

**Message from Mr Firmin Edouard Matoko,  
Assistant Director-General for Priority Africa and External Relations of UNESCO  
on the occasion of the Albinism Awareness raising session during the  
Celebration of the African Child Day**

16<sup>th</sup> June 2020

Dear IK, the very first UN Independent Expert on Albinism,

Dear Commissioner for Social Affairs,

Ambassadors, colleagues and friends,

Firstly, I would like to take this occasion to thank you for joining us today, the International Day of the African Child, to celebrate the International Albinism Awareness Day that recently took place on the 13<sup>th</sup> June.

The reason we have invited you to attend this session today is to raise awareness and attention about the experiences of the African children with albinism. Unfortunately, across the continent people with albinism face incredible hardships and are prevented from enjoying their basic human rights and the rights to live in a safe environment without fear of attacks or harassment. Persons with albinism on the continent have been and continue to be victims of stigmatization, discrimination and cruel attacks because of myths and erroneous widespread beliefs that still reign on the continent.

We learnt from the last report of the Independent Expert on the enjoyment of human rights that women and children with albinism are the most vulnerable as their lack of skin pigmentation adds another factor of vulnerability to the ones other disadvantaged children face.

So indeed, when our friend IK, reached out to us in January this year, to both thank UNESCO for the work that has been done on the continent so far and to also request that we intensify actions to improve the conditions of this very vulnerable group, we responded by organizing this session. I am convinced that the insights that are going to be shared today will gain your support and you will join us on this journey, together with the African Union, the UN Independent Expert, the activists and the organizations on the ground who have made their mission to raise awareness and shine light on the plight of persons with albinism.

UNESCO's mission and main areas of work lent itself well to contribute to this important cause:

Through education we can contribute by ensuring that bullying and discrimination of children with albinism is eliminated at the school level including inclusion of awareness raising in civic education content.

Through Communication and information we can help disseminate messages and information to counteract the prejudices and misconceptions around albinism.

Through Social and Human Sciences we work on defeating exclusion and promoting the human rights of Persons with Albinism.

Through Culture, we can mobilize traditional leaders and healers against witchcraft practices counteracting the believes that body parts of people with albinism have magical properties.

Sciences on other hand can help in establishing relationships with companies producing sun cream lotions and to enable the purchase at a special price as well as support science-based messaging.

On another note, in this period where countries are struggling to overcome the COVID-19 pandemic crises, we need also to bear in mind its impact on the already precarious conditions of PWA. The closure caused by the pandemic could led in many cases to the aggravation of their fragile status. This means for us the necessity to strengthen our common efforts to ensure their protection and defend their human rights. In this respect, integrating the issue of Persons with Albinism in current Counteracting plans will help reduce their increased vulnerability.

We have recently seen that by bringing the issue of persons of Albinism to high level policy events allows for their particular concerns to be included in important policy orientations captured in the Declaration of the Pan-African Conference on Education held in Nairobi Kenya in 2018 and most recently, the recommendations of the 1<sup>st</sup> Edition of the Culture of Peace Biennale of Launda held in Angola in September last year.

UNESCO strongly supports the UN Independent Expert in her mandate to give an international voice to persons with albinism and to identify best practices for the realization of their human rights. n that regards I would like to reaffirm here that

UNESCO remains committed to support the materialization of the Regional Action Plan, side by side with the African Union Commission and the UN

In 2016, for the very first time and in collaboration with the Pierre Fabre Foundation and Peter Ash's *Under the Same Sun*, we celebrated the International Albinism Awareness Day at the UNESCO HQ. I would like to take this opportunity to thank Peter Ash for joining us here again today, albeit online.

Since then, several other multi-sectorial interventions and mobilization activities have been carried out by UNESCO in other African countries, notably in Tanzania, in Mozambique and Namibia. My colleagues will briefly tell you more about the specific actions undertaken in those 3 countries, actions that have helped to shape the Regional Action Plan on Albinism in Africa (2017–2021) endorsed by the African Commission on Human and Peoples' Rights and that exemplify what we as UNESCO can do for this cause.

