
A Guide to Navigating LHON with Money in Mind

**Information & Resources for the
Georgia LHON Community**

May 2025

Purpose

Individuals who carry an LHON mutation can experience sudden-onset blindness at any age. When this occurs, it is a life-changing event for the individual affected, their family, and loved ones.

There are many ways in which LHON onset can have a significant financial impact on all involved. Fortunately, there are also many resources available that can help mitigate that financial impact.

The goal of this document is to help the Georgia LHON community become familiar with resources that can limit negative financial impacts. While designed for the LHON community, some of the information may be of value to others with vision loss. It provides descriptions and contact information of agencies and programs that can create a better financial outcome for affected patients and their loved ones. Unaffected carriers can also benefit by being better prepared in case they experience LHON vision loss one day.

The organizations and services listed in this document are those that provide free or low-cost assistance. There are many other valuable fee-for-service agencies available. In some cases, those may be a better fit for you. To access them simply search blind or low-vision services in your city/region.

This document is intended as a general guide only. It was developed by LHON volunteers and is subject to change. It does not purport to provide legal, financial or tax guidance. You should check with each listed provider and your own advisors for your specific situation.

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TRAINING & TECHNICAL RESOURCES

Georgia Vocational Rehabilitation Agency (GVRA)

The Blind and Low-Vision Field Services division of GVRA provides customized vocational rehabilitation to Georgians who are visually impaired, aiming to enhance independence and self-sufficiency. Services include vision-loss counseling, worksite assessments, daily living skills training, orientation and mobility training, access technology training, and braille assistance.

<https://gvs.georgia.gov/sensory-services/blind-and-low-vision-field-services>

Center for the Visually Impaired

The Center for the Visually Impaired offers services to individuals experiencing vision loss and provides financial assistance to ensure accessibility. The resources include a Low Vision Clinic, rehabilitation classes (white cane travel, assistive technology, financial management, and emergency preparedness), and youth services (technological skill developments and IEP consultations). Located in Atlanta, the Center also offers support groups for those undergoing or living with vision loss.

<https://cviga.org/resources/>

The Department of Veterans Affairs – Blind Rehabilitation Services

The Department of Veterans Affairs provides blind and visual impairment rehabilitation services (BRS) to eligible veterans and active-duty service members. Veterans Affairs is the first and only national healthcare system to integrate rehabilitation services completely and seamlessly into its health benefits for patients with vision loss.

<https://www.rehab.va.gov/blindrehab/>

DisABILITY LINK

DisABILITY LINK's assistive technology programs and programs for the blind play critical roles in the assessment process and assisting consumers in setting their own goals to increase or maintain independence. Programs include braille training, computer instruction, orientation and mobility assistance, job development services, and outreach, referral, and resources.

<http://disabilitylink.org/deafblind-services>

Georgia Council for the Blind (GCB)

Affiliated with the American Council of the Blind, the Georgia chapter is a statewide membership organization promoting the social, economic, and educational betterment of individuals who are blind or visually impaired. This is done through peer support, public education, and an annual convention to offer timely and informative resources and tools. There are several chapters throughout the state (Athens, Augusta, Northwest, Savannah, Hall County, etc) for individuals to participate in events with the community.

<https://www.georgiacounciloftheblind.org/>

Georgia's Foundation Fighting Blindness

Georgia's Foundation Fighting Blindness drives research to provide preventions, treatments, and cures for people affected by retinal degenerative diseases such as LHON. Assistance is provided in learning about the disease and clinical trials, finding retina specialists, and connecting with others who are visually impaired.

<https://www.fightingblindness.org/chapters/atlanta-chapter>

Georgia Lions Lighthouse

The Georgia Lions Lighthouse offers a variety of free and low-cost vision services to uninsured or underinsured Georgia residents.

<https://lionslighthouse.org/>

The Georgia Vision Collaborative

The Georgia Vision Collaborative is a statewide coalition of public and private agencies addressing aging eye disease in Georgia. It helps individuals locate services such as low-cost eye exams, reduced cost eyeglasses, vision rehabilitation, low vision resources and programs specifically designed to enhance the quality of life for aging adults.

<https://www.georgiacollaborative.com/who-we-are/our-mission-values/>

Hadley

Hadley offers free online learning opportunities in assistive technology, daily living, recreation, employment, Braille, and other topics. Additionally, they offer podcasts and online discussion groups covering a wide array of topics.

<https://hadleyhelps.org/>

Lighthouse for the Blind and Visually Impaired

Lighthouse for the Blind is a private, not-for-profit social enterprise that has provided employment, support, and training opportunities for people who are blind since 1918. They offer a multitude of programs at their various locations throughout the United States including: Training on accessible technology, independent living and moving effectively with a cane, social and recreational activities, health and wellness, and Braille instruction.

