

# PIERRE FABRE FOUNDATION: AIDING PEOPLE WITH ALBINISM IN AFRICA

The social consequences of the genetic condition known as albinism in Africa are often cited: social rejection, stigmatization, violence, mutilation, and even murder. It is less common to hear about the consequences for health, such as sunburn, wounds and skin cancers, despite the higher number of victims involved. Since the end of 2015, the Pierre Fabre Foundation has been engaged in a new combat concerning this topic: prevention and dermatological care for albinism sufferers in Africa. Béatrice Garrette, Director General of the Foundation, tells us about this major initiative.

## Béatrice Garrette, why the interest in albinism?

It all started with a request from Anida, a small association devoted to this cause in France and Africa, which drew our attention to the matter. We looked into it, and discovered the severity and broad scope of dermatological problems related to albinism in Africa, particularly in Tanzania. This genetic condition is four to five times more common here (partly due to endogamy) than in the rest of the world, affecting up to one in 1,500 people in certain regions.

“ Sun exposure has terrible consequences for albinos. ”

## And the pathology itself is just part of the problem?

Yes, on the one hand, albinos lack knowledge about their own condition, and on the other hand, they are victims of superstitions which aggravate the morbidity and mortality connected with the pathology. Sun exposure has terrible consequences for albinos.



Béatrice Garrette, Director General of the Pierre Fabre Foundation, in Tanzania.



A family attending a prevention meeting.

The available studies\* indicate that the majority of them die of skin cancer at the age of 30 to 40 years, because they are not informed about the dangers of the sun, and therefore do not protect themselves. On top

“ Protecting patients’ health and restoring their self-esteem, including how others perceive them. ”

of this, the rejection and beliefs affecting people with albinism make them doubly vulnerable. They are marginalized for being different, or worse, are in danger as a result. Pseudo-sorcerers or healers claim that various parts of an albino’s body can be used as talismans, leading to mutilation and murder. Since 2007, organizations have recorded attacks in connection with beliefs and witchcraft in over 25 countries.

## So how can this population be helped?

We need to act on two levels: protecting patients’ health and restoring their self-esteem, including how others perceive them. We need to raise awareness and provide care, by developing a pragmatic and reproducible method that works in close proximity with patients. We do this with assistance from local players who have developed the necessary expertise and good practices.

## This sounds like an innovative approach for the Foundation.

Yes, that’s right. At the end of 2015, we launched an innovative call for projects among thirty associations in Africa. We received 10 proposals. With the expertise of our dermatology working group, consisting of Prof. Lorette, Dr. Guerrero and Dr. Poli, as well as the Foundation’s Scientific Committee, we short listed three projects, which were chosen for observation missions on the ground. Eventually, two projects were chosen: the “Skin Cancer Prevention” program from the Standing Voice association in Tanzania, and the project in Mali from the SIAM Association (Solidarity for the Integration Albinos in Mali).

## What practical actions do these associations carry out in the field?

We wanted to associate ourselves with their work, because they address the two issues of prevention and access to health care. In Tanzania, where I went in May this year, adults and children (alone or in families) with albinism are invited to “clinics” (medical meetings in listed locations) every four months. These are held in hospitals, schools

## DEFINITION

### ALBINISM:

A group of genetic disorders characterized by a pigmentation deficiency of the skin, hair, body hair, and eyes. This deficiency causes extreme sensitivity to the sun with a significant risk of developing skin cancers and skin conditions. The melanin deficiency causes severe myopia, leading to pain and migraines.

and "protectorate centers" (a type of orphanage). Over the space of one to three days, these individuals attend education and awareness sessions run by dermatologists. This helps them to find the answers to all of their questions about their condition, the increased risk of skin cancer, and the preventive actions that can be taken. Then, each person is offered a dermatological consultation, leading to treatment if necessary (for example, treating wounds, burns and pre-cancerous lesions with cryotherapy) or a referral to a hospital if they require major surgery. On a pragmatic level, hats and sunglasses are given out at the end of the meetings, as well as two pots of sun cream, made locally in Moshi at the foot of Mount Kilimanjaro. The two pots provide four months of protection, until the next consultation, and must be brought back empty.

