



National Organization for Albinism and Hypopigmentation

FOR IMMEDIATE RELEASE

June 27, 2023

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National Organization for Albinism and Hypopigmentation (NOAH) Research Program Announces 2023 Grant Recipients

East Hampstead, NH – June 27, 2023 – The National Organization for Albinism and Hypopigmentation (NOAH) is pleased to announce the award of research grants totaling \$125,000, presented to four institutions conducting albinism research. This funding is provided through the NOAH Research Program, established in 2021, to support and fund patient-centered research that leads to developing a greater understanding of albinism. In 2023, the NOAH Research Program expanded its focus of research priorities to include both vision/the visual system as it relates to albinism and dermatology as it relates to albinism.

NOAH's Research Program accepted grant applications for two funding categories – Established Researcher Program Grant and Pilot/New Innovations Program Grant. The Established Researcher Program Grant was intended to provide bridge funding for or support the expansion of existing projects from established researchers. The Pilot/New Innovations Program Grant was intended to provide funding to generate pilot data for new projects led by junior or established researchers. Upon thorough review of all applications, four Established Researcher Program Grant applicants were selected to receive 2023 NOAH Research Program funds at either a \$50,000 or \$25,000 level.

The Weill Cornell Medical College of Cornell University received \$50,000 in funding from NOAH's Research Program under the Established Researcher Program Grant category. Dr. Jonathan Zippin, his lab team, and collaborators (Dr. David Adams and Dr. Peter Meinke) proposed the project *Development of soluble adenylyl cyclase inhibitors to improve ocular pigmentation*. Their work aims to develop new drugs to block the soluble adenylyl cyclase (sAC) pathway. The team predicts that these drugs will lead to new treatments for albinism.

The following three institutions each received \$25,000 in funding from NOAH's Research Program under the Established Researcher Program Grant category:

Medical Faculty of the Otto-von-Guericke-University Magdeburg (Magdeburg, Germany), with Prof. Dr. Michael B. Hoffmann and PD Dr. Wolf Harmening as Principal Investigators proposed the project *High-resolution multimodal imaging to understand the maldevelopment of foveal and binocular vision in albinism - from single cones to visual function*. By applying cutting-edge in-vivo retinal and brain imaging, their team will take this opportunity to set the foundation for a systematic investigation of the eye-brain-function relationship to make a difference for albinism.

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Institut de la Vision (Paris, France), with Principal Investigator Dr. Alexandra Rebsam, key personnel, and Collaborators at the Saint-Pères Paris Institute for the Neuroscience (Paris, France) proposed the research project *Signaling pathways at the origin of retinal deficits in albinism*. Their project aims at finding the mechanisms in albinism leading to the altered retinal development, downstream of tyrosinase, known to be at the origin of OCA1.

University of Southampton (England, UK), with Dr. Jay Self as Principal Investigator and Dr. Eloise Keeling as Senior Post-doc Researcher, proposed the project *High-throughput drug screening to identify novel targets for OCA1 treatment*. Having developed a way to test hundreds, even thousands of possible medications for albinism - aiming to restore the pigment and rescue the visual problems, the funding from NOAH will allow this team to test almost 1000 possible drug treatments for albinism on our assay and identify hits which we can evaluate further and aim to translate into clinical trials.

The commitment of NOAH's Research Program to becoming a leading voice in albinism research is being realized through funding the projects of Dr. Zippin; Prof. Dr. Hoffmann and PD Dr. Harmening; Dr. Rebsam; and Dr. Self. NOAH's Executive Director, Karen Bly, shares "In our second full year of the NOAH Research Program, we have expanded our reach and increased interest on a global scale. Our application review team, including our Scientific Advisory Board members, has done a phenomenal job selecting projects with the potential to improve the lives of those with albinism."

NOAH's Research Program anticipates future funding opportunities. Research priorities, eligibility requirements, and application deadlines will be posted on the NOAH website at www.albinism.org/research/.

About the National Organization for Albinism and Hypopigmentation

Since 1982, National Organization for Albinism and Hypopigmentation (NOAH) has focused on providing information and support to the albinism community. Recognizing the inherent value that comes when people who share a rare genetic condition gather, NOAH acts as a conduit of information about all aspects of living with albinism and provides a place where people with albinism and their families can find acceptance, support and fellowship. NOAH's development, steady growth and accomplishments have been fueled by the dedication of many volunteers who have shared their time, talent and treasure in service to the albinism community.

For more information about albinism and NOAH - www.albinism.org or info@albinism.org.

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