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## Blueprint Genetics, InformedDNA and the Foundation Fighting Blindness launch an open access program for patients with inherited retinal disease in the United States

**COLUMBIA, Maryland – October 2, 2019** – Blueprint Genetics, InformedDNA and the Foundation Fighting Blindness have announced that beginning in October 2019, a new open-access program will be launched, offering patients with inherited retinal disease (IRD) no-cost genetic testing and genetic counseling in the United States. The program will streamline clinical workflow by providing the highest possible diagnostic yield, enabling faster and more straightforward follow-ups to patients.

The new program is an expansion of the My Retina Tracker genetic testing program established in 2017, when the Foundation Fighting Blindness partnered with Blueprint Genetics and InformedDNA to launch the My Retina Tracker genetic testing study. Previously, patients were only eligible for the genetic testing if they were seen by an eligible specialist and if they enrolled in the registry.

Now, My Retina Tracker will become available to all US patients with a clinical diagnosis of an inherited retinal disease (IRD). With over 6,000 patients tested to date, and hundreds more tested monthly, the program aims to further grow the largest volume IRD genetic testing program in the United States.

“With the increasing number of therapies being developed, an accurate genetic diagnosis is critical for any person affected with an inherited retinal disease. We are also encouraged by the large number of patients enrolling in the registry who are continuing to drive progress in the field, including access to clinical trials. Our goal is to test over 20,000 IRD patients in this program within the next few years,” says **Brian Mansfield**, executive vice president research, interim chief scientific officer from the Foundation Fighting Blindness.

The previous My Retina Tracker genetic testing program has already significantly expanded the membership of the Foundation’s My Retina Tracker patient registry, designed to share de-identified information within the research and clinical communities to help accelerate the discovery of treatments, cures and access to clinical trials for rare IRDs such as retinitis pigmentosa, Usher syndrome, Leber congenital amaurosis and Stargardt disease.

"We are very excited to participate in this initiative. The genetic test provided for these patients includes over 260 IRD genes. The test offers excellent coverage of RPGR, one of the most important retinitis pigmentosa genes, inclusion of high-resolution copy number variant detection and targeting of clinically relevant deep intronic variants. These unique features result in the highest diagnostic yield available in the market," comments Blueprint Genetics' chief medical officer and co-founder **Tero-Pekka Alastalo**.

"We are honored to be a key part of this program and to bring specialty level genetic counseling services to all patients, regardless of geographic location or ability to pay. I have worked with patients and families affected with inherited retinal diseases for the past 18 years and the My Retina Tracker genetic testing initiative has done more to give patients access to genetic testing than anything else I have seen in my career. Every patient with an inherited retinal disease deserves to know the cause, and to discuss those results with a genetics expert," says **Karmen Trzupek**, director of Ocular Genetics Services at InformedDNA.

In short:

- The My Retina Tracker genetic testing program is expanding to be an open access, no-cost program for patients with a clinical diagnosis of an inherited retinal disease.
- The program is sponsored by the Foundation Fighting Blindness.
- Blueprint Genetics provides the genetic testing with an over 260-gene Retinal Dystrophy Panel and high-quality clinical interpretation.
- InformedDNA provides genetic counseling by certified genetic counselors with IRD expertise.
- All patients are encouraged to enroll in the My Retina Tracker patient registry, however, enrollment is not mandatory.
- The program is funded by Foundation Fighting Blindness and in the future by selected bio-pharma partners.

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**About Blueprint Genetics**
Blueprint Genetics is one of the fastest growing genetic diagnostics businesses globally in the field of clinical genetic testing of rare inherited diseases. The company is based in Helsinki and Seattle, with a customer base spanning over 70 countries. www.blueprintgenetics.com.

**About InformedDNA**
InformedDNA is the authority on the appropriate use of genetic testing. It leverages the expertise of the largest full-time staff of lab-independent, board-certified genetics specialists in the U.S. to help ensure health plans, hospitals, employers, clinicians and patients all have access to the highest quality genetic services. Key offerings include clinical genetic counseling, genetic testing utilization management, genetic testing payment integrity, and clinical trial support. www.InformedDNA.com.

**About the Foundation Fighting Blindness**
Established in 1971, the Foundation Fighting Blindness is the world's leading private funding source for retinal degenerative disease research. The Foundation has raised more than $750 million toward its mission of accelerating research for preventing, treating, and curing blindness caused by the entire spectrum of retinal degenerative diseases including: retinitis pigmentosa, age-related macular degeneration, Usher syndrome, and Stargardt disease. Visit FightingBlindness.org for more information.

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