



"I feel privileged to meet people with albinism like my daughter. She is only 8-1/2 months old and I hope we can make it to every conference. I've never felt so much love."

What is Albinism?

Albinism is a genetic condition that reduces the amount of melanin pigment formed in the body. Albinism occurs in all racial and ethnic groups throughout the world. In the United States, it is estimated that one in 18,000 people has some type of albinism. In other parts of the world, incidence of the condition can be as high as one in 3,000.

Since melanin is essential for proper eye development, all people with albinism have low vision to varying degrees. Some people with albinism are considered legally blind in the United States (visual acuity between 20/40 and 20/200). Most people with albinism also experience other ocular symptoms such as nystagmus (involuntary, rapid eye movements) and photophobia (an increased sensitivity to glare).

Research has identified several different types of albinism. **Oculo-cutaneous albinism**, which is the most common type, results in a lack of pigment in the hair, skin and eyes. **Ocular albinism** is a type that only affects the eyes. Individuals with this type of albinism are otherwise normally pigmented for their ethnic group. Most types of ocular albinism are believed to be passed by X-linked hereditary patterns. **Hermansky-Pudlak Syndrome (HPS)** is a rare, but serious syndrome characterized by albinism and other potentially serious medical issues.

OTHER RESOURCES FOR PEOPLE WITH ALBINISM:

Hermansky-Pudlak Syndrome Network Inc.
One South Road
Oyster Bay, NY 11771-1905
Phone: 516.922.3440
Fax: 516.922.4022
Toll Free: 1.800.789.9HPS
dappell@hpsnetwork.org
www.hpsnetwork.org

Positive Exposure
43 East 20th St.
6th Floor
New York, NY 10003
Phone: 212.420.1931
Fax: 212.228.0592
rick@positiveexposure.org
www.positiveexposure.org

MEMBERSHIP



NOAH®

National Organization for
Albinism and Hypopigmentation

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NOAH's mission

NOAH's mission is to: provide information and support to individuals and families with albinism and related conditions; provide community outreach, enhance public awareness, and educate professionals about these conditions; and encourage research and funding of projects that will improve the diagnosis and management of albinism.

NOAH provides information to the albinism community

- NOAH is the world's most comprehensive source of information about albinism. Material is available in print, video and on the Web.
- NOAH's Web site, www.albinism.org, contains valuable information about albinism, lists upcoming events as well as links to sites related to albinism and hosts an online community with hundreds of members, blogs and a photo gallery.
- *Albinism InSight*, NOAH's quarterly magazine reports on the latest news in the albinism community while sharing individual stories and opinions.
- Published by NOAH in 2008, *Raising a Child with Albinism: A Guide to the Early Years* is a comprehensive resource guide for a family with a young child with albinism complete with practical advice and caring insights from experienced parents and adults with albinism.
- Information Bulletins published by NOAH provide detailed information on major topics of interest to the albinism community. Subjects include albinism and driving, sun protection and low vision aids.
- The video *Albinism, The People, The Challenge* provides a compact overview of the condition and the challenges those affected face.



Photos courtesy of Positive Exposure, Rick Guidotti

NOAH supports the albinism community in a wide variety of ways:

NOAH provides opportunities for the albinism community to connect on both local and national levels. People with albinism of all ages have the chance to meet others like themselves and to share common experiences at:

- National conferences held in different areas of the country every two years.
- One-day regional conferences closer to home.
- Adult weekend gatherings designed to promote understanding and fellowship.
- Family camps meant to build relationships among children while having lots of fun.
- Local group meetings to stay connected.



Other NOAH programs are designed to welcome affected individuals and families to the albinism community.

- A toll-free number – 1-800-473-2310 – is available to provide information and to connect individuals and families to one another.
- The Rapid Response team connects experienced parents with anxious families just receiving a diagnosis.
- Supportive gifts for families of young children newly diagnosed with albinism welcome and connect them to the albinism community.

NOAH is active in advocacy, education and research!

- The general public, the media and even medical professionals often know little to nothing about albinism. For this reason, the challenge of educating others and advocating for the albinism community is essential to NOAH's goals. From large-scale media efforts to advocacy for individual members, NOAH works to improve public understanding and acceptance of albinism.
- NOAH collaborates with researchers and physicians to advance the understanding of albinism and care for those affected.
- NOAH takes an active role in encouraging research to improve the diagnosis and management of albinism, collaborating with academic and government research programs at the cutting edge of genetics and visual sciences. The organization connects researchers to interested volunteers from the membership.

What can I do for NOAH?

Volunteer: NOAH is staffed almost entirely by volunteers. Lend your time and talents so that NOAH can expand its service and outreach.

Share: Mentor a young person or lend an ear to a parent. When you share your experience, you will make a difference in someone's life.

Contribute: NOAH is primarily funded by member dues and donations. Your financial generosity will allow programs to continue and new projects to be developed.

Visit www.albinism.org to learn about the many ways you can contribute.



Join NOAH today!

Name: _____

Address: _____

City/St/Zip: _____

Country: _____

Telephone: _____

Email: _____

Please check all that apply:

I am willing to connect with people/families with albinism in my area

I wish to receive information about participating in albinism research

I am: A person with albinism

A parent/guardian Grandparent

A professional Other

Year of birth of person/s with albinism in your family: _____

Annual Membership Dues (payable via check, money order, or credit card in US funds):

\$30 U.S. \$35 International \$40 Professional

Please consider making an additional contribution: \$ _____

Total enclosed: \$ _____

Credit Card Payment:

To pay your dues by Visa or MasterCard, complete the following info:

Cardholder Name: _____ MC Visa

Billing Address: _____

Credit Card #: _____ Exp Date: _____

Amount \$ _____ Signature: _____

Send completed form and payment to:

NOAH, PO Box 959, East Hampstead, NH 03826-0959