



## UNESCO Webinar **A Briefing on the Situation of Persons with Albinism including the Way Forward**

On the occasion of International Albinism Awareness Day  
&  
International Day of the African Child  
16 June 2020

### Summary Report

#### Opening Session

**Mr Firmin Edouard Matoko**, Assistant Director-General for Priority Africa and External Relations of UNESCO opened the floor by welcoming all the participants and thanking them for joining the Webinar. In his address he reiterated UNESCO's commitment to support persons with albinism (PWA) in Africa, through the lens of the organization's. Mr Matoko informed on UNESCO's recent actions to include concerns on PWA in high level policy events, citing the Pan-African Conference on Education held in Nairobi in 2018 in collaboration with the African Union Commission (AUC) and the government of Kenya and the Biennale on the Culture of Peace held in Luanda co-organized by the AUC and the Angolan government. Referring to the COVID-19 crisis, he called attention to the need for a concrete integration of their concerns in the current counteracting plans.

He reminded that this was the second celebration of International Albinism Awareness Day (IAAD) since the UN inception of the day by the UN, the first having taken place in 2016 in collaboration with the Pierre Fabre Foundation and Under the Same Sun. He recalled also that on the ground, several multi-sectorial interventions and mobilization activities have been implemented since, notably in Tanzania, Mozambique and Namibia, in support of the shaping and implementation of the [Regional Action Plan on Albinism in Africa](#)<sup>1</sup>. He finally called upon the support of the African Permanent Delegations to UNESCO and the National Commissions to intensify the actions to ensure the enjoyment of human rights for PWA.

Addressing the floor on behalf of H.E. Mrs Phyllis Kandie, the Chairperson of the Africa Group and Permanent Delegate of the Republic Kenya at UNESCO, **H.E. Mrs Hellen Gichuhi** the deputy permanent Delegate of Kenya to UNESCO, started by providing a short description of the situation of PWA in the continent. She then proceeded highlighting three main points: the need for African countries to commit to put restorative solutions in place; the UN and AU's engagement through the regional forums on Albinism and the Regional Action Plan on Albinism; the significant role played by civil society's in support of this cause. Referring to her own country as an example on how to support PWA, she informed that yearly the equivalent of 1 million USD is budgeted by government for skin care products and access to hospitals for eye treatments for over 3000 PWA. She also praised the example of Senegal,

---

<sup>1</sup> To view the African Commission on Human and Peoples' Rights resolution on the Regional Action Plan on Albinism in Africa (2017-2021), please use this link: <https://bit.ly/3dvNylk>

where local companies have produced sunscreen at reduces prices. She concluded by appealing to UNESCO to intensify sensitization not only for children but also for parents and educators. She also suggested to engage the UNESCO Institute of Statistics to collect further data on PWA.

**Dr. Jane Marie Ong'olo**, Head of Social Welfare, Vulnerable Groups and Drug Control Division and Division in charge of Albinism, Representative of the AU Commissioner for Social Affairs, 4took the floor on behalf of the African Union Commissioner for Social Affairs, H.E. Ms. A. Elfadil Mohammed Elfadil. She started by reiterating the AU's commitment to the promotion of an inclusive society and the protection of all human rights. In this respect, she announced that an all-inclusive Social Agenda framework, with the support of Social Protection Protocol, has been developed by the AUC. She continued by mentioning some recent and very important achievements from the February 2020 AU Assembly of Head of States and Government: (i) the adoption of the Plan of Action on ending attacks and other human rights violations on PWA; (ii) the decision to appoint a Special Envoy on Albinism; (iii) the adoption of the African Union Disability Architecture (AUDA). This last, she affirmed, has been ratified by only 8 countries although it has been put in place in 2018. Therefore, she called on the need for a mutual beneficial cooperation and a deepened support to bring those actions into force and ensure an equal access to human rights for all.

**Ms Ikponwosa "I.K." Ero**, UN Independent Expert on Albinism started her remarks by praising the Webinar as an occasion not only to highlight problems that subsist for this particular group of people but also to celebrate successful stories and best practices. She then left the floor to the two young witnesses.

