****

**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. Albinism affects people from all races.

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 form 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 syndromic forms of albinism (HPS and CHS) which involve other medical issues such as problems with blood clotting, or problems with hearing.

**NOAH**

NOAH is a genetic support group that acts as a conduit for accurate and authoritative information about all aspects of living with albinism. NOAH sponsors conferences, meetings and camps where people with albinism and their families in the U.S. and Canada can find acceptance, support, and fellowship.

**NOAH Programs and Services**

* quarterly magazine – *Albinism InSight*
* website – www.albinism.org
* parent books

*Raising a Child with Albinism: A Guide to the Early Years*

*Raising a Child with Albinism: A Guide to the School Years*

* biennial national conferences
* New parent program:

Parent Liaison

Welcome Toolkit

* Parent Connections Teleconference
* Grandparent Connections Teleconferences
* adult weekend
* family camp
* annual leadership scholarship
* annual Space Camp for Interested Visually Impaired Students scholarship
* outreach to doctors and educators
* advocacy