

My Retina Tracker®: Open access genetic testing program for patients with inherited retinal degeneration (IRD)

The My Retina Tracker® Program

The My Retina Tracker® Program provides individuals with a clinical diagnosis of inherited retinal disease (IRD) no-cost genetic testing and genetic counseling.

This program is offered by the Foundation Fighting Blindness®, a nonprofit organization dedicated to finding treatments for IRD. The genetic testing is performed at Blueprint Genetics and the genetic counseling services are provided by InformedDNA®.

You can find more information at blueprintgenetics.com/my-retina-tracker-program.

How to order

- Go to blueprintgenetics.com/my-retina-tracker-program to find more information and to order a My Retina Tracker Program sample collection kit with pre-paid return shipment labels.
- Obtain the Genetic Testing Program Informed Consent from the patient. For further assistance, please contact support.us@blueprintgenetics.com.
- To place the order, log in to nucleus.blueprintgenetics.com. If you are a new user, create an online account free of charge.
- Select medical specialty “Ophthalmology” and then select “My Retina Tracker” program panel.
- Fill in the requisition form and submit. A printed copy of the order is not required.

Benefits for your patient

- This test is specifically targeted to the inherited retinal diseases. It is one of the most accurate, scientifically advanced, and highest quality tests widely available to patients today.
- Patients are eligible to receive comprehensive genetic counseling through InformedDNA to review their results at no cost.
- A genetic diagnosis can lead to personalized treatment and medical management.
- Testing may identify family members who are at risk to develop IRD. The genetic counselors at InformedDNA can support those family members, regardless of geographic location.
- Patients have the opportunity to enroll in the Foundation Fighting Blindness My Retina Tracker Registry to support research and development in the field of IRD.

Eligibility

The individual must:

- Be clinically diagnosed with one of the inherited retinal diseases listed on the program website at blueprintgenetics.com/my-retina-tracker-program
- Not have had genetic testing of more than 32 IRD-related genes in or after 2016
- Live in the USA or US territory

This test is not a screening tool and must not be used for attempted molecular diagnosis of: age-related macular degeneration, glaucoma, optic neuropathy, cornea/anterior chamber disease, diabetic eye disease, and nongenetic ocular or retinal damage diagnosis not listed in the requisition.

Read more:

www.blueprintgenetics.com/my-retina-tracker-program.

Highest possible diagnostic yield, enabling faster and more straightforward results to patients.

High-quality genetic testing

Blueprint Genetics' 322-gene panel is one of the most comprehensive and high-quality IRD tests on the market and includes:

- Excellent coverage of the difficult-to-sequence RPGR gene which explains 70%-90% of cases of X-linked retinitis pigmentosa
- High resolution of copy number variants (CNVs), maximizing the diagnostic potential for your patient. According to our research, approximately 5% of all patients with IRD have a CNV that would not be detected by sequencing alone
- Clinically relevant noncoding variants (not included in most available IRD genetic tests)
- Mitochondrial genome covered by the test

Informed Consent and data sharing

- The genetic testing provider, Blueprint Genetics, will only share deidentified patient data with Scientific Collaborators. These data are limited to the clinical diagnosis, age range, sex, and genes and variants associated with IRD. No patient identifiable information or raw sequence data will be shared
- We may share information on the healthcare provider taking care of the patient, such as contact information
- Scientific Collaborators can be biopharmaceutical companies, their affiliates and partners, research organizations, and patient advocacies engaged in approved research, studies, and clinical trials related to inherited retinal diseases and in delivering therapies and treatments for these diseases
- Blueprint Genetics may use the samples and data internally to improve the understanding and diagnostics of IRD. No samples or identifiable research data will be shared with third parties without express permission from the patient
- Eligible patients who wish to participate in the no-cost genetic testing program are required to provide Informed Consent. Download the Genetic Testing Program Informed Consent document at blueprintgenetics.com/my-retina-tracker-program

Comprehensive genetic counseling

- During the online test requisition process, the healthcare provider will have the opportunity to request no-cost genetic counseling through InformedDNA or indicate they will provide counseling locally
- Each of the genetic counselors at InformedDNA has undergone extensive training in ophthalmology genetics. This expertise is highly valued by the patient community, leading to >95% patient satisfaction scores
- The sessions at InformedDNA are comprehensive, with a review of medical and family history, interpretation of genetic variants, correlation with disease, and medical management recommendations
- Following the sessions, patients and providers receive a formal summary report and a detailed pedigree taken by expert genetic counselors

Encourage your patients to join the My Retina Tracker Registry

Support prevention, treatments, and cures for people affected by blinding retinal diseases.

The Foundation Fighting Blindness My Retina Tracker Registry enables patients with inherited retinal disease, their doctors, and research community to actively work together and promote research and development in the field. Individuals with IRD are encouraged to enroll in the My Retina Tracker Registry; however, enrollment is not mandatory. Patient brochures about the Registry are available for your office on request from

Coordinator@MyRetinaTracker.org.