



United Nations  
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des Nations Unies  
pour l'éducation,  
la science et la culture



UNDER THE  
SAME SUN



FONDATION PIERRE FABRE



FRANCE  
MÉDIAS  
MONDE



# INTERNATIONAL ALBINISM AWARENESS DAY

13 June 2016

UNESCO, PARIS

# SUMMARY


1	Programme.....	p. 2
2	Speaker's Bio.graphies.....	4
2.1	Scientists.....	4
2.2	Associations.....	5
2.3	Foundation.....	9
3	Artist's	
3.1	Biographies.....	10
3.2	The Film Director.....	10
	The Photographer.....	10

**PROGRAMME**  
**“Live with albinism”**

<b>14:00 – 14:30</b>	<b>Official ceremony (IV)</b>
	<p><b>Opening addresses:</b></p> <ul style="list-style-type: none"> <li>- H. E. Mr Jacques Kabale, Ambassador of the Republic of Rwanda to France, and President of the African Group</li> <li>- Mr Peter Ash, Founder and President, Under the Same sun</li> <li>- Mr Edouard Firmin Matoko, Assistant Director-General for Africa</li> </ul>
<b>14:30 – 17:40</b>	<b>Symposium (Room IV)</b>
14:30 – 14:40	<p><b>Introduction :</b> Mr Casimiro Vizzini, Expert, Division of Science Policy and Capacity-Building, Natural Sciences Sector</p>
14:40 – 15:45	<p><b>Panel of Scientists : “Medical Perspectives on Albinism”</b></p> <ul style="list-style-type: none"> <li>- Prof. Robert Aquaron, Honorary Professor, Biologist-Geneticist</li> <li>- Prof. Levi Kandeke, Ophtalmic-Surgeon</li> <li>- Prof. Benoît Arveiler, Head of the Unit of Biological Genetic, University Hospital Center of Bordeaux (CHU)</li> <li>- Prof. Gérard Lorette, Dermatologist, Professor emeritus, University of Tours</li> </ul> <p>• <b>Presentation</b> by Mr Casimiro Vizzini : “Data sharing, the experience of the Human Variome project”</p> <p><b>Moderator :</b> Prof. Komlavi Francisco Seddoh, President of the Programme and External Relations Commission of the Executive Board of UNESCO</p>
15:45 – 16:00	<b>Coffee-break (Foyer Room I)</b>

16:00 – 17:20	<p><b>Associations Panel : “Albinism on a daily-basis - Testimony”</b></p> <ul style="list-style-type: none"> <li>- Anida, France</li> <li>- <i>Alba, Espagne</i> (to be confirmed)</li> <li>- Genespoir, France</li> <li>- Hema (albinos Association of Hema Nayele), France</li> <li>- SACRI international (Association against ritual crimes), France</li> <li>- Siam (Solidarity Association Solidarité the inclusion of Albinos), Mali</li> <li>- Under The Same Sun, Canada</li> </ul> <ul style="list-style-type: none"> <li>• <b>Presentation</b> by Mr Christophe Cornu, Senior Programme Specialist and Team Leader, Respect for All in a Safe and Healthy Environment Section of Health and Education, Division for Inclusion, Peace and Sustainable Development, Education Sector: “Health Education”</li> </ul> <p><b>Moderator :</b> Mr Christophe Cornu</p>
17:25- 17:40	<p><b>Closure</b></p> <ul style="list-style-type: none"> <li>- Mrs Béatrice Garrette, Director-General, Pierre Fabre Foundation</li> <li>- Mr Edouard Firmin Matoko, Assistant Director-General for Africa</li> </ul>
17:45 – 19:25	<p><b>Screening of the documentary film “Black man, white skin”</b> (Room IV) Debate with M. José Manuel Colón, Film Director</p>
19:30 – 20:00	<p><b>Inauguration of the Exhibition :</b> « White Ebony » (Rooms Miro) Mrs Patricia Willocq, Photographer</p>
20:00 – 21:00	<p><b>Reception</b> (Ségur Hall)</p>

