The diagnosis of a blinding retinal degenerative disease is often overwhelming. But if you or a loved one has been recently diagnosed, 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 SPECIALIST WHO UNDERSTANDS INHERITED RETINAL DISEASES (IRDs)

There are some Retina Specialists (visit the Resources section of our website) who see and study patients 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

- 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 285 genes associated with retinal degenerative diseases. Visit the Genetic Testing under Resources section of the Foundation’s website for more information.

3. REGISTER AT MyRetinaTracker.ORG

My Retina Tracker® Registry (the Foundation’s patient database) 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
PATIENT RESOURCES

NEWLY DIAGNOSED

4 PARTICIPATE IN FOUNDATION CHAPTERS AND EVENTS

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. 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. 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.

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.

For more information, visit FightingBlindness.org or call 888-394-3937.