UNESCO commits to continue working closely together with African partners to ensure the implementation of the Regional Action Plan in relation to UNESCO's domains of competence. We call also on the support of our African Permanent Delegations and National Commissions to join us and at country level engage with our Regional and National Offices. We are convinced that joining efforts will help to stop the violation of human rights of people with albinism and ensure that they can live safely and peacefully and prosper in an environment free of fears where their human rights are guaranteed.

Thanking you for your attention I would like to welcome the representative of the Commissioner of Social Affairs to take the floor, Ms Dr Jane-Marie Ongolo, Head of Social Welfare, Vulnerable Groups and Drug Control Division.

**REMARKS BY H.E. PHYLLIS KANDIE, CHAIR OF THE AFRICA GROUP AT UNESCO, ON THE OCCASION OF THE INTERNATIONAL DAY OF THE AFRICAN CHILD AND INTERNATIONAL ALBINISM AWARENESS DAY – 16 JUNE 2020**

**Mr Firmin Matoko - ADG for Priority Africa & External Relations**

**Ms Amira Elfadil, Commissioner African Union**

**Ms Ikponwosa Ero - first UN Independent Expert on Albinism and our most esteemed chief guest today**

**Distinguished Panelists including my Senator Hon Isaac Mwaura, welcome Sir**

**Excellencies, Ladies & Gentlemen**

On this auspicious day to mark the international day of the African Child and in the context of the International Albinism Day, allow me on behalf of the Africa Group and its Chairperson Ambassador Phyllis Kandie to welcome you all to this webinar. I warmly appreciate and congratulate UNESCO for organising this initiative to address an urgent and yet not sufficiently tackled issue of the sufferings of Children born with Albinism in Africa.

Albinism remains misunderstood in several countries. And a lot of mystic powers have been associated with albinism with tragic outcomes. But, albinism is just an inherited genetic condition which reduces the amount of melanin pigment. This leads to sensitivity to the sun and to bright light, leading to eye problems and sometimes to higher risks of certain skin conditions.

Statistically, the prevalence of albinism in Sub-Saharan Africa is about 1 in 2000–5000 persons. Persons born with albinism face some of the most extreme forms of human rights violations including Abuse of their rights as children; Abuse of their rights as persons of disability; and Abuse to their rights as citizens. Children and women make up a majority of the victims. The stigma, violence and discrimination is also extended to mothers of children with albinism. Statistics further indicate that more than 90% of people living with the condition in Africa sadly die young, mainly due to preventable causes.

Fortunately the horizon is beginning to look less bleak. Rays of hope filter in through three main action areas. First, African countries are undertaking to put restorative solutions into place. Second, the United Nations and the African Union are pioneering initiatives through regional forums on Albinism in collaboration with other development partners, as well as the Regional Action Plan on Albinism in Africa 2017 to 2021. And third, the active participation of civil society has led to tangible changes for people living with albinism. Cultural events and other gatherings have been held to raise awareness on, and to celebrate persons with Albinism.

In Kenya for example, in 2015, the government set aside KSh144 million for skin care products' programme for over 3000 people living with albinism, and access to government hospitals for

eye treatments was made easier. In Senegal, local companies have produced bottles of sunscreen at reduced prices.

Despite the progress made, Albinism remains an urgent issue requiring stronger and focused action globally. UNESCO could lead in sharing innovative practices in line with UNESCO's mandate, such as this event today.

Within the Education sector for example, the rights of children and persons with Albinism could be addressed through global sensitization manuals and education material not just for the children, but also for the parents and educators on how to handle and support the children.

Another area for collaboration could be with the UNESCO Institute of Statistics to collect data on the experiences of children and persons living with albinism which is hitherto missing. This collaboration could be extended to other data agencies, particularly in Africa.

Together, we can work to bring an end to the discrimination and violence suffered by children and people living with albinism and contribute to empowering them to be fully functioning members of society.