## BIOGRAPHIES : SCIENTISTS

<b>Professor Robert AQUARON</b>	<b>Honorary Professor, Geneticist-Biologist</b>
	<p>Professor Aquaron holds a Doctorate in Pharmacy (1966) and Medicine (1967). He was a Professor of Biochemistry at the Faculty of Medicine of Yaoundé, Cameroon, 1972-1977. He got involved in albinism when he was Professor of Biochemistry in the Faculty of Medicine of Marseille (1977-2003).</p>
<b>Professor Benoît ARVEILER</b>	<b>Molecular Geneticist</b>
	<p>Benoît Arveiler is a professor in Medical Genetics at the Faculty of Medicine (University of Bordeaux) and a Practitioner at the Hospital of Bordeaux. He is considered as an international reference for molecular diagnosis of patients with albinism. In addition, he closely collaborates with some African doctors to ensure the diagnosis of patients on the continent.</p>
<b>Professor Levi KANDEKE</b>	<b>Ophthalmic Surgeon</b>
	<p>Levi Kandeke is the first trained ophthalmologist in Burundi. He is one of the rare ophthalmologists in the country who is specialized in the treatment of children. He is currently the Head of the Ophthalmology Department at the Hospital of Kamenge, Burundi, Child Eye Health Tertiary Center.</p>
<b>Professor Gérard LORETTE</b>	<b>Dermatologist</b>
	<p>Professor Gerard Lorette holds a PhD in Medicine. He is currently a Dermatologist and a Professor Emeritus at the University of Tours. He is also a member of the Scientific Committee of the Pierre Fabre Foundation and the President of the French Society of Dermatology.</p>

## PARTICIPATING ASSOCIATIONS

### ALBA

(Spanish Association)



Ms Ana Yturralde  
Representative



Ana Yturralde is a Spanish freelance photographer based in Valencia (Spain). She specializes in people, portraits and photojournalism covering humanitarian and social issues and her work has been exhibited in several galleries, museums, and institutions such as the Parliament of Cantabria and the Casa África. She also worked for several publications in different magazines and newspapers, and had published some books about the problems faced by people with albinism in Africa. Today she represents the ALBA association, with which she works closely.

ALBA is a non-profit association based in Valencia, Spain. The purpose of ALBA is to break down barriers faced by all people with albinism and to fight for their causes.

**Main objective :**

To raise societal awareness about issues related to albinism and to train medical staff (pediatrician, dermatologist, ophthalmologist) for early detection of the disease.

### ANIDA

(French Association)



Mrs Adrienne  
Ntankeu  
Founder



The National and International Association for Albinos' Rights was founded in 2011 in Versailles by Adrienne Ntankeu (Cameroon).

When she was 5, she was sent to France to live with a member of her family because of her albinism. She had a very rough childhood, being continually subjected to humiliation and abuses.

Taken into care by social services at the age of 19, she was offered the opportunity to return for six months in Cameroon, to reconnect with her family. There she became aware of the difficulties faced by people with albinism in Africa.

**Main objectives :**

To create awareness and to demystify the disease of albinism among the African people

To foster economic and social integration of albino people in Africa.

## GENESPOIR

(French Association)



Mrs Beatrice  
Jouanne  
President



GENESPOIR is an association based in Rennes (France), which was founded in 1995 (16 branches in France and Belgium). Mrs. Beatrice Jouanne is its President since 2003.

Beatrice Jouanne, born in 1955, is the mother of three children with albinism. After the birth of her children, she and her husband decided to lead normal lives and to give their children the best possible education by encouraging them not to set boundaries for themselves. They joined the Genespoir Association in 1997.

Under her leadership, the association has continued to develop and expand its actions towards promoting medical and social research. She notably started the European Days of Albinism in Paris in 2012.

**Main objectives :**

To offer financial support for research on albinism;  
To defend the interests of persons with albinism.

## Les Albinos d'HEMA Nayélé

(French Association)



Ms Mariam Maiga  
Founder



The Association HEMA Nayélé was created in 2009 in Compiègne (France) to help people with albinism in France and Africa, particularly in Burkina Faso.

The launch of a sensitization caravan will be held in 2018. During three months, she will present lectures and raise awareness about persons with albinism in several regions of Burkina Faso.

**Main objectives :**

To foster social integration of persons with albinism;  
To provide support to families with children with albinism.

## SACRI International

(French Association)



Mr Nic Geordan  
Mbandinga  
President



The Association was established in 2013 to help fighting against ritual attacks, including human sacrifice of children and people suffering from albinism in Africa.

Nic Geordan Mbandinga (Gabon) is a Professor of Earth and Life Sciences in the French National Education. In May 2013, after initiating a petition with over 1500 signatures against ritual crimes in Gabon and other parts of Africa, and also proposing the creation of SACRI International, he became the President of the organization since June 2013.

