



United Nations
Educational, Scientific and
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Organisation
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la science et la culture



UNDER THE
SAME SUN



FONDATION PIERRE FABRE



FRANCE
MÉDIAS
MONDE



CONCEPT NOTE

INTERNATIONAL ALBINISM AWARENESS DAY

13 June 2016

What is albinism

Albinism is a hereditary genetic condition which originates from a malfunction in the synthesis system of the pigment melanin. The role of this color pigment, found in the skin, hair and the membrane in the eye, is to protect the skin from the sun's ultraviolet rays. This malfunction is reflected through alterations in the visual system such as decreased vision, sensitivity to light, a permanent, jerky movement in the eyes and an eventual squint which can be accompanied by cutaneous hypo-pigmentation of varying degrees of strength.

There is great disparity between the global levels of albinism occurrence. The most affected regions are Africa and South America; the least, Western Europe.

In certain countries people with albinism face great discrimination and suffer from all sorts of abuse related to societal myths and witchcraft, which go against the values stated within the Universal Declaration of Human Rights.

Context

On 13 June 2013, on its 23rd session, General Assembly of the United Nations adopted a resolution on the subject of attacks and discrimination against persons with albinism.

"It urges States to take all measures necessary to ensure the effective protection of persons with albinism, and their family members; ensure accountability through the conduct of impartial, speedy and effective investigations into attacks against persons with albinism falling within their jurisdiction, and to bring those responsible to justice, and to ensure that victims and family members have access to appropriate remedies; to take effective measures to eliminate any type of discrimination against persons with albinism, and to accelerate education and public awareness-raising activities.

It encourages States to share best practices in protecting and promoting the rights of persons with albinism, [and] Invites relevant special procedures of the Human Rights Council, as appropriate, in the framework of their mandate, to address the relevant aspects of the safety and non-discrimination of persons with albinism.

Finally, it invites States, in collaboration with relevant regional and international organizations, to promote bilateral, regional and international initiatives to support the protection of persons with albinism.

On 18th December 2014, the General Assembly of the United Nations proclaimed the 13th June as the International Albinism Awareness Day.

UNESCO supports initiatives which favor human rights and the fight against exclusion and discrimination. In response to the call from the General Assembly of the United Nations, the Director General, Irina Bokova, decided to commemorate the day of the 13th June by encouraging its member States and all its partners to fight against the discrimination and stigmatization from which persons with albinism are victims, and to target the root cause of this in order to allow them to live with dignity and prosperity.

Objectives

This International Albinism Awareness day offers an opportunity to understand or deepen our understanding of this genetic condition, the medical difficulties it produces, and the social challenges which those with albinism face. It is also a call to UNESCO member States, all governments and civil society to reaffirm their commitment to human rights by launching discussions and action which will lead to propositions/solutions to relieve these challenges.

As the Director General, Irina Bokova, said in March 2014, "*Respect and tolerance are liberating acts, whereby the differences of others are recognized as the same as our own and whereby the riches of another culture are taken as the wealth of all*".

Demystification of the genetic characteristic

This Day will be punctuated by several powerful moments. The idea being to favor respect for the rights of those with albinism, social justice, and equality in order to allow them to exercise their right to be entirely the citizens they are. This world also belongs to them, as well as their right to aspire towards a better future.

The screening of a film documentary, the colloquium and the lively debates by specialists in ophthalmology, dermatology and genetics, as well as the exhibition, will all have the goal of making the public aware of and demystifying this genetic condition.

The works of art expositions and the stands will show the buried treasures in the heart and soul of our fellow citizens, in whom the desire which deserves to exist is, unfortunately, spent fighting against discrimination and marginalization. It will also be the occasion to discover or meet with the campaigning associations, the partners and the sponsors of persons with albinism, to find out about the different projects devised or already implemented to further the cause and make a contribution.

Associations

- ALBA, Spain
- ANIDA France
- Ecole de l'espoir, France
- Genespoir, France
- HEMA (Association des albinos d'Hema Nayele), France
- SACRI, France
- SIAM (Association Solidarité pour l'Insertion des Albinos), Mali
- Under the Same Sun, Canada

Sponsors

- Pierre Fabre Foundation
- Under the Same Sun
- France Media Monde
- Patricia Willocq

Doctors/Specialists :

- Prof. Robert Aquaron, Geneticist
- Prof. Benoît Arveiler, Head of the Unit in charge of biological genetic, University Hospital of Bordeaux
- Prof. Levi Kandeke, Ophthalmic surgeon
- Prof. Gérard Lorette, Dermatologist, Professor Emeritus at the University of Tours