As we say in Swahili "the laughter of a child lights up the house". Likewise, investing in children and persons with albinism, and in their rights to full and fulfilling lives, is crucial in building a healthy, sustainable and peaceful society which in turn will build the Africa that we want.

I thank you.

## **Commemoration of the International Albinism Awareness Day: Introductory Remarks**

Jane Marie Ongolo  
Head of Social Welfare, Vulnerable Groups and Drug Control

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It is timely that this commemoration of the International Albinism Awareness Day, takes place on the Day of the African Child. As we know, Children with albinism suffer disproportionate human rights abuse and violation.

Under the theme “Access to a Child friendly Justice in Africa”, on this Day, AU is calling on Member States of the African Union to create and enhance child-friendly justice system which caters for the specific needs of children in their territories.

Access to justice is a fundamental right in itself and an essential prerequisite for the protection and promotion of all other human rights; this is especially true for children, and in this case, children with albinism.

I would like to assure you at outset that the AUC is concerned about the realization of an inclusive society where all members, including persons with albinism and other often-marginalized and vulnerable populations, have an equal say and standing in Members States; hence the development of an all-inclusive Social Agenda framework with a supporting Social Protection Protocol.

I am pleased to inform you that the recent AU Assembly of Heads of State and Governments that took place in February 2020 adopted the Plan of Action on Ending Attacks and Other Human Rights Violations on Persons with Albinism. In this regard, let me acknowledge the collaboration we have enjoyed with the Independent Expert on the Enjoyment of Human Rights of Persons with Albinism, Ms Ikponwosa Ero, which started in earnest in 2017.

Significantly, the Assembly also approved the appointment of a Special Envoy on Albinism, processes are ongoing to operationalise.

As you may be aware already, the First and Second African Decades of Persons with Disabilities was declared from 1999 – 2009, -2019 with the goal

of full participation, equality, inclusion and empowerment of people with disabilities in Africa; leading to significant achievements in the Continent:

**1.1. The African Union Disability Architecture (AUDA)**, which has the [i]. **Legal Pillar** (Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa), currently signed by 8 Member States since January 2018; The **Programme Pillar** (AU Disability Strategic Framework); the **Regional Specialised Office Pillar** (AU Disability Institute – AUDI).

**1.2. The Plan of Action on Ending Attacks and Other Human Rights Violations on Persons with Albinism** which I have just mentioned above.

- Addressing these concerns is a common shared responsibility therefore we looking forward to mutually beneficial cooperation in the following areas:
- Implementation of the Plan of Action on Ending Attacks and Other Human Rights Violations on Persons with Albinism; as well as support to the office of the Special Envoy.
- Implementation of the AU Disability Strategic Framework; including promoting the ratification of the Protocol on Disabilities.
- Adequately resourcing disability agenda, and in particular persons with albinism.
- Supporting the Committee of Experts on the Rights and Welfare of the Child to focus on children with disabilities and children with albinism.



**AFRICAN CHILD AND COMMEMORATION OF INTERNATIONAL ALBINISM**  
**AWAWARENESS DAY: JUNE 16<sup>th</sup>, 2020**

**Name: MANYASHI EMMANUEL**

**Place: MWANZA- TANZANIA**

**Subject: LIFE STORY AND RECOMMENDATIONS ABOUT CHILDREN WITH ALBINISM**

Hello, everyone!

My name is Manyashi Emmanuel I am a person with albinism

I was born in 1999. In our family we were 6 children two of the children were having albinism, In our family two children passed away including one child with albinism who was my young sister. But now we are 4 children remaining. At home I live with my mother, my sister and two young brothers, all we are schooling under the sponsorship of Under The Same Sun.