<https://lhblind.org>

National Federation of the Blind of Georgia

The National Federation of the Blind (NFB) is the oldest and largest nationwide organization of blind Americans. Founded in 1940 and headquartered in Baltimore, the NFB consists of affiliates, chapters, and divisions in all 50 states. Through its network of blind members, it coordinates many programs, services, and resources, providing information and support to children and adults. It offers training and career mentoring, as well as scholarships and awards. Additionally, the NFB sponsors the Free White Cane Program, where any blind individual in the fifty states can request a cane for their personal use. Requests can be made as often as every six months.

<https://nfb.org/programs-services/free-white-cane-program>

Patient Advocate Foundation

The Patient Advocate Foundation (PFA) provides case management and assistance to patients with chronic, life-threatening, and debilitating illnesses, including help with insurance and financial issues. PFA case managers provide free 1 on 1 management for patients and families. Case management services include helping with accessing therapies and assistive devices, paying for living and treatments, finding employment, getting disability insurance, or helping with income.

<https://www.patientadvocate.org/>

Savannah Center for Blind and Low Vision

The Savannah Center for Blind and Low Vision offers programs and services that promote independence and dignity for people who are vision impaired or blind,

their family, friends, and the community. The Center serves 29 counties throughout southeast Coastal Georgia. Services are offered in the following areas: orientation and mobility, assistive technology, vision rehabilitation, social and peer support, youth, and job readiness, and placement. All services are customized to meet individual and personal goals and support the adjustments necessary for vision loss.

<https://savannahcbly.org/>

VisionAware

VisionAware is a free, easy-to-use informational service for adults with vision loss. They provide practical tips and resources for adults, their families, friends, caregivers, and related professionals. The information includes eye diseases and disorders, ways to connect with others through social media channels like Twitter and Facebook, the VisionAware blog, the 'Visually Impaired, Now What?' blog by Peer Advisors, and a searchable, free Directory of Services.

<https://visionaware.org>

Vision Rehabilitation Services of Georgia (VRS)

VRS assists individuals from Georgia who are blind or visually impaired to function independently through personalized rehabilitation services including help with work, school, and daily life. Services include low-vision evaluations, daily living skills training, orientation and mobility training, access technology training, job readiness, and personal adjustment counseling. VRS also offers a transition academy for young adults to help successfully transition from home and high school to the next phase of their lives in college or work. Individuals can also benefit from a variety of assistance tools such as magnifier reading devices, glare control, bump dots, writing guides, canes, and other adaptive equipment.

<https://vrsga.org/>

Visually Impaired Specialized Training and Advocacy Services (VISTAS)

VISTAS offers advocacy, support, and training services to visually impaired Georgians. Services include expanding public policy initiatives, daily living skills, workshops, computer instruction, braille instruction, cane instruction, and consumer training. VISTAS also offers the Project Independence Older Blind Program which offers Georgians aged 55 years and older free or reduced cost eye exams, canes, talking watches, canes, other assistive devices and

independent living training. The primary service delivery area includes Athens, the 10-county northeast Georgia area, and beyond.

<https://www.vistascenter.com/>

Walton Options for Independent Living

Walton Options for Independent Living, located in Augusta, GA, offers independent living services and advocacy for individuals with disabilities including those with visual impairments. They aim to promote equality, inclusion, and independence through personal choice, personal responsibility, community access, education and employment. Walton Options offers project independence which is a program administered by the Georgia Vocational Rehabilitation Agency and provides services that can help Georgians who are 55 years or older experience vision loss.

<https://www.waltonoptions.org/programs/ga-vision-program-for-seniors/>

ASSISTIVE TECHNOLOGY

Aira

Aira delivers instant access to visual information. Aira’s trained, professional agents remotely assist people who are blind or have low vision with virtually any task, all without a sighted assistant nearby. Through an app on your smartphone, you can connect with a trained Aira agent. Pick the plan that makes the most sense for you, sign up in a couple of minutes, and download the Aira app to your smartphone. Access agents on-demand for almost any task, take advantage of ride-share integration to get you where you need to be, and use one of the ever-growing list of free Aira Access offers to save you money while doing it. To discover all available free Aira Access offers, just tap on the “Search & Apply a Free Offer” button on the home screen of your Aira app.

