How Can I Participate?

This program is sponsored by the Foundation Fighting Blindness, and genetic counseling is provided by InformedDNA, a telephone-based counseling service.

The program provides patients with a 285 gene panel targeting relevant genes associated with an IRD. Unique features of the panel include full RPGR coverage, high resolution copy number variant detection and comprehensive coverage of IRD related non-coding variants.

A person with an IRD, should speak to their retinal healthcare provider (ophthalmologist, retinal specialist, optometrist) and ask if they qualify for the test, and if so, ask their retinal healthcare provider to order the My Retina Tracker Panel from Blueprint Genetics.

The health professional can find more information about the My Retina Tracker Program, and how to order the test, by visiting us online at: www.FightingBlindness.org/genetics.

If your doctor has questions, they should contact Blueprint Genetics directly. Please do not try to order the test by contacting Blueprint Genetics yourself. Speak to your eye doctor as they are the only ones authorized to order the test.

What Does The Test Cost?

There is no cost to the participant or their insurance company for the genetic test, or for the genetic counseling through InformedDNA. You may need to cover the cost of a visit to speak with your clinician about the test, and for any tests they may want to do before ordering the test for you.

My Retina Tracker Registry is free to join and participate in. Visit MyRetinaTracker.org.

For more information about the registry or genetic testing, contact Coordinator@MyRetinaTracker.org or 1-800-683-5555.
Who Is Eligible for Testing?

Any person with a clinical diagnosis of an IRD. The list includes retinitis pigmentosa, Leber congenital amaurosis, Stargardt disease, Usher syndrome, Best disease, choroideremia, achromatopsia and any of the other 25 covered diseases.

What Are the Benefits?

With the increasing number of gene-specific therapies being developed, an accurate genetic diagnosis is very important for anyone with an IRD.

This genetic test is specifically targeted to those with an IRD and is the most accurate, scientifically advanced, and highest quality test widely available to patients today.

Joining the My Retina Tracker Registry allows input of your genetic testing results and other important data of interest to researchers and companies planning studies and trials.

My Retina Tracker Registry

My Retina Tracker® Registry is a research database of people and families affected with an IRD. The purpose of the My Retina Tracker Registry is to accelerate the delivery of therapies for IRDs by determining the causes and prevalence of the different IRDs, supporting the research community to actively collaborate and promote research and development in the field of IRD and efficiently enable people to connect to relevant clinical trials.

My Retina Tracker Registry is provided by the Foundation Fighting Blindness, a U.S.-based nonprofit organization with the mission to help find treatments and cures for the inherited retinal diseases.

Why Join?

✅ The registry data drives more research.

✅ More registrants with a specific IRD draw researchers’ focus and help support study and trial planning and funding.

✅ Registrants enter and control their own data and can withdrawal at any time.

✅ Registrants have improved access to announcements regarding focus groups, disease progression studies, genetic studies and clinical trials recruitment and updates.

✅ Your data and privacy is protected and only de-identified information is shared with researchers and clinicians.