

NEWLY DIAGNOSED

The diagnosis of a retinal degenerative disease is often overwhelming. But if you or a loved one has been recently diagnosed with an inherited retinal condition or age-related macular degeneration (AMD), getting connected to the Foundation Fighting Blindness is a great way to get educated, better manage your condition, and find support.

Here are some helpful steps you can take to get on a positive path moving forward:

1 FIND A RETINAL SPECIALIST WHO UNDERSTANDS INHERITED RETINAL DISEASES




Inherited retinal diseases (IRDs) are rare. Many ophthalmologists and retinal doctors therefore only see IRD patients on occasion and may not have extensive experience in managing the conditions.

However, there are some **Retina Specialists**, under **Resources** section of the website, who see and study patients with IRDs on a regular basis. These experts are often better able to:

-  **Manage any complications**
-  **Conduct appropriate tests and exams**
-  **Discuss your prognosis**
-  **Suggest potential clinical trials for emerging therapies**

2 CONSIDER GENETIC TESTING IF YOU HAVE AN IRD

Virtually all IRDs are caused by mutations in a single gene. Getting a genetic test to determine which mutated gene is causing your condition can be helpful for a number of reasons including the following:

-  **Gives you a definitive diagnosis for which disease is causing vision loss.**
-  **Confirms the inheritance pattern – that is, which family members may be at risk of having or inheriting the condition.**
-  **Helps you qualify for clinical trials of emerging therapies. Some studies may require a genetic diagnosis.**



Researchers have identified **more than 270 genes** associated with retinal degenerative diseases.

For more information on the genetic testing process, visit the **Genetic Testing** under **Resources** section of our website.

3 REGISTER AT MYRETINATRACKER.ORG

My Retina Tracker (the Foundation's patient registry) provides valuable information and data on IRDs to pre-screened researchers and companies for:

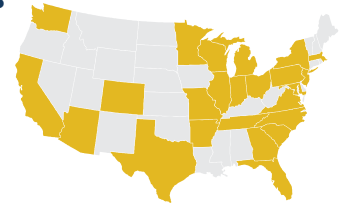
-  **Developing therapies**
-  **Recruiting for clinical trials**
-  **Performing other disease-related studies**

A patient's personal information is never available to or seen by the researchers and companies accessing My Retina Tracker.



4 PARTICIPATE IN FOUNDATION CHAPTERS AND EVENTS

Getting involved with the Foundation is a great way to stay informed about ongoing research for treatments and meet other people and families affected by retinal degenerative diseases.




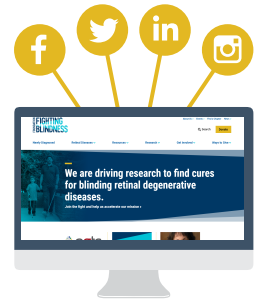
The Foundation maintains a network of chapters around the U.S. and holds seminars and meetings that provide information on research, low vision resources, and other helpful topics. Joining a chapter is a great way to meet other people and families with retinal degenerative diseases in your area who can provide support and information on local resources.

5 FOLLOW THE FOUNDATION ONLINE

The Foundation's website, **Facebook**, **Twitter**, **LinkedIn** and **Instagram** are great resources for learning about the latest developments in the retinal degenerative disease space.

Visit the **Retinal Diseases** and **Research** sections of our website for extensive information.

-  **Sign up** for email updates and news



6 VISIT THE RESOURCES SECTION FOR FURTHER SUPPORT

There are innumerable resources, including assistive and accommodative technologies and support organizations, available for people with low vision and blindness. The Foundation maintains a list of several of these resources in the **Living and Thriving** pages on our website.



7 DRIVE SIGHT-SAVING RESEARCH

The Foundation is a world leader in driving the research that is eradicating the entire spectrum of retinal degenerative diseases. Much of our revenue comes from affected patients and families.

-  Visit the **Ways to Give** section of our website to learn about the ways you can help drive the research.
-  Visit **VisionWalk.org** to learn about our signature fundraising walks held around the country.

