

Living With Stargardt Disease

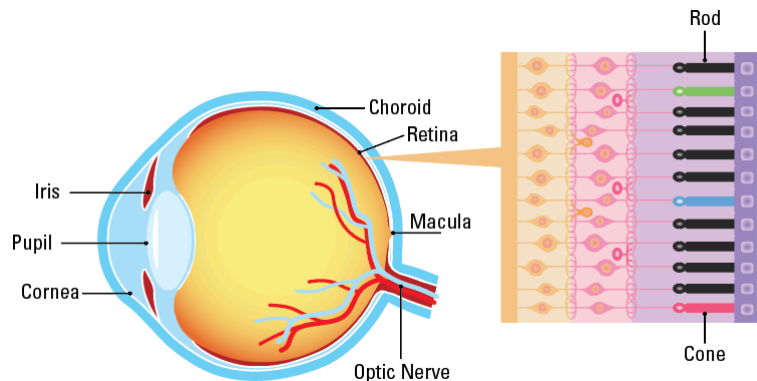
Factsheet 2 of 2 in a series. Find the rest of the series at PreventBlindness.org/stargardt-disease

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What is Stargardt disease?

Stargardt disease, also called Stargardt macular dystrophy, causes vision loss due to a buildup of fatty material in the **macula**. The macula is a small area in the center of the **retina** that is responsible for sharp, straight-ahead vision. Stargardt disease is a rare eye genetic disease – part of a group of conditions called inherited retinal diseases (or IRDs), generally caused by a variation in one or more **genes**, causing the gene to not work properly. Stargardt disease affects about 1 in 10,000 people in the United States.¹



This disease typically causes central vision loss in both eyes during childhood or adolescence, but sometimes it occurs later in life. Central vision loss can cause difficulty recognizing faces and reading. Side (peripheral) vision is usually not affected, so it is rare for a person with Stargardt disease to lose all of their vision.

Things to consider with Stargardt disease

You can live well with Stargardt disease as it progresses and affects your vision over time. Know that you can do almost anything by making adaptations, finding community, and empowering yourself throughout your journey.

“It’s [so important] to maximize your environments for successful living with low vision.”

– Charlie C., motivational speaker and Stargardt patient

To live successfully with low vision, maximize the vision you have.

Low vision specialists are trained to help a patient with vision loss learn how to use their remaining vision to its fullest potential. Find a vision rehabilitation center so you can learn how to maximize the use of the vision do have to help you work, do daily activities, and do the things you enjoy. This can include:

- Improved lighting techniques, such as adding extra lighting for activities like reading, making meals, or other close work.
- Use of accessible technology, such as smart phones, tablets, VR, computers, smart homes.
- Use of low-tech solutions, such as magnifiers or simple home modifications.
- Find a **vision rehabilitation center** ([LowVision.PreventBlindness.org/finding-low-vision-rehabilitation-services](https://www.LowVision.PreventBlindness.org/finding-low-vision-rehabilitation-services)) near you.

Online resources for persons with vision loss:

Living Well with Low Vision: Prevent Blindness offers resources and help finding low vision clinics near you and clinical trials for individuals with vision loss on the Living Well with Low Vision website: ([LowVision.PreventBlindness.org](https://www.LowVision.PreventBlindness.org)).

Blind Life: Blind Life website ([TheBlindLife.net](https://www.TheBlindLife.net)) and YouTube ([YouTube.com/c/theblindlife](https://www.YouTube.com/c/theblindlife)) channel provides videos, tips, and insight for those living with vision loss.

Thriving Blind Academy: ([ThrivingBlindAcademy.org](https://www.ThrivingBlindAcademy.org)) is dedicated to promoting literacy, employment and financial awareness in the blind community. Free and paid programs are available for people of all ages.

Stargardt Disease

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“[Stargardt is] progressive. That means you know that things are going to get challenging, but with the right mindset you will be able to overcome adversity.”

– Charlie C., motivational speaker and Stargardt patient

Hadley: Hadley (HadleyHelps.org) offers practical help, connection and support free of charge to anyone with a visual impairment, their families and professionals supporting them.

