



PROGRAM
SPOTLIGHT

NOAH's Research Program

Extending our ongoing support for albinism research

NOAH Supports Albinism Research

Supporting albinism research has been part of the National Organization for Albinism and Hypopigmentation (NOAH) since its inception. In 1982, Dr. Carl Witkop - an albinism researcher from the University of Minnesota and seminal contributor to our understanding of albinism - attended a workshop held in Philadelphia for people with albinism where he is credited as one of NOAH's founders.

Throughout NOAH's 40-year history, our organization has drafted letters of support for those conducting albinism research projects, invited professionals to share information at our national conferences about current scientific findings and new technologies available to people with albinism, and provided information to our community for those interested in participating in research studies that may lead to a better understanding of the genetic condition of albinism.

As part of the NOAH Research Program, we maintain a Scientific Advisory Board, and we rely on their experience and expertise. With each new grant we award, we extend our network of advisors in albinism research. To say "we don't know what we don't know" is as true today as it was in 1982. The genetics of albinism - the science of the condition - and the unique spectrum of diversity albinism represents are all areas that have been supported through the efforts of albinism researchers and their findings.

NOAH Research Program Established

In 2021, NOAH's Board of Directors was honored to be selected as a steward of generous funds specifically designated for albinism research. This

restricted donation was the catalyst for extending NOAH's support of albinism research to form the NOAH Research Program.

The NOAH Research Program was established to support albinism research by formalizing a grant funding process, shaping research to answer questions most important to people with albinism, and developing a network of researchers engaged in the albinism community. This natural progression of NOAH's research support allows NOAH and the albinism community the opportunity to have an impact on what researchers study and which projects are funded. Since 2021, NOAH has received additional funding designated for albinism research. *To-date, all NOAH Research Program grants awarded have been entirely funded through donor-restricted gifts.*

NOAH Research Program Aims

NOAH has always been and will always be a place that supports the beauty of albinism. We understand we are a society for the entire albinism community - including those interested in research, those in life-threatening situations who benefit from research, and those who may not be interested in research. We realize having albinism is a big part of a person's identity. The aim of the NOAH Research Program is not to alter that in any way, but to support the ongoing research of the condition which could provide positive outcomes or interventions for those seeking them within the albinism community.

Through research, a greater understanding of the vision system and pigmentation of skin can be obtained and lead to outcomes that impact

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and advance equity and accessibility for people with albinism through improved technology development and/or enhanced management/support.

The following, but not limited to, are possible areas for albinism research:

- Could we improve the discomfort of photophobia?
- Are there better sunscreen options to prevent skin cancer?
- Are people with albinism at a higher risk for cataracts?
- Who is a good candidate for nystagmus surgery?
- Are there ways to improve current vision aids including glasses, contacts, or other devices?

While research often answers some questions, it frequently generates more, and it's not uncommon to have unexpected outcomes that benefit a wider population. Research using modern technology to study the back of the eye is currently providing advances in eyeglasses and low vision aids which could help provide focus and clarity to facial features/expressions.

A Plethora of Programming

NOAH supports a large and diverse community, and we acknowledge some NOAH community members may not embrace our expanded support of albinism research. NOAH offers a buffet of programming, and research is a small part of NOAH's offerings. NOAH hosts NOAHCon national conferences, Adults with Albinism Weekend, NOAH Family Camp, and NOAH Virtual Connections which provide numerous opportunities for support, growth and fellowship. In addition, NOAH offers the New Parent/Parent Liaison Program, a Leadership Scholarship, and other various education, outreach and awareness programs.

Acceptance and Awareness

NOAH will continue to encourage self-acceptance and improved awareness that will hopefully lead to better understanding and

acceptance outside our community. NOAH encourages every member of the albinism community to make the choices best suited to meet their needs and goals.

**Please visit
<https://albinism.org>
research to find
out more!**

Get Involved

If albinism research is an area of interest for you...

- **Fundraise** - Efforts are ongoing for NOAH programs, including the Research Program. Your designated gift could help support the next NOAH Research Program grant! (Visit <https://albinism.org/research/#support> for a direct link to donate to the NOAH Research Program.)
- **We want to hear from YOU!** - The NOAH Research Program Committee would welcome broader input from the community, including questions about albinism research. (Visit <https://albinism.org/share/> to share with NOAH.)
- **Stay up-to-date** on the projects and findings of NOAH's Research Program Grant recipients as well as any current opportunities available for participation in studies related to albinism.



NOAH
RESEARCH
PROGRAM
Commitment

NOAH will become a leading voice in albinism research through the work of its Research Program. Funded research will be community-centered and will help develop a greater understanding of albinism. This is an opportunity not just to fund albinism research, but also to shape research to answer questions most important to people with albinism.