**Main objectives :**

To fight against false beliefs;

To help and support to the victims and their families

## SIAM

(Solidarity organization for the integration of people with albinism in Mali)



Mrs Lalla Haicha  
Diakité  
President



SIAM was founded in Mali in 2009 to seek after solutions to the problems facing people with albinism in the society. Its action is based on equal opportunities and solidarity.

Mrs. Diakité is the President of the association since its creation. She holds a Master degree in Applied Foreign Languages and Communication. She worked as Director of Administration and Finance at the FGHM-SA (Mortgage Guarantee Fund of Mali). Since 2011, she is the Director of Operations of the FGHM -SA.

**Main objectives :**

To create awareness, support and protection for people with albinism;

To provide financial support for the management of vision problems associated with albinism.



**UTSS**  
(Under the Same Sun)  
(American-Canadian Association)



Mr Peter Ash  
Founder, CEO



This association was founded in 2009 by Peter Ash. Under the Same Sun promotes the rights and wellbeing of people with albinism in the world.

Peter Ash was born in Montreal, Canada, in 1965, as the youngest of a family of three boys. Peter and his younger brother are the only members of his family that have suffer from albinism. After obtaining a Bachelor degree in Theology, he undertook a decade-long career in Church Ministry as an ordained Pastor, and also completed a Master's degree in Counselling. He then moved on to a career in business as an Entrepreneur in Finance and Real Estate. He is married with a teenage son.

On 13th June 2013 and supported by Under the Same Sun, the Council for Human Rights of the United Nations in Geneva adopted a resolution on the issue of discrimination that people with albinism face in many countries.

**Main objectives:**

- To defend the interests of persons with albinism;
- To create awareness in society.

## THE FOUNDATION

### PIERRE FABRE FOUNDATION



Ms Beatrice Garrette  
Director General

Disinterestedly and independently, with a strictly humanitarian goal, the Pierre Fabre Foundation strives to enable communities from less advanced and emerging countries, as well as those plunged into severe crisis by political or economic upheaval and/or natural disaster, to access the quality and levels of everyday health care and the widely-used drugs defined by the WHO and other organizations as essential to human health.

Beatrice Garrette, the Director General is a graduate from HEC, she led part of her career in the media and publishing industry where she held a managerial post and then as the Director of the firm from 1986 to 2002. She worked as an editor at the Bayard Group and developed the educational press for youth abroad, as well as several magazines about science and nature. She then became the Head of the photojournalism agency Sipa Press and its US subsidiary from 2002 to 2011. During this period, she was President CEO of Editions du Rocher (2008 - 2009). She joined the Pierre Fabre Foundation as the Director General in 2013.

## THE FILM DIRECTOR

### JOSE MANUEL COLON *BLACK MAN, WHITE SKIN*



Mr José Manuel Cólón  
Film Director

José Manuel Colón is a fine story-teller, author of the documentary film *Black Man White Skin* (BMWS). The movie portrays the tragedy of people with albinism, who are virtually ignored. Colón's documentary tells 'wonderful stories filled with kindness,' the stories of many people who work selflessly for African albino people, one of the most vulnerable people in the world.

Colón wants his film to be a true token of Marca España. He sees Spain as a country ready to help, whose doctors, humanitarian workers and ordinary people are always ready to save lives. He knows he 'has not learned to be detached,' but he does not regret it. Currently, he is trying to raise funds for Mafalda Soto, a Spanish chemist who makes sunblock that she distributes among people suffering from albinism in Tanzania.

## THE PHOTOGRAPHER

### PATRICIA WILLOCQ *WHITE EBONY*



Mrs Patricia Willocq  
Photographer and Film Director

After having completed her translation studies at the Higher Institute of Translators and Interpreters (ISTI) in Brussels, Patricia Willocq decided to travel around the world while developing her photographic skills. Among the assignments she performs across the world, she devotes a part of her time supporting associations and NGOs which advocate for Human Rights.

White Ebony, one of her last photographic essay which has been awarded by the UNICEF Photo contest in 2013, has been by the High Commissioner of the United Nations Human Rights.

In September 2015, she received the price for the best picture on the theme of peace in the contest *Alfred Fried Photography Prize*. The photo has been exposed at the Austrian Parliament.

She strives to avoid photographing misery and her work is most often associated with projects which promote tolerance and dignity.