

States are failing to protect human rights of people with albinism

“Persons with albinism face significant barriers restricting their participation in society on an equal basis with others and preventing them from realising basic rights such as the right to physical and mental health, including access to adequate health care, and the right to education, social services, legal protection, and redress for rights abuses.”

*United Nations Independent Expert on the enjoyment of human rights by persons with albinism **Ms. Ikponwosa Ero** in a statement issued today to commemorate the International albinism awareness day*

13 June marks the “International Albinism Awareness Day”. The international albinism awareness day is a recognition of the need to increase awareness and understanding of albinism—a rare, non-contagious, congenital condition characterised by a lack of pigmentation in any or all of the hair, skin and eyes and the human rights situation of persons with albinism globally.

Ahead of this year’s commemorations the [International Bar Association's Human Rights Institute](#) (IBAHRI) launched a report on 8 June in London Titled *'Waiting to disappear' International and Regional Standards for the Protection and Promotion of the Human Rights of Persons with Albinism* . The report which the **Centre for Human Rights** contributed to, provides a detailed analysis of the obligations of states to protect persons with albinism from human rights violations, attacks and discrimination. It highlights the relevant provisions of applicable international and regional laws, norms and interpretative frameworks and the current gap between these agreements and current state practices.

Speaking at the launch of the report United Nations Independent Expert **Ms. Ikponwosa Ero** and Chairperson of the United Nations Committee on the Rights of the Child **Professor Benyam Dawit Mezmur** reiterated the need for States as primary duty bearers to take action through a holistic approach and with the involvement of all stakeholders in particular persons with albinism.

Detailed in the report are a number of recommendations for states to protect the rights of persons with albinism, ensure accountability and guarantee equal access to health, education and work, including:

- Enact, when necessary, clear laws criminalising and punishing any acts of violence, including harmful practices against persons with albinism, clarifying ambiguities, where they exist, in laws relating to witchcraft and traditional health practice.
- Guarantee the right of victims to prompt, adequate, fair and effective reparation, including compensation and rehabilitation.
- Taking all necessary steps to strengthen international cooperation by multilateral, regional and bilateral arrangements for the prevention, detection, investigation, prosecution and punishment of cross-border crimes affecting persons with albinism, notably trafficking of persons, children and body parts.
- Urgently implement programmes and plans of action to address multiple and intersecting forms of discrimination affecting persons with albinism, including awareness-raising campaigns, human rights education and training among the judiciary, public security personnel, healthcare personnel, teachers, community leaders and family members.
- Take steps to address the lack of data on persons with albinism, in particular disaggregated data on the number of persons with albinism.

Peter Ogik of Uganda is one of the case studies included in the report, and was the inspiration for the report's title. In the below extract, he describes how he spent his childhood 'waiting to disappear'.

'There were two of us in my family with albinism - my sister and I. When I was young, I was told that I would not die. They said I would disappear because people like me - people with albinism - are not like other people and do not die. I spent my childhood waiting to disappear. Every day I wondered whether that would be the day I would disappear until the day my sister died in a tragic car accident. That is when I realised that, just like everyone else, people with albinism die.'

'There were a lot of people at my sister's funeral. At first, I thought it was because we had many friends, but I soon discovered it was because people couldn't believe someone with albinism had died. They wanted to see for themselves that she had actually died.'

'My father spent many nights sleeping next to my sister's grave. He wanted to make sure no one came to take her body because people think you can get powers from body parts of persons with albinism. They don't know that we are just human like everyone else.'

The report concludes that states have fallen short of obligations set out under international and regional treaties, and persons with albinism continue to be victims of human rights abuses.

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