZAMBIQUE

- 10:55-11:05** "The Role of Public Education in the Way Forward Concerning the Rights of
Persons with Albinism"
Mr. Moussa-Elkadhum, Country Representative, UNESCO Mozambique
- 11:05-11:25** "An Overview of the Experience of Persons with Albinism in Mozambique:
Challenges and Recommendations on the Way Forward"
Mr. Wiliamo Tomas, President, ALBIMOZ
- 11:25-11:40** Q&A

INTERNATIONAL

- 11:40-11:55** "The Important Role of International Actors in Promoting the Rights of
Persons with Albinism: Promise, Challenges and Hope"
Mr. Peter Ash, CEO, Under The Same Sun
- 11:55-12:10** Q&A

12:10-13:45 Lunch Break
12:20-13:00 **"Love is Here to Stay" Performance by Connie Chiu, jazz singer with albinism (1st Fl.)**

Session 2: Government Engagement, Legal and Other Tools (13:45-15:30)

Moderator: Mr. Moussa-Elkadhum

13:45-14:00 "Engaging Government: Successes and Challenges"

Mr. Jake Epelle, Founder, the Albinism Foundation of Nigeria

14:00-14:15 Q&A

14:15-14:30 "Disability Approach: Successes and Challenges in South Africa"

Ms. Nomasonto Mazibuko, Head, the Albinism Society of South Africa/
Head, the Pan-African Albinism Alliance

14:30-14:45 Q&A

14:45-15:00 "Conditions Necessary for the Enjoyment of Human Rights by Persons with Albinism: Personal and Professional Reflections"

Ms. Mumbi Ngugi, Judge of the High Court of Kenya

15:00-15:15 "The Kenyan Experience in Championing for the Rights of Persons with Albinism: Collaborations of Government and Civil Society—Challenges and Opportunities"

Senator Isaac Mwaura, National Coordinator, the Albinism Society of Kenya

15:15-15:30 Q&A

15:30-16:15 Coffee Break

Session 3: Promoting Involvement, Building Sustainability (16:15-17:30)

Moderator: Ms. Ikponwosa Ero

16:15-16:30 "My Story, and My Experience in Tanzania"

Mr. Daisuke Ito, Japan International Cooperation Agency (JICA) ,
Japanese Albinism Network (JAN)

16:30-16:45 "Sky's the Limit: The Story of a Model, Jazz Singer and Dreamer"

Ms. Connie Chiu

16:45-17:25 DISCUSSION

17:25-17:30 Closing Remarks

Mr. Ichiro Kabasawa, Executive Director, The Nippon Foundation

18:00-20:00 Reception "White Ebony" welcoming photographer Ms. Patricia Willocq (1st Fl.)