Standing Voice now manages 27 "clinics" in the country, for 2,000 patients. The first results of this remarkable work, which began three years ago, are highlighted in particular in the 71% drop in skin cancer among the 465 patients monitored in five "clinics" in the Mwanza region.

**Are these partnerships now up and running?**

The partnership agreements have been signed, with a four-year mutually binding

commitment. They set precise and ambitious objectives, for example the training of eight dermatologists and the opening of 16 new "clinics" in Tanzania. The aim is to double the number of care recipients, to reach 4,000 people. In Mali, the SIAM association will also train health workers in six regions of the country, to carry out preventive actions, with care provided by dermatologists from CNAM (the national support center for the fight against disease) in Bamako.

**“ This is the vocation and the honor of the Foundation to work on these neglected illnesses. ”**

**Does this action concern other countries?**

The model developed by Standing Voice in Tanzania is designed to be replicated in other countries in Sub-Saharan Africa. Of course, a network of associations, available health personnel and minimum support from the state will be necessary. Over the next four years, we want to extend this project to two other countries. Malawi would be an appro-

priate choice, and the model could also be proposed to countries in French-speaking Africa.

**Dermatology in tropical environments clearly seems to be a major focus of the Foundation's work.**

Absolutely. In poor countries in the South, even common or benign dermatoses actually hide conditions which cause stigma, and may become serious because they are not adequately treated, and for which populations need prevention, care and essential drugs. Dermatological reasons account for almost 30% of consultations (according to a study conducted in Mali), yet there are very few dermatologists in Africa, and medical staff have little training on these matters. As recently summarized by Prof. Ousmane Faye, head of the dermatology department at the Bamako CNAM: "Severe prevalence, severe harm, severe need for care" Many fields of intervention are yet to be explored, for example, the problem of chronic wounds or keloid scars, brought to our attention by several dermatologists working in African university hospitals. This is the vocation and the honor of the Foundation to work on these neglected illnesses which affect large numbers of people.

Interview by  
**Agathe Amara Colombié**



Learning the basic sun protection precautions from a young age.



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If necessary, cryotherapy sessions can be used alongside preventive actions.



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Living together, regardless of our differences.

**UNESCO INVITATION FOR INTERNATIONAL ALBINISM AWARENESS DAY**

For the International Albinism Awareness Day, UNESCO organized an international conference entitled "Living with albinism" in Paris on June 13, 2016. The objective of this event was to draw attention to this genetic peculiarity, which in some countries can cause those affected to be the victims of serious discrimination. The Foundation wanted to show its commitment to health care access for persons with albinism by supporting the event. The event, which was held at the Organization's headquarters, opened with a round table entitled "Medicine's approach to albinism". It brought together internationally renowned dermatologists, including Gérard Lorette, emeritus professor at Tours University and member

of the Pierre Fabre Foundation Scientific Committee. The floor was then turned over to a panel of associations who had come together to raise the issue of combating the discrimination experienced by people with albinism. One of the participants in this discussion was Lalla Aicha Diakité, President of the SIAM Association. Side by side with Edouard Firmin Matoko, UNESCO's Assistant Director General for Africa, Béatrice Garrette, Director General of the Pierre Fabre Foundation, closed the day by reiterating the need to improve health care access for this particularly vulnerable population and to rely on local associations when implementing action programs.

**+ MORE INFORMATION**

can be found on the Foundation's website:

<http://www.fondationpierrefabre.org/en>. You can also subscribe to news updates from the Pierre Fabre Foundation on the website.

\*Report by Ikponwosa Ero, United Nations independent expert - 2015

**A FEW FIGURES**

**ON ALBINISM IN TANZANIA BY STANDING VOICE'S "SKIN CANCER PREVENTION" PROGRAM**

**27**

«clinics» in

**9**

regions concerned,

**2,000**

patients monitored

**3**

consultations per patient per year

**12,000**

pots of sun cream per year produced and given out at consultations

**20,000**

albinism sufferers identified by the TAS (Tanzanian Albinos Society)