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## **Prevent Blindness Declares Third Annual Inherited Retinal Disease (IRD) Genetic Testing Week as May 16-22**

***- Prevent Blindness enters third year of raising awareness and promoting education about inherited retinal diseases and the importance of genetic testing -***

**CHICAGO (May 11, 2022)** – [Prevent Blindness](https://www.preventblindness.org), the nation’s leading nonprofit eye health and safety organization, has declared May 16-22, 2022 as the third annual “Inherited Retinal Disease (IRD) Genetic Testing Week.” Educational materials, such as a fact sheet, social media graphics, and a dedicated webpage, [preventblindness.org/inherited-retinal-diseases/](https://www.preventblindness.org/inherited-retinal-diseases/), are available.

New this year to IRD Genetic Testing Week are two informational videos. Alina V. Dumitrescu, M.D., Clinical Associate Professor of Ophthalmology and Visual Sciences, Pediatric Ophthalmology and Strabismus, Inherited Eye Disease at the [University of Iowa Hospitals and Clinics](https://www.uiowa.edu), is featured in a new “IRD and Genetic Testing” episode in the [Focus on Eye Health Expert Series](https://www.preventblindness.org/focus-on-eye-health-expert-series).

Additionally, Mariagrazia Buttitta provides a patient testimonial about her experience as an individual living with Cone Dystrophy. Ms. Buttitta is also a graduate of the [A.S.P.E.C.T. \(Advocacy, Support, Perspective, Empowerment, Communication, and Training\) Patient Engagement Program at Prevent Blindness](https://www.preventblindness.org/a-s-p-e-c-t). This program equips participants with knowledge, skills, and confidence to share their personal stories and become advocates for vision and eye health- at the individual, peer-to-peer, community, state, or national levels.

For the third consecutive year, IRD Genetic Testing Week at Prevent Blindness is supported by [Spark® Therapeutics](https://www.sparktherapeutics.com), a fully integrated company and member of the Roche group dedicated to challenging the inevitability of genetic disease. Spark offers educational resources on IRDs and genetic testing through the [Eye Want 2 Know®](https://www.eyewant2know.com) website and a genetic testing initiative, [ID YOUR IRD®](https://www.idyourird.com), which offers genetic testing at no cost to eligible patients.

Inherited Retinal Diseases, also referred to as inherited retinal disorders, are a group of diseases that can cause severe vision loss or even blindness. The most common types of IRDs include Retinitis Pigmentosa, Choroideremia, Stargardt Disease, Cone-rod Dystrophy, and Leber Congenital Amaurosis.

Identifying the genetic cause of disease is an important part of care for patients with IRDs. Knowing the exact type of IRD a person has can better define the treatment

approach in a timely manner. Because many IRDs begin manifesting during childhood, it is important for parents and caregivers to have their child's eyes examined and begin treatment as soon as possible.

Vision loss from IRDs takes both an economic and emotional toll. According to the recent "[The Impact of Inherited Retinal Diseases in the United States of America \(US\) and Canada from a Cost-of-Illness Perspective](#)" study, the annual cost of IRDs to society, is estimated to total at least \$13.4 billion in the US and \$1.6 billion in Canada.

The study also found that the majority of participants living with an IRD reported their wellbeing was negatively impacted due to having an IRD. In the U.S., approximately three-quarters (76%) of respondents reported experiencing anxiety, three-fifths (67.1%) reported depression and over one-third (36.5%) reported social isolation.

"Through early detection, specifically through genetic testing, and treatment, severe vision loss and blindness from Inherited Retinal Diseases can be avoided in many cases," said Jeff Todd, president and CEO of Prevent Blindness. "By educating the public on the many resources that are available, we can work together to save sight from IRDs."

"Spark Therapeutics has been working to make the critical step of genetic testing more accessible to those living with an IRD, as it is the only potentially definite way to verify the root cause of a disorder," said Jay Newman, Head of US Commercial, Spark Therapeutics. "By providing a definitive diagnosis, genetic testing has the potential to end uncertainty, guide disease management, build community, and encourage research that can benefit future generations."

For more information on IRDs and genetic testing for vision issues, please call Prevent Blindness at (800) 331-2020 or visit <https://www.preventblindness.org/inherited-retinal-diseases>. For a listing of vision care financial assistance programs in English or Spanish, visit <https://www.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](http://preventblindness.org), and follow us on [Facebook](#), [Twitter](#), [Instagram](#), [LinkedIn](#) and [YouTube](#).

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