Guide Dogs of America: Many patients with Stargardt disease and vision loss benefit from use of a guide dog. A guide dog is a specially trained service animal that helps an individual with vision loss or blindness. Information on guide dog services in the United States can be found at GuideDogsofAmerica.org, and GuideDog.org

Stargardt Disease Masterclass taught by Bradford Manning, Founder of Two Blind Brothers: Didit.org/courses/bradford-manning-teaches-stargardt-disease

Participate in a support group for patients with Stargardt disease or connect to an online community.

- Global Genes: GlobalGenes.org
- MD Support: MDSupport.org
- Eye2Eye: [Eye2Eye \(SHP.Rutgers.edu/psychiatric-rehabilitation/eye2eye\)](http://SHP.Rutgers.edu/psychiatric-rehabilitation/eye2eye) is a free, phone-based, peer support program, designed to assist adults who are blind or visually impaired and their families.

Talk to your loved ones about how you are feeling and describe to them how you see. It will help your family and friends understand what you can and cannot see as they are part of this journey with you. Share with them how they can help you with your vision loss and the support needed from schools and employers. Talk to them about your emotions about your change in eyesight and how you can manage together, and keep having this conversation as vision needs change.

Stargardt Disease

(continued)

Connect with a local organization

that provides services and support for people who have vision loss or are blind. Every state has a department of rehabilitation supported by the National Council of State Agencies for the Blind. Support services include vocational rehabilitation (including job retraining), mobility training, evaluation for assistive technology devices, and individualized counseling. Local support services can be found at NCSAB.org or VisionServeAlliance.org/visionloss-resources/lost-your-vision. A variety of organizations supporting individuals with an IRD can be found at: ASharedVision.com

Find an eye doctor that you trust.

It is important to have an eye doctor that listens, makes you feel comfortable, and that you are able to talk to and ask questions. They will be with you on your journey so make sure you find one that works best for you and your needs.

Complete genetic testing.

This provides your eye care team with the most detailed diagnosis and allows them to recommend the best possible treatment for your specific IRD. Genetic testing is also often a requirement before a patient can participate in clinical trials.

Learn more about genetic testing:

Learn more about IRDs and benefits of genetic testing at FightingBlindness.org/genetic-testing.

Find a provider to help you access genetic testing:

The Foundation Fighting Blindness's list of Retina Doctors (FightingBlindness.org/retinal-specialists) makes it easy to find a genetic testing specialist or health care provider in your area of the United States who can discuss your testing options and assist you in learning more about your IRD.

Stay up to date on clinical trials.

Clinical trials (PreventBlindness.org/clinical-trials-for-eye-diseases-and-vision) are research studies evaluating how effective a medical, surgical, or behavioral intervention will work in people. Clinical trials for eye diseases and conditions can take years to complete, however, it is the safest known approach to developing new treatments and therapies against disease.

To learn more about clinical trials for Stargardt disease at ClinicalTrials.gov:

- Learn about current clinical trials for Stargardt disease: FightingBlindness.org/research/stargardt-disease-research-advances-6

Stargardt Disease

(continued)

- Search studies in the U.S. that are currently active or recruiting people aged birth to 65+ who have Stargardt disease: [ClinicalTrials.gov/ct2/results?cond=Stargardt+Disease&cntry=US&Search=Apply&recrs=a&recrs=d&age_v=&age=0&age=1&age=2&gender=&type=&rslt=](https://clinicaltrials.gov/ct2/results?cond=Stargardt+Disease&cntry=US&Search=Apply&recrs=a&recrs=d&age_v=&age=0&age=1&age=2&gender=&type=&rslt=)

When considering a clinical trial, talk to your eye doctor. Consider the following advice from the Federal Trade Commission when looking at a clinical trial.

- **Never participate in a study that asks you to pay** to be in their study or to learn about their study.
- **Never participate in a study that asks for your Social Security number, bank account, or credit card** during recruitment or screening.
- **Do an online search** before you join any study. Search using the name of the clinical trial and the words “scam,” “review,” or “complaint.”

Participate in patient data registries such as **My Retina Tracker** ([Fightingblindness.org/my-retina-tracker-registry](https://fightingblindness.org/my-retina-tracker-registry)). The My Retina Tracker Registry is a research database of people and families affected by IRDs. The registry is designed to share de-

identified (i.e. non-traceable to any one individual) information within the IRD research and clinical communities about people with an IRD to help speed up the discovery of therapies and cures. The registry helps to connect patients with clinical research. There is no charge for the use of this service.

