FOR IMMEDIATE RELEASE

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

Prevent Blindness Offers New Resources for Education and to Raise Awareness for Stargardt Disease

- Prevent Blindness provides free resources on Stargardt disease, including a webpage, fact sheets, expert interview video and social media graphics, to educate the public and professionals on the inherited retinal disease -

CHICAGO (May 21, 2024) – Prevent Blindness, the nation's leading nonprofit eye health and safety organization, has created new educational materials on Stargardt disease, a form of inherited retinal disease (IRD). Coinciding with May's IRD Genetic Testing Awareness Month, Prevent Blindness now offers a dedicated webpage, fact sheets, a new Focus on Eye Health Expert Series episode, and social media graphics. The effort is supported by funding from Alkeus Pharmaceuticals, Inc.

Stargardt disease is sometimes referred to as Stargardt macular degeneration, Stargardt macular dystrophy or juvenile macular dystrophy. Stargardt disease affects central vision due to a buildup of fatty material in the macula and is most commonly caused by a variant in the ABCA4 gene. According to the Cleveland Clinic, there are an estimated 30,000 to 200,000 people with Stargardt disease in the United States.

The most common symptom of Stargardt disease is a slow loss of central vision in both eyes. Other symptoms may include:

- Dark, gray, black, or hazy spots in the center of your vision
- Sensitivity to light
- Blurry vision that cannot be corrected with glasses
- Difficulty seeing small details
- Needing more time for your eyes to adjust between light and dark places
- Difficulty seeing in the dark or low light
- Color blindness
- Lack of depth perception
- Lack of contrast

As part of its Focus on Eye Health Expert Series, Prevent Blindness offers the new episode, "Stargardt Disease," featuring Elias Traboulsi, MD, MEd, Pediatric Ophthalmologist and Geneticist, Department of Ophthalmology, Cleveland Clinic.

Genetic testing is important for IRD diagnosis, including Stargardt disease. It may help to identify potential treatment options and create clinical trial opportunities for patients, as well as inform them about the potential risk of disease to other family members. To

learn more about IRDs and benefits of genetic testing, visit Foundation Fighting Blindness at FightingBlindness.org/genetic-testing.

“Although there is no known cure for Stargardt disease today, there is promising new research being conducted through clinical trials,” said Jeff Todd, president and CEO of Prevent Blindness. “We encourage patients to speak with their eye doctors about their risk for Stargardt disease and other IRDs, as well as how to complete genetic testing to determine the best treatment path to preserve their vision.”

For more information on Stargardt disease, please visit PreventBlindness.org/stargardt-disease. For additional information on inherited retinal diseases and genetic testing for vision issues, visit PreventBlindness.org/inherited-retinal-diseases. Alkeus Pharmaceuticals also offers the free online resource, “Your North Starg,” designed for people living with Stargardt disease, their families, and care partners, to provide educational information and support.

For information on clinical trials specifically for eye disease and vision, please visit PreventBlindness.org/clinical-trials.

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 and YouTube.

###