In 2008, I was in a difficult time in which I was so much worried of my life to be attacked and killed in that time. This is because of my young sister Mariam who was attacked and killed by three people, and, one of the people was our closely relative who used to come at home. So, I was in a difficult time and my sister's death gave me unhappy life. The time when I was a small boy people didn't know how to call me well. They called me bad names like **Zeruzeru /mbuli mweru (White goat)** and so many names, but, I lived with them like in that way, but when they killed my young sister, I was afraid of them. My sister's death was like this:

One day in the evening after we have taken our dinner, we went to sleep. My elder sister and my young sister Mariam went to sleep together, but I went to sleep with my grandfather. During the night at 3am, three people came directly to the house

that we used to sleep, destroyed the door and got inside directly to the room where Mariam was sleeping, they took her down to the floor, killed her like an animal whereby they took off her tongue and her legs. That situation was so much painful to me and my members of the family. After that bad event I was taken to a special center which they care for people with albinism called **Mitindo in Mwanza Tanzania**, the School that is where I started my standard one in the year 2008.

During that year 2008 one person from Canada who heard about the killings of the people with albinism in Tanzania who is Peter Ash, the founder of Under The Same Sun Organization came at school (**Mitindo**) in which I was sent. For the first time he saw me he lifted me up by his hand like my father, though I was not able to say anything to him, but he showed a great love to me in which he took me to special English medium school. I was the first person to be sponsored with the founder of under the same sun Organization Peter Ash.

For the first time to be in English medium school in 2010, I got a hard task to know English language where it made me to restart the same class, but after three months I started capturing the language through the reading English books and doing practices. The results were very poor I didn't perform well in class, which was because of the low vision I had. It was difficult for me to see well in the blackboard. Through all these difficulties I faced I got eye glasses, Dome lens and monocular, these are the tools that raised my academic performance.

After proceeding with my education in primary level, I managed to graduate grade 7, which was the start of my education journey that was in 2015. I got a good grades to join secondary school.

I spent four years for my secondary school education and completed in November 2019. After all I graduated  my secondary education with good grades which allow me to join High School this year.

## **JOINING HAKI YETU PHASE TWO PROJECT**

Haki yetu project was to fight against discrimination to people with albinism in a certain society. I was among team members in the project, through the project I gained a lot of experiences, confidence and ability to socialize with people in the society. Also through the project I gained a lot of confidence to stand in front of people which was a problem to me before, that was my first time to stand in front of many people like that.

During the project we traveled to different regions like Shinyanga and Mwanza. Some of the places it was my first time reach. So this was a special to my life. I thank God for that and all who made me to join the project.

## **RECOMMENDATIONS**

### **1. Safety**

People with albinism should be safe whereby the society should have the truth about people with albinism because the society it is the one which can protect people, so what is needed is to provide education to the society.

### **2. Inclusion**

Children with albinism should be included in various programs so that they build confidence, awareness and employment for their life.

**Thank you for listening!**



**AFRICAN CHILD AND COMMEMORATION OF INTERNATIONAL ALBINISM**  
**AWAWARENESS DAY: JUNE 16<sup>th</sup> , 2020**

**Name: JENIPHER ALPHONCE**

**Place: MWANZA- TANZANIA**

**Subject: RECOMMENDATIONS ON CHILDREN WITH ALBINISM**

Hi, everyone!

My name is Jenipher Alphonce from Mwanza Tanzania. I am 16 years old. First of all, I would like to appreciate on this chance for welcoming me here today.

As a child with albinism, I feel unhappy when I see children with albinism are discriminated in the society. On this special day, I would like to make the following recommendations to UNESCO about children with albinism:

**1. Health care to a child with albinism:**

- a. A child with albinism is supposed to put on long sleeve clothes, apply sunscreen lotions to protect against skin cancer
- b. Wearing hat with wide surface and sun glasses when walking in the sun

**2. Education- Due to low vision:**

- a. A child with albinism has to sit in front of the classroom in order to see well on the chalk board.
- b. Using reading glasses, monocular, dome lenses in order to help him or her to see well and do well in our studies.
- c. Teachers have to use large print when providing lesson notes to children with Albinism.

These will enable a child with albinism to get a quality education and realize their dreams.

**Thank you so much for Listening!**

**Have a bright day!**