FOR IMMEDIATE RELEASE

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

-- National non-profit group, Prevent Blindness, continues to educate public on importance of genetic testing, various types of retinal diseases and support resources available --

CHICAGO (May 14, 2021) – <u>Prevent Blindness</u>, the nation's oldest nonprofit eye health and safety organization, has declared the second annual "Inherited Retinal Disease (IRD) Genetic Testing Week" as May 16-22, 2021. As part of this initiative, Prevent Blindness will be posting a series of educational graphics on its social media channels, including Facebook, Twitter and Instagram.

The group also provides a dedicated webpage including detailed information on causes, risk factors, therapy and research options, financial assistance services, and more. A free downloadable Inherited Retinal Diseases fact sheet is also available. These resources may be found at: <u>preventblindness.org/inherited-retinal-diseases/</u>.

IRDs are a group of diseases that can cause severe vision loss or even blindness. They can affect individuals of all ages and can progress at different rates. Many are degenerative, which means that the symptoms of the disease will get worse over time. 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. Having the genetic diagnosis may help to identify potential treatment options for patients, inform them about the potential risk of disease to other family members, and may identify the potential risk to other organs in the patient's body that can be affected. In the case of infants and young children, genetic testing may identify those children who are at risk of other health problems and who could benefit from early diagnosis and therapy.

According to the <u>American Society of Gene & Cell Therapy</u>, IRD patients are especially strong candidates for gene therapy treatments, due to the retina's unique physical makeup. Compared to other organs of the body, the eye is small and easy to access for treatment administration. And, the eye is an ideal location for gene therapy because it is considered "immune privileged," meaning that a body's normal immune response is not as active, and that anything that is implanted into the eye is less likely to be rejected.

<u>Spark Therapeutics</u>, a fully integrated company dedicated to challenging the inevitability of genetic disease, is partnering once again with Prevent Blindness in support of May's IRD Genetic Testing Week. Spark offers educational resources on IRDs and genetic testing through the <u>Eye Want 2 Know</u> website, and a free gene testing initiative, <u>ID</u> <u>YOUR IRD</u>, to appropriate US residents.

"By encouraging the public to educate themselves about IRDs and the positive impact that genetic testing may have on their health, we hope to save sight for patients in the near term and throughout their lives," said Jeff Todd, president and CEO of Prevent Blindness. "We thank Spark Therapeutics for their continued support of our important work during IRD Genetic Testing Week."

For more information on IRDs and genetic testing for vision issues, please call Prevent Blindness at (800) 331-2020 or visit <u>https://www.preventblindness.org/inherited-retinal-diseases</u>. For a listing of vision care financial assistance programs in English or Spanish, visit <u>https://www.preventblindness.org/vision-care-financial-assistance-information</u>.

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, Twitter, Instagram and LinkedIn.

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