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Prevent Blindness Declares May as Third Annual Inherited Retinal Disease and Genetic Testing Month, Offering Resources to Public and Healthcare Allies, to Help Save Sight

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

CHICAGO (April 27, 2026) – [Prevent Blindness](#), the nation’s leading patient advocacy organization dedicated to protecting and preserving eye health, has designated May as its third annual “Inherited Retinal Disease (IRD) and Genetic Testing Month.” Prevent Blindness offers a variety of free, expert-approved resources on IRDs, including [webpages](#), patient and expert videos, a new podcast episode, social media graphics, and fact sheets in English and Spanish. Prevent Blindness IRD and Genetic Testing Month and Stargardt Disease Week are supported by Gold Sponsors [Belite Bio](#) and [BlueRock Therapeutics LP](#), and Silver Sponsor [Alkeus Pharmaceuticals](#).

IRDs are a group of diseases that affect the retina, the layer of cells at the back of the eyeball that converts light into nerve signals, sending those signals along the optic nerve to the brain. The brain processes those signals into the sense of vision, according to the [Cleveland Clinic](#).

Types of IRDS include:

- Achromatopsia
- Choroideremia
- Cone-rod Dystrophy
- Leber Congenital Amaurosis
- [Retinitis Pigmentosa](#) (RP)
- Stargardt Disease

Genetic testing is key to helping doctors identify the disorder early and provide the correct diagnosis and treatment plan. Doctors may also direct patients to participate in [clinical trials](#) for therapies that may have the potential to save the patient’s vision.

“Promising research on new sight-saving treatments and therapies is currently underway to help prevent significant vision loss from several IRDs,” said Jeff Todd, president and CEO of Prevent Blindness. “By accessing eyecare and undergoing genetic testing, patients can partner with their healthcare teams to save their sight and provide critical information to their families.”

Once again Prevent Blindness has designated the third week of May, (May 18-24), as Stargardt Disease Week to provide education and support specifically for those with Stargardt disease (also referred to as juvenile macular degeneration). Free resources include [a dedicated webpage](#), social media graphics and fact sheets in English and Spanish, and videos.

New this year, Prevent Blindness is debuting a Stargardt Disease patient video, featuring Havah Fleisner, age 17. She competes in pageants and advocates through her platform, "[Through Her Eyes: Living Life Legally Blind](#)." And, Emmy Award-winning writer and performer [Ellen Gould](#) is featured in the May [Prevent Blindness Focus on Eye Health Podcast](#). Ms. Gould discusses the musical she created about her experiences as a person living with Stargardt Disease, titled "Seeing Stars."

Additional Prevent Blindness IRD videos include:

- "[Stargardt Disease: A Conversation with Bryan and Bradford Manning of Two Blind Brothers](#)."
- "[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.
- RP videos featuring [Prevent Blindness ASPECT Patient Engagement Program](#) participants, including [Mara Hutchinson](#), [Roshundra Holt](#), [Brenda Niccum](#), and [Kim Owens](#).
- "[Cone Dystrophy](#)" with Prevent Blindness ASPECT Patient Engagement Program participant, [Mariagrazia Buttitta](#).

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

Prevent Blindness is the nation's leading eye health and safety organization dedicated to preventing blindness and preserving sight. The organization raises awareness about the importance of eye health and its connection to overall health, advocates for eye health policies and funding, supports professional education and training, and empowers those living with vision loss. With the generous support of its network of affiliates, volunteers, partners, and the public, Prevent Blindness provides free resources on the full spectrum of eye diseases and conditions that can significantly affect vision and quality of life, and advances initiatives that identify vision problems

early and connect individuals to eye care. For more information, visit [PreventBlindness.org](https://www.preventblindness.org), and follow Prevent Blindness on [Facebook](#), [X](#), [Instagram](#), [LinkedIn](#), [TikTok](#), and [YouTube](#).

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