

FOR IMMEDIATE RELEASE

For more information:
Prevent Blindness
Sarah Hecker
Phone: (312) 363-6035
shecker@preventblindness.org

May is the Second Annual Inherited Retinal Disease and Genetic Testing Month at Prevent Blindness

- Prevent Blindness Declares May as Inherited Retinal Disease (IRD) and Genetic Testing Month with the goal to educate patients on various forms of IRDs, and the importance of genetic testing -

CHICAGO (April 29, 2025) – [Prevent Blindness](#), the nation's leading patient advocacy organization dedicated to preventing blindness and preserving sight, has designated May as its second annual "Inherited Retinal Disease (IRD) and Genetic Testing Month." To educate the public and allied health professionals, Prevent Blindness offers a variety of free resources on IRDs, including educational videos featuring medical experts and individuals living with an IRD, webpages, and shareable social media graphics and fact sheets in English and Spanish.

IRDs are a group of diseases that can cause severe vision loss or even blindness, and can affect individuals of all ages. An IRD is a genetic disorder, meaning a change or variant, in one or more genes that contribute to proper retinal function. Identifying the specific type of gene variant helps doctors to provide the correct diagnosis to the patient and may allow him or her to direct patients to [clinical trials](#) for therapies that may save their vision. Genetic testing is now available to identify most, but not all, gene variants that cause IRDs.

IRDs include conditions such as choroideremia, cone-rod dystrophy, Leber congenital amaurosis, retinitis pigmentosa (RP) and Stargardt disease. (New Prevent Blindness downloadable fact sheets and a dedicated webpage on RP are slated to debut in May.)

Prevent Blindness has designated the third week of May to provide education and support specifically for those with Stargardt disease and their care partners, offering resources including [a dedicated webpage](#), social media graphics and fact sheets in English and Spanish, and videos. These resources are made possible with support from [Alkeus Pharmaceuticals](#).

New this year, Prevent Blindness is debuting the Focus on Eye Health Series episode, "[Stargardt Disease: A Conversation with Bryan and Bradford Manning of Two Blind Brothers](#)." Jeff Todd, president and CEO of Prevent Blindness, speaks with the brothers about their journey with Stargardt disease, advice for parents of children with the eye disease, and their non-profit business that was created to provide funding to cure blindness. The interview will also be featured in the new [Prevent Blindness Focus on Eye Health Podcast](#).

Other Focus on Eye Health Series episodes related to IRDs include:

- “[Stargardt Disease](#),” with Elias Traboulsi, MD, MEd, Pediatric Ophthalmologist and Geneticist, Department of Ophthalmology, Cleveland Clinic.
- “[Inherited Retinal Disorders and Genetic Testing](#),” with Alina V. Dumitrescu, MD, Clinical Associate Professor of Ophthalmology and Visual Sciences, Pediatric Ophthalmology and Strabismus, Inherited Eye Disease at the University of Iowa Hospitals and Clinics.

Additional IRD patient testimonials include RP patient [Brenda Niccum](#), and cone dystrophy patient [Mariagrazia Buttitta](#), who discuss their vision issues and vision impairment journeys. Both are graduates of the [Prevent Blindness ASPECT Patient Engagement Program](#).

And, the [National Center for Children's Vision and Eye Health at Prevent Blindness](#) offers the free webinar recordings [Inherited Retinal Diseases and Children's Vision and Eye Health: What You Need to Know](#), and [Pathway to Diagnosis: Genetic Testing for Inherited Retinal Diseases](#).”

“Early detection and access to treatment is the key to preventing significant vision loss, including for inherited retinal diseases. And genetic testing may also save sight for patients and their family members,” said Todd. “We encourage the public and health professionals to utilize our various free resources to learn more about IRDs, genetic testing, and steps to take today to save vision in the future.”

For more information on IRDs and genetic testing for vision issues, visit [PreventBlindness.org/inherited-retinal-diseases](#). For information on Stargardt disease, visit [PreventBlindness.org/stargardt-disease](#). For a listing of vision care financial assistance programs in English or Spanish, visit [PreventBlindness.org/vision-care-financial-assistance-information](#).

About Prevent Blindness

Founded in 1908, Prevent Blindness is the nation's leading volunteer eye health and safety organization dedicated to fighting blindness and saving sight. Focused on promoting a continuum of vision care, Prevent Blindness touches the lives of millions of people each year through public and professional education, advocacy, certified vision screening and training, community and patient service programs and research. These services are made possible through the generous support of the American public. Together with a network of affiliates, Prevent Blindness is committed to eliminating preventable blindness in America. For more information, visit us at [PreventBlindness.org](#), and follow us on [Facebook](#), [X](#), [Instagram](#), [Threads](#), [LinkedIn](#), [TikTok](#), and [YouTube](#).

###