2008 Bowl-a-thon
FACT SHEET

Albinism - The word albinism 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 impairment of vision because the eye does not have a normal amount of pigment. Many people with albinism are legally blind. 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. Albinism 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 (HPS and CHS) which involve other medical issues such as problems with blood clotting, or problems with hearing.

NOAH - The National Organization for Albinism and Hypopigmentation (NOAH) 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 persons 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 newsletter quarterly, the maintenance of a website (www.albinism.org), and a national conference every other year. Over 650 persons attended the 2004 NOAH Conference in Atlanta, GA.
2008 Bowl-a-thon – Hundreds of NOAH members and supporters will participate in NOAH’s second annual national fundraising event across the United States and Canada on the weekend of February 15, 2008. One hundred percent of the money raised from the bowl-a-thon will go directly to the following NOAH programs.

- **2008 National Conference** – NOAH will use funds raised to keep the cost of attending a conference affordable for families and individuals affected by albinism. Conference costs to be covered will include speaker expenses, audio visual, printing, postage, supplies and personal grants to those who cannot afford to attend. Please note that all personal grants require recipient contribution.

- **NOAH Family Summer Camp** – NOAH is in the planning stages of its third family summer camp for the summer of 2009. NOAH’s first two family summer camps at Beacon Lodge Lions Camp in Mount Union, Pennsylvania brought more than 100 children and adults together for a wonderful few days to connect and grow, helping to shape life-long memories for everyone. While riding in a paddleboat, one of the campers expressed his evaluation of the camp out load by saying that it had been “the best four days of my life.” Funds raised as part of NOAH’s bowl-a-thon can help to bring more of these special days to other youngsters and families from across the US and Canada in the summer of 2009.

- **Regional Activities** – NOAH seeks to continue its work to promote and support regional activities across the United States and Canada. For many who are not able to attend a national conference, this is their chance to experience the magic that happens at a NOAH event.

In addition to these programs, money raised by the 2008 NOAH Bowl-a-thon will support advocacy and outreach programs, the Hermansky-Pudlak Syndrome (HPS) Network (www.hpsnetwork.org) and Positive Exposure (www.positiveexposure.org).

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