



Permanent Mission of
the Republic of Malawi



Permanent Mission of
the Republic of Mozambique



“Still Standing Strong”
**Side-event for persons with albinism during the 12th session of the Conference
of States Parties to the Convention on the Rights of Persons with Disabilities**
New York, 13 June 2019
UN Headquarters, New York
1:15pm-2:30pm

Background

Since the establishment of the mandate of the Independent Expert on albinism in 2015¹, much has been accomplished in bringing the voices of persons with albinism to the forefront of human rights discussions and actions. Some of the activities undertaken by the Independent Expert include various country visits to Africa and Asia-Pacific; presenting 14 reports to the Human Rights Council and the General Assembly on a range of thematic issues; meeting with persons with albinism around the world, many of whom were victims of human rights violations; engaging in international, regional and national fora; meeting with representatives of States, UN entities, agencies and programmes, civil society organizations, academia, medical and health professionals and even members of the entertainment industry, including the fashion industry, Hollywood acclaimed film-makers and renowned musicians with albinism. As envisioned by goal 17 of the sustainable development goals, broad partnerships like this are needed to accelerate the enjoyment of human rights by those who have been left behind such as persons with albinism.

“Still Standing Strong”

“Still Standing Strong” is the theme for this year’s International Albinism Awareness Day. This is a call to recognise, celebrate and stand in solidarity with persons with albinism around the world, and to support their cause – from their accomplishments and positive practices to the promotion and protection of their human rights. Persons with albinism have faced, and continue to face, ongoing hurdles and challenges that seriously undermine their enjoyment of human rights. From stigma and discrimination, to barriers in health, education, and invisibility in social and political arenas. In addition, in several countries they are subject to heinous attacks and killings. Despite all these

¹ The Human Rights Council adopted resolution A/HRC/RES/28/6 on 26 March 2015, establishing the mandate of the Independent Expert on the enjoyment of human rights by persons with albinism.

challenges, persons with albinism remain positive and are STILL STANDING STRONG!

The figures on violations against persons with albinism are telling. Since 2010, there have been around 700 cases of attacks and killings of persons with albinism in 28 countries in Sub-Saharan Africa. These are reported cases alone. The attacks have several root causes including ignorance, longstanding stigma, poverty and most abhorrently, harmful practices emanating from manifestation of beliefs in witchcraft. The alarming reality is that these horrendous practices continue today.

Due to a lack of melanin in the skin and eyes, persons with albinism often have permanent visual impairment which often lead to disabilities. They also face discrimination due to their skin colour; as such, they are often subject to multiple and intersecting discrimination on the grounds of both disability and colour.

With regard to health challenges, the lack of melanin means persons with albinism are highly vulnerable to developing skin cancer. In some countries, a majority of persons with albinism die from skin cancer between 30 and 40 years of age. Skin cancer is highly preventable when persons with albinism enjoy their right to health. This includes access to regular health checks, sunscreen, sunglasses and sun-protective clothing. In a significant number of countries, these life-saving means are unavailable or inaccessible to them. Consequently, in the realm of development measures, persons with albinism have been and are among those “left furthest behind.” Therefore, they ought to be targeted for human rights interventions in the manner envisioned by the Sustainable Development Goals.

COSP 12th session

The UN Independent Expert on albinism has partnered with the Governments of Malawi and Mozambique, as well as the International Disability Alliance to organise a side-event in the margins of the 12th session of the COSP to the CRPD. This year will be the first time that the Independent Expert will hold a side event during the COSP. Coincidentally, the IAAD falls within the session period of the COSP. The theme of the COSP this year is highly relevant – “ensuring inclusion of persons with disabilities in a changing world through the implementation of the CRPD.”

Persons with albinism are often relegated to the shadows when it comes to mainstream discourse and policy decisions that impact their lives. Many who live in poverty are even more marginalised and excluded in their society. This COSP session provides an opportunity for persons with albinism to engage with the disability community, of which they are also constituents, and share their experiences while learning from relevant best practices. The CRPD is a critical legal framework for the realisation of the rights of persons with albinism. It was one of a number of important legal frameworks that formed a compendium developed by the Independent Expert on albinism for the protection and promotion of human rights of persons with albinism. The Independent Expert has also regularly engaged with the Committee on the Rights of Persons with Disabilities and the Special Rapporteur on the rights of persons with disabilities through consultations, communications to governments concerning alleged human rights violations and through activities aimed at raising awareness about the plight of persons with albinism.

Format of the Side-Event

The side-event is composed of a diverse group of panellists who have played an important role in bringing persons with albinism “out from the shadows” and into the fore of mainstream discussions and policy changes.

Panellists

- Opening remarks - Member State(s) supporting the side-event
- Remarks - Ms. Ikponwosa Ero, UN Independent Expert on albinism
- Remarks - International Disability Alliance

Panel 1: Innovative Awareness-Raising

- Innovation and advocacy for albinism awareness – Senator Isaac Mwaura, Kenya
- Awareness through the modelling industry – Ms. Diandra Forrest, supermodel, USA
- Global campaign on the skin component – Mr. Stephan Bognar, NYDG

Panel 2: Updates on Attacks: Progress and Challenges

- Perspective of a victim with albinism – Progress and how he is “still standing strong” – Panellist from Tanzania
- The Power of Education in saving lives: a ten year reflection on successes and challenges – Mr. Peter Ash, CEO, Under The Same Sun
- Resiliency of persons with albinism in Malawi and Africa – Mr. Overstone Kondowe, President, Association of Persons with Albinism, Malawi and President of the African Union for Persons with Albinism

Q&A segment to follow.

Date and Time:

Thursday, June 13, 2019, 13:15 – 14:30

Room: TBD

Outcome

The side-event aims to, first and foremost, commemorate International Albinism Awareness Day by introducing the issue to the plethora of disability constituents at the COSP. The aim is that wider community of persons with disability would not only become conversant on the issues faced by person with albinism but would also become advocates on the matter.

The event brings together speakers from various backgrounds, who together demonstrate the utility of conventional and non-conventional measures in promoting the human rights of persons with albinism. This would also enable a “stock-taking” of progress made to date and note subsisting challenges.

A call for solidarity! In solidarity with persons with albinism worldwide, remember to use the hashtags [#stillstrong](#) [#iaad](#) [#iaad2019](#) [#AlbinismDay](#) [#standupforhumanrights](#)