



National Organization for Albinism and Hypopigmentation

2015 Bowl-a-thon Fact Sheet

Albinism - The word refers to a group of inherited conditions. People with albinism have little or no pigment in the eyes, skin and hair (or in some cases, in the eyes alone). They have inherited genes that do not work correctly. These genes do not allow the body to make the usual amounts of pigment called melanin. One in 17,000 people has some type of albinism. About 18,000 people in the United States are affected. Albinism affects people from all races. 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), and a national conference every other year. More than 820 persons attended the 2014 NOAH Conference in San Diego, CA.

2015 Bowl-a-thon – Hundreds of NOAH members and supporters will participate in NOAH's 10th annual national fundraising event across the United States and Canada on the weekend of March 20-22, 2015. One hundred percent of the money raised from the bowl-a-thon will go directly to the following NOAH programs:

- Parent Services Programs – opportunities for parents to connect and support each other while discussing a variety of topics
- Adult Services Program - Online discussion groups and webinars featuring topics of interest to adults with albinism
- Youth Services Programs - Providing safe, healthy and fun opportunities for youth with albinism to develop lasting relationships, build confidence and create a "Tool Box" for living with albinism
- Outreach to the medical community – NOAH attendance at medical conferences
- Webinar Series - Monthly online sessions covering topics of interest to the albinism community
- The Hermansky-Pudlak Syndrome Network – Provide information for people with the condition as well as medical professionals who treat the condition (www.hpsnetwork.org)

For more information, please contact NOAH at info@albinism.org or 1-800-473-2310.

PO Box 959, East Hampstead, NH 03826-0959 USA
Phone: (800) 473-2310 • (603) 887-2310 • Toll-free fax: (800) 648-2310
www.albinism.org • Email: info@albinism.org