### **Keynote interventions**

The following session brought the experience of a young man and an adolescent girl with albinism as well a description by the UN Independent Expert on Albinism on the current situation in Africa as well as the outline of the Regional Action Plan.

The first testimony was shared **Mr Manyashi Emmanuel Mabula** a 20 years old young man from Mwanza, a region in Tanzania, where attacks against PWA rose to high levels from 2014 to 2016, calling the attention of the international press. He addressed the Webinar by sharing how his horrific experience as a small boy child witnessing the brutal murder of his little sister at the home of his grandfather, marked him for life including his constant fear for his own life. He also shared how meeting Peter Ash, the founder of "Under the Same Sun", in 2008 was a turning point in his life. His support provided him with the opportunity to continue his studies in an English school where, despite all the initial challenges of discrimination and bullying, he succeeded in graduating at primary and later at secondary level, allowing him to be ready to start his journey into high school. He particularly emphasized the surprise of people from his village in realizing the achievements he made despite of his condition as a person with albinism. He concluded by making two recommendations: the importance of ensuring safety for PWA by educating the public on the truth of their condition and the need to include them in programs aiming at promoting social integration and employment opportunities.

The second witness statement was given by **Jenipher Alphonse**, a 16 years old girl with albinism also from Mwanza, Tanzania. She took the floor by making two recommendations to UNESCO. She stressed the health care and precaution that a child with albinism must take to protect himself from sunburst and therefore from skin cancer. She also explained the challenges that children with albinism have in their education learning path, notably due to low vision. CWA need particular support-tools to succeed in their education and realize their dreams.

**Ms Ikponwosa "I.K." Ero** then took the floor and provided a brief background on the issues regarding the stigmatization, violence and harmful practices faced by PWA. She highlighted the major role played by UNESCO through its support and resources. She plead for urgent action given that PWA are not only having their human rights enjoyment being threatened but more importantly, their right to life being

at stake. Stressing that lives jeopardy did not only stem from violent attacks, she informed that the high mortality rate of PWA is also caused by skin cancer, particularly in Africa.

While mentioning the important achievement represented by the development of the Regional Action Plan, she expressed her wish to create an alliance to act fast with the trusted support of UNESCO and the African Union. She thanked UNESCO for the support for the organization of the sensitization events of the plight of PWA called upon UNESCO for more data on the situation of PWA as well as more public awareness programmes through the media. Referring to the UN agenda on counteracting harmful practices such as early marriage and female genital she asked for UNESCO support, given its mandate in culture to include PWA attacks into this agenda.

The next session reflected on best practices addressing the issues of PWA on the continent. The first two speakers spoke about their respective experiences as activists while the three other reported on UNESCO specific intervention in Southern Africa.

**Mr Ouro Yondou (SURAJI)**, the President of the *Association Nationale de Albinos* du Togo began his speech by thanking UNESCO for the opportunity to share the experiences of people with Albinism in Togo. He shared some of the measures that have already been undertaken by his association, and others that have been planned to promote the rights of persons with albinism (PWA) in 39 districts across Togo. The measures highlighted include an awareness raising capacity building workshop - arranged for the media, a census data of PWA in Togo segregated by age and region; partnership with Togo association of dermatologist to help to tackle skin cancer; teacher training to support children with albinism in schools and quarterly and annual reports. These measures and many others have helped to improve the experiences of PWA in Togo. However, there is still more to be done and in that regard Mr Yondou called for higher level support from UNESCO to make sure that the advocacy is closer to regional blocks like ECOWAS and SAMC. He also called for UNESCO to help with awareness raising work, through community media to make albinism better known in the more remote areas as the regional action plan requires. He called for UNESCO to support inclusive education by developing action plans for member states to address challenges faced by PWA at school due to visual and skin impairment.