Advocate for yourself!

Stargardt disease is not common. It can be normal for healthcare providers not to be familiar with it. Stay informed of your condition, talk to your doctor, and share resources. Here are some other ways to advocate for your health:

- **Understand your condition:** Make sure you understand what your doctor shares with you. Restate to your doctor the information you have learned.
- **Pick a doctor you are comfortable with:** If you are not comfortable with your doctor, do not be afraid to get a second opinion or change doctors.
- **Read reliable information:** Read trusted information from trusted resources.
- **Receive equitable care:** Make sure you are getting fair care and if you are not, say something.

Stargardt Disease

(continued)

- **Share your experience for policy:** Share your health experiences with your state and federal senators and representative to advocate on your behalf for the healthcare you need. Learn more about advocating for vision and eye health at Advocacy.PreventBlindness.org/vision-advocacy-101

How can Stargardt disease affect mental health?

Stargardt disease can cause loss of vision. For some, loss of vision can lead to feelings of depression, anxiety, and loss of independence. Not everyone who has vision loss will experience depression or anxiety. Some individuals may notice a change in their desire to socialize with others, or increased frustration with the additional time it may take to accomplish tasks of daily living. If you do experience any of these symptoms, know there is help available.

If you are in crisis, please seek help immediately. Call or text 988 or chat 988lifeline.org

To help support your mental health as you deal with Stargardt disease:

- **Talk to your primary care doctor, mental health professional, or eye doctor:** Talk to your doctor about any changes to your emotional well-being. Ask your eye doctor questions on how Stargardt disease will affect your daily life and work. Seek assistance on how to deal with the changes in your life due to Stargardt disease.
- **Seek support:** Look for support groups of others who are experiencing Stargardt disease. **MD Support** (MDSupport.org) provides a list of support groups near you on their website. These groups can help you learn about your condition, share your experience, and find support.
- **Connect with others and the things that bring you joy:** Stay connected with friends and family to keep you from feeling isolated. Over time, you can find new ways to do the things you love or to discover new hobbies that bring you happiness.
- **Exercise** can help symptoms of depression or anxiety and make you feel better. Talk to your health care professional to determine what exercise routine may work best for you, especially if you have changes to your vision due to Stargardt disease.

Stargardt Disease

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- **Seek vision rehabilitation:** Ask your eye doctor to recommend a low vision specialist. The specialist can help to maximize the use of the vision you have.

To learn more about your mental health, check out the following resources:

- **Vision Loss and Mental Health** [CDC.gov/visionhealth/resources/features/vision-loss-mental-health.html](https://www.cdc.gov/visionhealth/resources/features/vision-loss-mental-health.html)
- **Centers for Disease Control and Prevention (CDC): The Mental Health of People with Disabilities** [CDC.gov/ncbddd/disabilityandhealth/features/mental-health-for-all.html](https://www.cdc.gov/ncbddd/disabilityandhealth/features/mental-health-for-all.html)
- **American Psychological Association: Depression** [APA.org/topics/depression](https://www.apa.org/topics/depression)
- **National Alliance on Mental Illness (NAMI): Signs and Symptoms** [NAMI.org/About-Mental-Illness/Warning-Signs-and-Symptoms](https://www.nami.org/About-Mental-Illness/Warning-Signs-and-Symptoms)

Find more information about Stargardt disease.

- **National Eye Institute – Stargardt Disease:** [NEI.NIH.gov/learn-about-eye-health/eye-conditions-and-diseases/stargardt-disease](https://www.nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/stargardt-disease)
- **Foundation Fighting Blindness:** [FightingBlindness.org/diseases/stargardt-disease](https://www.fightingblindness.org/diseases/stargardt-disease)
- **Your North Starg:** [YourNorthStarg.com](https://www.yournorthstarg.com)

Reference:

1. Farnoodian M., et al (2022). Cell-autonomous lipid-handling defects in Stargardt iPSC-derived retinal pigment epithelium cells. *Stem Cell Reports*, 17(11) 2438-2450. <https://doi.org/10.1016/j.stemcr.2022.10.001>.

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