Fact Sheet

ALBINISM

Compiled by Tanni L. Anthony

Information found at: http://www.albinism.org

What is Albinism? The word “albinism” refers to a group of inherited conditions. People with albinism have little or no pigment in their eyes, skin, or hair. They have inherited altered genes that do not make the usual amounts of a pigment called melanin. One person in 17,000 in the U.S.A. has some type of albinism. 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.

Types of Albinism: While most people with albinism have very light skin and hair, not all do. Oculocutaneous albinism involves the eyes, hair, and skin. Ocular albinism, which is much less common, involves primarily the eyes. All types of albinism are associated with vision problems.

Vision Problems: People with albinism always have problems with vision (not correctable with eyeglasses) and many have low vision. The degree of vision impairment varies with the different types of albinism and many people with albinism are “legally blind,” but most use their vision for many tasks including reading and do not use Braille. Some people with albinism have sufficient vision to drive a car. Vision problems in albinism result from abnormal development of the retina and abnormal patterns of nerve connections between the eye and the brain. It is the presence of these eye problems that defines the diagnosis of albinism. Therefore the main test for albinism is simply an eye examination.

Skin Problems: While most people with albinism are fair in complexion, skin or hair color is not diagnostic of albinism. People with many types of albinism need to take precautions to avoid damage to the skin caused by the sun such as wearing sunscreen lotions, hats and sun-protective clothing.

Types of Visual Problems: Eye problems in albinism result from the lack of pigment in the eyes. Visual problems may include:

- Nystagmus (horizontal back and forth movement of the eyes)
- Strabismus—muscle imbalance of the eyes resulting in crossed eyes or other eye deviations
- Photophobia or light sensitivity
➢ Refractive error or the need to wear glasses due to nearsightedness or farsightedness

➢ Low vision or reduced visual acuity due to the lack of pigment in the retina and the eye’s inability to screen out stray light coming into the eye (light normally enters the eye only through the pupil, the dark opening in the center of the iris (colored part of eye), but in albinism light can pass through the iris or the colored part of the eye as well.

Treatment of the refractive error and/or light sensitivity requires the involvement of an eye doctor for glasses, sunglasses, and/or possible surgical correction of any eye deviation. Various optical aids may be helpful to people with albinism. A low vision evaluation is important to ensure that the individual has the opportunity to see if magnification devices and other optical devices are helpful.

Resources
The National Organization for Albinism and Hypopigmentation  
PO Box 959  
East Hampstead, NH 03826-0959  
Phone: 603 887-2310  
Web: http://www.albinism.org

Hermansky-Pudlak Syndrome Network  
One South Road  
Oyster, NY 11771-1995  
Phone: 800-789-9HIPS  
Web: www.hpsnetwork.org

NOAH has produced a book entitled, Raising a Child with Albinism: A Guide to the Early Years. It is a 200-page volume containing contributions from close to 20 different writers. Edited by NOAH member Susan DuBois, mother of two children with albinism, the reassuring and comforting book is illustrated with color photos contributed by Positive Exposure’s Rick Guidotti and eight others. Topics include: (a) what is albinism?; (b) how will albinism impact my child’s development?; (c) how do I stimulate my child’s vision?; (d) the social impact of albinism; (e) sun safety; (e) early intervention and IEP programs. For more information, contact:http://www.albinism.org/Raising_a_Child_with_albinism.html

For more information about the CO Services for Children and Youth with Combined Vision and Hearing Loss Project and the project’s services specific to Colorado children who are deafblind, please contact:

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Web Page Address:  
http://www.cde.state.co.us/cdesped/Deafblind.asp

Fact Sheets from the Colorado Services to Children and Youth with Combined Vision and Hearing Loss Project are to be used by both families and professionals serving individuals with vision and hearing loss. The information applies to children, birth through 21 years of age. The purpose of the Fact Sheet is to give general information on a specific topic. More specific information for an individual student can be provided through personalized technical assistance available from the project. For more information call (303) 866-6681 or (303) 866-6605. Updated: 10/10