



## **International Albinism Awareness Day Fact Sheet**

**Albinism** - Albinism is an inherited genetic condition that reduces the amount of melanin pigment formed in the skin, hair and/or eyes. Albinism occurs in all racial and ethnic groups throughout the world. In the U.S., approximately one in 18,000 to 20,000 people has some type of albinism. In other parts of the world, the occurrence can be as high as one in 3,000. Most children with albinism are born to parents who have normal hair and eye color for their ethnic backgrounds.

Since the eye needs pigment to develop normal vision, people with albinism have impaired vision. Many people with albinism are legally blind. In addition, people with albinism will sunburn easily because their bodies do not produce the pigment that protects the skin from the harmful rays of the sun. Also, the condition may cause social problems because people with albinism look different than their families, peers and other members of their ethnic group.

There are several less common types of albinism such as Hermansky-Pudlak Syndrome (HPS) and Chediak-Higashi Syndrome (CHS) which involve other medical issues such as problems with blood clotting, or problems with hearing.

**NOAH** - The National Organization for Albinism and Hypopigmentation is a 501(c)3 non-profit organization staffed primarily by member volunteers. NOAH's purpose is threefold. NOAH works to provide information and support to persons with albinism and their families. NOAH strives to educate medical and education professionals and the general public about albinism. And, NOAH seeks to further scientific and medical research on the condition.

NOAH was founded in 1982 in Philadelphia by a small group of people attending a medical conference. Since then, NOAH has grown to an active membership of over 1,000 individuals, families and organizations. NOAH's primary activities are the production and distribution of printed information bulletins about albinism, the production of a quarterly magazine, the maintenance of a website ([www.albinism.org](http://www.albinism.org)), and a national conference every other year. More than 1,000 persons attended the 2016 NOAH Conference in Pittsburgh, PA.

### **History of International Albinism Awareness Day**

On November 18, 2014, the United Nations' General Assembly adopted a resolution establishing June 13th as International Albinism Awareness Day. This historic resolution confirms the global focus on albinism advocacy. NOAH joins with the worldwide albinism community in encouraging everyone to celebrate and promote albinism awareness on Monday, June 13, 2017.

The late Ambassador of the Mission of Somalia to the U.N., Geneva, Yusuf Mohamed Ismail Bari-Bari, led the effort to pass the resolution in cooperation with Under the Same Sun, an organization that promotes and protects the rights of people with albinism, particularly in Africa. Shortly thereafter, NOAH participated in a U.N. "side event" to celebrate the adoption of the International Albinism Awareness Day resolution. The late Excellency Bari-Bari made opening and closing remarks at the event, which included sharing a story of his audience with Pope Francis during which he informed the Pontiff of the atrocities committed against people with albinism in Africa. Many other dignitaries also attended the event, and each made brief statements in support of the resolution. These attendees included representatives from the U.N. delegations from Italy, Israel, Canada and the United States, the U.N. Special Representative on Violence against Children, a representative from UNICEF, and several key individuals in the albinism community.

**For more information about International Albinism Awareness Day,  
please contact NOAH at [IAAD@albinism.org](mailto:IAAD@albinism.org) or 1-800-473-2310  
[www.albinism.org](http://www.albinism.org)**