<https://aira.io/>

Be My Eyes

Be My Eyes is a free app that connects blind and low-vision people with sighted volunteers and company representatives for visual assistance through a live video call. It works similarly to Aira. You connect via either an IOS or an Android app on your phone. During the call, you and a volunteer can communicate directly and solve a problem. The volunteer can help guide which direction to point your camera and what to focus on. A blind or a low-vision user may need help with anything from checking expiration dates, distinguishing colors, reading instructions or navigating new surroundings.

Additionally, Be My Eyes has recently introduced Be My AI, a state-of-the-art visual assistance tool that helps vividly describe images via the use of a phone app. Calls can still be escalated to a human, but this is only required in 10% of use cases.

www.bemyeyes.com

Seeing AI

Seeing AI is a free app developed by Microsoft that helps people with vision impairment convert visual info into audio. Optimized for use with the iPhone’s VoiceOver setting, the app enables you to recognize:

- Short Text – Speaks text as soon as it appears in front of the camera
- Documents - Provides audio guidance to capture a printed page, and recognizes the text, along with its original formatting
- Products - Scans barcodes, using audio beeps to guide you, allowing you to hear the name, and package information when available
- People - Saves people’s faces so you can recognize them, and get an estimate of their age, gender, and emotions
- Currency - Recognizes currency
- Color - Identifies color
- Handwriting - Reads handwritten text like in greeting cards
- Photo browsing experience - Describes photos on your phone

<http://SeeingAI.com>

Apple Pay

Once set up, Apple Pay is easy and works with your Apple devices. You can make contactless, secure purchases in stores, apps, and on the web. You can also send and receive money from friends and family. Apple Pay is safe, helping you avoid touching buttons or exchanging cash. For many people with low vision, it is often simpler and more secure than using a physical card. Apple Pay can be used at any store that accepts tap-to-pay, and at restaurants, vending machines, trains, and taxis.

Assistive Technology Fund

Operated by the Association of Blind Citizens, the ATF will provide funds to cover 50% of the retail price of adaptive technologies for the blind and visually impaired. An individual is eligible for this fund if they are legally blind, they have a family income less than \$50,000, and the products covered are between \$200 and \$6,000.

https://www.blindcitizens.org/assistive_tech.htm

Computers for the Blind (CFTB)

CFTB is a non-profit organization located in Richardson, Texas, devoted to providing refurbished computers with assistive technology to persons who are blind or visually impaired, at very low cost. There are no income or age requirements. There is a processing fee for a desktop or laptop with JAWS or ZoomText installed. Shipping is free in the United States.

<https://computersfortheblind.org/>

Friends of Disabled Adults and Children (FODAC)

FODAC provides home health equipment to people of any age or any disability including visual impairment for medically necessary and medically helpful reasons. FDOC recycles home medical equipment and assistive technology providing over \$10 million dollars annually in equipment and services to individuals with disabilities, which enhances their quality of life so they can attend school, keep jobs, and live independently. Clients do not have to qualify financially, but the waiting lists place a priority on medically necessary and low income individuals. FODAC's statewide partners include Northeast Georgia Area Agency on Aging, Multiple Choices, Walton Options, BAIN, Access2Independence, Disability Resource Center, Disability Connections, Cobb Senior Services, LIFE, and more.

<https://fodac.org/>

Georgia Tech Tools for Life Program

The Tools for Life lending library allows individuals with disabilities such as vision loss to learn about and try the assistive technology that best meets their needs. TFL staff provide free assistive technology device demonstrations to low vision individuals and their families considering assistive technology options. The lending library allows individuals to borrow and use assistive technology for a limited period without cost. All services are based out of the Georgia Institute of Technology campus in Atlanta.

<https://gatfl.gatech.edu/services>

DISABILITY INSURANCE

Family Medical Leave

Both federal (FMLA) and Georgia laws require covered employers to provide family and medical leave for eligible employees. These laws require employers to provide up to 12 weeks off in a consecutive 12-month period for the employee's serious health condition, or for the employee to care for a family member with a serious health condition. This leave need not be taken consecutively. In the state of Georgia, the eligibility requirements for FMLA are the following:

- Have been employed by the state of Georgia for at least a year
- Have worked at least 1,250 hours during the previous year
- Have an FMLA-qualified reason (i.e. care of family member with serious health condition)
- Have not used all available leave

Upon return from FMLA leave, an employee must be restored to his or her original job or to an equivalent job with equivalent pay, benefits, and other terms and conditions of employment. An employee's use of FMLA leave cannot be counted against the employee under a "no-fault" attendance policy.