**Hon. Isaac Mwaura**, Senator of the Republic of Kenya and Head of the Albinism Society of Kenya spoke of Africa's leadership when it comes to the rights of PWA. He spoke about some of the progress already being made on the continent to secure rights for PWA, like ensuring that albinism is a stand-alone human rights issue and also within the discourse of disability to have it as part and parcel of AU disability architecture in regards to the regional action plan (now the AU action plan). In Kenya, Mr Mwaura spoke about the advances made in the country, where he was elected as the first Member of Parliament with albinism. In his role, he has been able to push in parliament for government to allocate \$1,000,000 a year to provide free sunscreen lotion, protective clothing, skin cancer treatment, eye care services, awareness creation as part of government programme. He also spoke about the recent victory to include the albinism question in the last census that took place in 2019. The senator also highlighted that despite these advances, since the time when the first PWA was killed – there have been an increase in such killings. As a result, he called for unity and synergy so that governments, and institutions, and economic blocks can be pushed to see that PWA matter, not because of numbers, but because when you look at the numbers, they look negligible. In fact the voices of PWA can be amplified to show that there is a lot that PWA can do for society. He concluded by summarising the experience of PWA saying that 'we are black, but not black enough. We are white but not white enough; disabled but not disabled enough'. We suffer from that inbetweeners, we must break the barriers and self-define so that the African child albinism can be cultured as a true African, a black child with white skin.

**Ms Zulmira Rodrigues**, Chief of Section for Cooperation with Regional Organizations in Africa of UNESCO shared the work undertaken in Tanzania by UNESCO from 2014 to 2016 when she was the Head of Office. She explained that UNESCO engaged in the advocacy and support of PWA initially as

part of the electoral support programme, expanded later given the seriousness and continuation of attacks to PWA. The multi-sectorial programme consisted of five main areas of intervention:

1. National Sensitization Campaign

A digital poster and video campaign was carried out presenting a positive image of people with albinism. This campaign featured photographs and short video.

2. Community Sensitization through Community Radios

UNESCO carried out training of journalists of eight Community Radios in the Lake Region, where atrocities against PWA were most prevalent. Specific programmes were produced and broadcasted helping identifying and countering issues through accurate, unbiased reporting relating to PWA.

3. Mobilization of Community Leaders for community level support of PWA

Workshops using a socio-cultural approach were carried out in four districts in the Lake Region where discrimination, stigma and persecution of people with albinism were more prevalent. They enabled awareness creation and the identification of factors contributing to exclusion and persecution of PWA within the communities. Key community leaders - traditional healers, traditional leaders, religious leaders, teachers, health workers - and PWA themselves, influential persons and interest groups representatives and the Council for Human Rights and Good Governance and Regional and District authorities were brought together for an exchange on how best to tackle the issues. 12 villages benefited from these sessions resulting in the elaboration of actions plans around the 3 Rs: Prevention, Prosecution and Protection that were executed by the different stakeholders.

These workshops resulted in a clear mobilization of communities reflected in the adoption of districts programmes and budget for PWA; awareness raised through village assemblies and preaching in churches and mosques; parents adopting protecting measures against sunshine exposure and healthcare, including skin cancer screening and treatment actions to remove pre-cancerous lesions being carried out.

4. Zero Tolerance against bullying in schools

To respond to the issue of discrimination in schools that arose from the dialogue sessions, a programme was put in place to ensure that schools became safer places for children with albinism bearing in mind that schools should be an essential component of a safe and inclusive community. Training workshops targeting teachers and headmasters were carried out in four pilot primary schools in (one in each district) to showcase how to implement human rights education and create an environment of respect for all within the schools. The programme was later expanded to the other schools in the 4 districts and the participation of one of the Education officials in the Global Education Conference in Incheon, South Korea, that resulted in the SDG 4 framework, to elucidate the importance of tackling bullying in schools.

5. Training of care givers in centres for children with albinism

As more children were placed in special centres to shield them from attacks and reports on the situation on the centres indicated deplorable living conditions, trainings were organized targeting the care givers at the two main centres hosting children with albinism. The training resulted in caregivers having a better understanding of the needs of children with albinism and the correct emotional and physical support they should provide and the portion of integrated services including the appointment of medical staff in the centres.

