

# Understanding Albinism

## What is Albinism?

Albinism is an inherited genetic condition characterized by reduced melanin pigment in the skin, hair, and eyes. It affects individuals across all racial and ethnic groups globally. In the United States, about 1 in 18,000 to 20,000 people have some form of albinism, while in certain areas of the world, the occurrence can rise to as high as 1 in 3,000.

## Types of Albinism

Albinism manifests in different forms, primarily:

- **Oculocutaneous Albinism (OCA):** Involves the eyes, skin, and hair, resulting in very light pigmentation.
- **Ocular Albinism (OA):** A rarer form that affects only the eyes, while skin and hair may resemble those of other family members.

Other less common types include:

- **Hermansky-Pudlak Syndrome (HPS)**
- **Chediak-Higashi Syndrome (CHS)**
- **Griscelli Syndrome (GS)**

These conditions may present additional health issues, especially if there are unusual bleeding or bruising symptoms.

## Vision Considerations

Individuals with albinism typically experience some degree of low vision (visual acuity between 20/60 and 20/400) that cannot be completely corrected with glasses. Common eye-related issues include:

- **Nystagmus:** Involuntary eye movement.
- **Strabismus:** Misalignment of the eyes.
- **Photophobia:** Sensitivity to bright light.
- **Foveal Hypoplasia:** Abnormal retina development.
- **Optic Nerve Misrouting:** Abnormal nerve signal pathways.
- **Refractive Errors:** Issues with focusing.
- **Reduced Depth Perception:** Difficulty judging distances.



## Dermatological Considerations

Due to their fair complexions, individuals with albinism are at a higher risk for sun damage. It is crucial for them to take protective measures, such as wearing sunscreen, hats, sunglasses, and sun-protective clothing, to prevent life-threatening skin cancers.

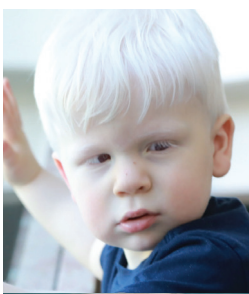
## Other Medical Considerations

Most individuals with albinism lead a normal life, have a normal lifespan, and encounter similar health challenges as the general population. However, those with Hermansky-Pudlak Syndrome may face serious complications that can shorten their lives, including bleeding disorders and lung disease.

## Social Considerations

Social isolation is a significant concern for individuals with albinism, often stemming from misunderstandings about the condition. Stigmatization can be particularly pronounced in communities of color, where questions about race or parentage may arise. It is essential for families and schools to foster inclusion by integrating children with albinism into group activities.

This document serves to inform and advocate for the understanding and support of individuals with albinism. Your attention to and action on these matters can help improve the lives of those affected by this condition. Thank you for your commitment to awareness and inclusion.



Photos courtesy of Rick Guidotti, Positive Exposure

# About the National Organization for Albinism and Hypopigmentation

Since 1982, NOAH has supported individuals with albinism and their families. We understand the power of community and strive to be a source of information, acceptance, and fellowship for those affected by this rare genetic condition. Our growth and accomplishments are driven by the commitment of our volunteers who share their time and talents to uplift the albinism community.

## NOAH Programs:

### EARLY INTERVENTION

- **New Parent Program:** Offers support and comfort to families of newly diagnosed children with albinism.
- **Parent Liaisons:** Connects new parents with trained volunteers who understand their journey.
- **Info Packet and Toolkit:** Includes our guidebook, *Raising a Child with Albinism: A Guide to the Early Years*, along with useful resources.

### PUBLICATIONS

- **Albinism InSight:** Our quarterly magazine featuring stories and contributions from the albinism community.
- **Information Bulletins:** A series of bulletins providing valuable insights about albinism.
- **Parent Books:** Two essential guides for parents: *Raising a Child with Albinism: A Guide to the Early Years* & *Raising a Child with Albinism: A Guide to the School Years*.

### WEBSITE

- Visit [www.albinism.org](http://www.albinism.org) for comprehensive resources on living with albinism and details about NOAH programs.

### VIRTUAL EDUCATION AND SUPPORT

- **NOAH Connections:** Regular virtual calls that foster community and support.
- **NOAH Workshops:** Educational programs focused on topics relevant to the albinism community.

### EVENTS

- **National Conferences:** Biennial gatherings offering education, activities for children, and fellowship.
- **Family Summer Camps:** A fun camping experience for families with children who have albinism.
- **Adults with Albinism Weekend:** A chance for adults with albinism to connect and enjoy time together.

### SCHOLARSHIPS

- **McGowan Leadership Scholarship:** Annual award to empower young leaders with albinism.
- **SCIVIS Space Camp Scholarship:** Annual award for students with albinism in Grades 4–12 to attend Space Camp at the U.S. Space and Rocket Center.

### NOAH RESEARCH PROGRAM

- **Funding Impactful Research:** Grant funding for albinism research projects from Established Researchers as well as Pilot/New Innovations projects.
- **Building a Network:** Providing opportunities for researchers to be engaged with the albinism community.

### ADVOCACY AND AWARENESS

- Recognizing the importance of global advocacy, NOAH seeks partnerships with organizations and individuals who share our mission to promote understanding and support for those with albinism.

Your engagement and support  
will make a difference in the lives  
of individuals with albinism.



National Organization for  
Albinism and Hypopigmentation

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