

NOAH Membership Application

Name _____
Address _____
City _____ State _____ Postal Code _____
Country _____ Telephone _____ E-mail _____

NOAH Networking

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

Albinism Research

I wish to receive information about participating in albinism research projects.

I am a:

- Person with albinism Parent/Grandparent/Guardian
 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)

\$20 Individual \$25 Family \$30 International \$35 Agency

Please consider making an additional contribution \$ _____

Total Enclosed \$ _____

Credit Card Payment

To pay your dues by Visa or MasterCard, complete the following information.

Cardholder Name _____ MC ___ Visa ___

Billing Address _____

Credit Card # _____ Expiration Date ___/___

Amount _____ Signature _____

Send completed form and payment to:

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



PO Box 959 East Hampstead, NH 03826-0959


NOAH

Albinism

 **NOAH**



**National Organization for
Albinism and Hypopigmentation**

info@albinism.org · www.albinism.org
PO Box 959 East Hampstead, NH 03826-0959
Ph. 603.887.2310 · 800.473.2310 Fax: 800.648.2310

WHAT IS ALBINISM?

Albinism is a genetic condition that reduces the amount of melanin pigments formed in the body. The condition of albinism can occur in all racial and ethnic groups throughout the world. It is estimated that one in 20,000 people has some type of albinism.

Melanin is essential for proper eye development and, as a result, all people with albinism have impaired vision to varying degrees. Some people with albinism are considered legally blind in the United States (visual acuity of 20/200 or less) while some can have visual acuities as high as 20/40. 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. **Oculocutaneous 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 impacts 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 medical issues.

WHAT IS NOAH?

Founded in 1982 in Philadelphia, Pennsylvania, NOAH is the National Organization for Albinism and Hypopigmentation. NOAH offers a wealth of resources and support for people with the condition, particularly children and their parents. While NOAH does not diagnose, treat or provide genetic counseling to its members, it does act as a national network



for people with albinism, parents of children with the condition, their friends and extended families, and the professionals who work with them. NOAH is a nonprofit organization that is staffed almost entirely by volunteers.

“. . . Over many years and lots of tears, just to know NOAH was there for me gave me strength. . . Arriving at the conference was like a huge hug from people that made one feel like you've known them all your life. . . My only regret is that I wish I had gone sooner.” Mary Beth, Mom to two sons with albinism, Michael and Conor



WHAT CAN NOAH DO FOR ME?

NOAH is dedicated to both serving the albinism community and educating the public about this often misunderstood and stigmatized condition. This work is accomplished through many avenues of service.



• Support

In addition to holding a large, biannual national conference to bring together the albinism community, NOAH's regional chapters work to coordinate local events to build strong networks and promote fundraising. Through its Web site (www.albinism.org) and Albinism Online Community, NOAH provides another great source of networking, information and support for members all over the world.

One of NOAH's most noteworthy strengths is in helping people with albinism and parents of children with albinism to connect with others on a local level. Because albinism is a rare condition, many people with albinism could otherwise go their entire lives without ever meeting another person like them.

• Education

New parents, 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 specific advocacy for individual members, NOAH works to improve the public understanding and acceptance of albinism. Since its founding, NOAH has worked to put accurate information in the hands of doctors and new parents, offering numerous publications and informational bulletins in addition to a quarterly member newsletter, *NOAH News*.

• Research

NOAH takes an active role in encouraging research and funding to improve the diagnosis and management of albinism. The organization connects researchers to interested volunteers from the membership.

OTHER RESOURCES FOR PEOPLE WITH ALBINISM:

- **Hermansky-Pudlak Syndrome Network Inc.**
One South Road, Oyster Bay, New York 11771-1905
Phone: 516.922.3440 Fax: 516.922.4022
Toll Free: 1.800.789.9HPS
hpsnet@worldnet.att.net • 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