Ms. Rodrigues concluded that given that a baseline and an end evaluation were undertaken, the UNESCO intervention was able to measure the [impact](#)<sup>2</sup> of the actions undertaken. The report was

---

<sup>2</sup> Impact Evaluation – PWA Tanzania

disseminated widely, resulting in the support of OSISA to Mozambique as well as the inclusion of UNESCO in posterior events organized by the UN Independent Expert within the context of the formulation and adoption of the Regional Action Plan. The UNESCO intervention in Tanzania was praised and reported to the UN Human Rights Council.

**Mr B. Djaffar Moussa-Elkadhum**, Head of UNESCO's Namibia Office spoke about the violation of the human rights of PWA. He recalled that these violations are due to a combination of socio-economical cultural anthropological factors linked to ignorance and poverty. To address these challenges, Mr Moussa-Elkadhum referred to the 2017-2021 regional action plan which recognises the need for a sustained public awareness raising campaign as the number one priority to support any intervention that addresses attacks on PWA in sub-Saharan Africa. He shared information on the ongoing work in Northern Mozambique where UNESCO and Open Society Institute for Southern Africa (OSISA) have implemented a pilot project to address challenges faced by PWA. Taking best practices from the experience in Tanzania, UNESCO and OSISA have mobilised and involve faith-based organisations and traditional healers and family members and PWA to support and disseminate information concerning the protection of PWA. He reminded the audience that we are 10 years to realise the ambitious goals of the SDGs and the concept of leaving no one behind; for that reason - he called for UNESCO to continue contributing to the enjoyment of rights by PWA, by supporting the implementation of the regional action plan. He also encouraged UNESCO to stand firm with PWA and make sure that their rights are preserved and reflected in UNESCO's new medium-term strategy (C4) and the upcoming programme and budget (41 C5).

**Mr Paul Gomis**, Head of UNESCO's Maputo Office spoke about the 6-capacity building training provided by UNESCO for more than 150 participants. He also spoke about the training provided to 25 radio journalists on sensitive reporting, protection of PWA, and gender and reporting. Mr Gomis explained that most journalists come from community radio, which are more influential in rural areas. The UNESCO team also planned and executed the PALOP conference and training on albinism with 120 participants from 7 countries with representation from NGOs, CSOs and UN agencies. The conference trained CSO of PWA on: leadership, organisational structure, fundraising, proposal writing, advocacy, planning and communication strategy. He committed to continue the work to secure the rights of PWA.

**Mr Peter Ash**, Founder and CEO of Under the Same Sun began his presentation by congratulating Mr Mayanshi Emmanuel Mabula and Ms Jenipher Alphonse for their presentation. He recalled that whilst in his home country of Canada, he decided to travel to Tanzania after reading a BBC article about the killings of PWA in the country. When he first met Mr Mabula along with other students in 2008, the 8-year-old Mr Mabula and his classmates were too terrified and would not smile or laugh because there had been a spate of killings of PWA. Mr Mabula at the time had seen the murder of his sister and was facing the psychological trauma from the event. Since then, Mr Ash decided to continue working to alleviate the discrimination and the suffering of PWA. He announced that after many years, with god's help and a lot of good people on the team, the organisation has been able and fortunate to make some good progress. Mr Ash spoke about how the public education programmes by Under the Same Sun have been very successful throughout the country. There have not been any killings in Tanzania for 5 years. He concluded by sharing the twin statement of Under the Same Sun: "I have a dream that one day, people with albinism will take their rightful place in every level of society and that the days of discrimination will one day be a thing of memory." He explained that that is the dream that the organisation works for, that the discriminations faced by PWA will one day be something that is a faint memory and not a reality anymore. He called for everybody present to work together to continue to labour to secure the rights for PWA.

**H.E. Mr Samwel William Shelukindo**, Ambassador of the United Republic of Tanzania took the floor to highlight a few points on the issue of violation human rights. He recalled that in 2008 the Tanzania government declared the ritual killing of people with albinism as a capital offence and explained that

since the current government came into power under the leadership President Magufuli, no killing or attack has been registered in the country. He also shared that the government has appointed PWA to cabinet positions, and to senior diplomatic roles with the country appointing the first PWA as an ambassador in Europe on behalf of the government of Tanzania. Mr Shelukindo concluded by confirming that efforts are being made to ensure that children with albinism, continue to access quality education. He spoke about the new inclusive education strategy of 2019-2024 recently undertaken in Tanzania, which includes, training teachers to provide adequate support for learners and ensuring availability of low vision aids, adaptive devices and large print materials, which in his view address some of the challenges raised by Jenipher Alphonse in the earlier session.

The Moderator, **Ms. Angela Melo**, Director Policies and Programme, Social and Human Sciences Sector, summarised the webinar by thanking those who participated for taking your time to present and share outstanding experiences and testimonies. As takeaway, she highlighted the importance of political will, public advocacy, media involvement, and data collection as necessary steps to ensure that the rights of PWA are secured. She also for the partnership between UNESCO and local partners to create momentum and move forward with all the recommendations and put made by participants. She requested the organizers of the Webinar to prepare the report of the webinar to be shared with all participants. She emphasised that she liked the recommendations put forward by Mrs Hellen Gichuhi, and Dr Jane Ong'olo. She concluded by congratulating PAX for providing this platform to discuss the issues affecting PWA and encouraged participants to make the albinism issues a part of national and global conversations.

**Mrs Hellen Adhiambo Gichuhi on behalf of H.E. Mrs Phyllis Kandie**, gave the closing speech by summarising her thoughts. Mrs Gichuchi explained that although she started the afternoon with some knowledge about issues faced by PWA, she expressed that she had been able to learn a lot more and understood the role that delegations can play to advance the issue. She stated that she wanted to believe that the other delegations have taken away something in their role towards making an all-inclusive society for PWA. She also asked questions about what appear to be an omission of calls for stricter and more punitive measures for people who abuse the rights of PWA. She called for harder prosecutions of those who commit crimes against PWA by making it clear that it is very costly to attack or discriminate against people living with albinism. She expressed that with political will and delegation pushing, and the AU working together with UNESCO, it might be possible to work together to have legislation that is more punitive and that actually works. Mrs Gichuchi also promised to work with partners to ensure that tools are put in place to avail sunscreens to PWA, because some of the things that seem small can make a significant difference. On the suggestion that PWA issues should be part of UNESCO's new medium term strategy (C4 and C5), she stated that this is indeed a timely moment propose programmes and promised to investigate the manner in which this can be done as delegates work to re-examine the C4 and C5. She concluded her remarks by expressing gratitude on behalf of the Africa group, for being included in the webinar. She thanked UNESCO's Priority Africa Sector for putting together the webinar to raise awareness on the plight of persons with albinism.

To view the questions raised during the Webinar with their respective answers, please use the following link: [https://en.unesco.org/sites/default/files/qa\\_webinar\\_iaad\\_16.06.20.pdf](https://en.unesco.org/sites/default/files/qa_webinar_iaad_16.06.20.pdf).

#### **Additional Resources:**

- Biographies  
[https://en.unesco.org/sites/default/files/qa\\_webinar\\_iaad\\_16.06.20.pdf](https://en.unesco.org/sites/default/files/qa_webinar_iaad_16.06.20.pdf)
- Presentations (PPT)  
[https://en.unesco.org/sites/default/files/ppt\\_webinar\\_iaad\\_16.06.20.pdf](https://en.unesco.org/sites/default/files/ppt_webinar_iaad_16.06.20.pdf)

- Speeches:  
[https://en.unesco.org/sites/default/files/speeches\\_webinar\\_iaad\\_16.06.20.pdf](https://en.unesco.org/sites/default/files/speeches_webinar_iaad_16.06.20.pdf)
- Programme Webinar EN:  
[https://en.unesco.org/sites/default/files/programme\\_en\\_webinar\\_iaad\\_16.06.20.pdf](https://en.unesco.org/sites/default/files/programme_en_webinar_iaad_16.06.20.pdf)