<https://doas.ga.gov/assets/Human%20Resources%20Administration/FMLA/FMLA%20FAQs%20-%20revised%20April%202022.pdf>

Long-Term Disability Insurance

Long-term disability (LTD) insurance is a private insurance policy that protects an employee from loss of income if he or she is unable to work due to illness, injury, or accident for a long period of time. LTD insurance ensures that an employee will still receive a percentage of their income if they cannot work for an extended period. It can be provided and paid for by employers or individuals. Your employer may offer an LTD option. If a company doesn't offer LTD insurance or if an employee wants additional coverage, he or she has the option to purchase an individual LTD plan.

Some employers, if they do not provide LTD insurance, will develop a relationship with an LTD insurance company to offer an employee discount for their staff who choose to purchase an LTD policy.

LTD insurance provided by an employer may be inadequate to meet your needs. In this case, you might want to consider purchasing supplemental LTD insurance. Since it's expensive for an individual to purchase, LTD insurance is often available through an employee's professional associations at a discounted rate.

LTD insurance benefits usually begin when short-term disability insurance benefits end. Payments to the employee from their employer's LTD insurance (such as where the employer subsidized the premiums) are taxable income.

Payments from an employee-purchased plan, and/or where the employee paid premiums themselves on an after-tax basis, are usually not taxable income.

LTD policies sometimes have offset language. For example, a policy may require an employee to secure Social Security Disability Insurance. The insurance company will then reduce the amount of its payment by the amount SSDI is providing. If someone is collecting on an LTD policy and returns to work, the insurance payout may be reduced by some percentage of the amount earned. Since there are so many complexities to the LTD insurance process, consider hiring a lawyer familiar with LTD insurance to help navigate the process.

Each LTD insurance policy has different conditions for payout, diseases, or pre-existing conditions that may be excluded, and various other conditions that make the policy more or less useful to an employee. Some policies, for example, will pay disability benefits if the employee is unable to work in his or her current profession. Others expect the employee to take any job they are capable of doing. LTD payments to the employee, in some policies, have a defined period. Others pay an employee until he or she is 65 years old.

Consider your health history, your family's history of LHON, and any other diseases to determine the amount of long-term disability insurance that you need.

EDUCATION

Babies Can't Wait (BCW)

Babies Can't Wait (BCW) is an early intervention program that offers a variety of coordinated services for infants and toddlers with disabilities or special needs from birth to three years of age. BCW builds on and provides support and resources to assist family members and caregivers to enhance children's learning and development through everyday learning opportunities.

<https://dph.georgia.gov/babies-cant-wait>

Early Childhood

Early Childhood Special Education (ECSE) services are designed for young children (aged 3-5) with disabilities who need specially designed instruction or related services and whose disability causes the children to be unable to participate in developmentally appropriate typical preschool activities.

School districts are required by law to ensure that a developmentally appropriate ECSE program and services are available. ECSE programs and services ensure that all children with disabilities have a free and appropriate public education (FAPE) that is designed to meet their unique needs and enable them to make progress in acquiring knowledge and skills, improving social relationships, and learning to take action to meet their needs within the general education program.

School Age

If someone becomes affected by LHON while in elementary, middle, or high school, it is important to contact their school district immediately. A discussion with the school principal, or Section 504 coordinator at the school district, is often the best first step to address concerns.

Section 504 of the Rehabilitation Act of 1973, commonly called "Section 504," is a federal law that protects students from discrimination based on disability. This law applies to all programs and activities that receive funding from the federal government, including Florida public schools.

Under Section 504, students with disabilities are entitled to accommodations, aids, and services to access and benefit from education. Section 504 requires that public schools provide a "free appropriate public education" to every student

with a disability, regardless of the nature or severity of the disability. A counselor or coordinator works with the student and their family, teacher(s), and the school to develop an Individualized Education Program (IEP) to support and accommodate the student's needs.

For detailed information on Section 504, please see the Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools:

www.ed.gov

Georgia Academy for the Blind (GAB)

Georgia Academy for the Blind provides quality education services to Georgia's students with visual impairments and/or visual impairments in conjunction with other disabilities to prepare them to achieve their highest level of independence in transition to college and career readiness. Located in Macon, they offer assistance to local school systems and provide professional training through internship/fieldwork placement in orientation and mobility, rehabilitation counseling, social work, special education, vocational rehabilitation.

<https://www.gabmacon.org/>

Higher Education

If someone becomes affected at college-age or beyond and seeks to continue higher education, it's important to establish a relationship with the disability/accessibility center on campus. Most colleges and universities offer low-vision assistance and resources such as notetakers and priority registration, as well as other support services.

American Foundation for the Blind Digital Inclusion Toolkit

The American Foundation for the Blind offers many resources for navigating educational advocacy as a blind student, parent of a blind student, or teacher. They provide digital inclusion toolkits for each of these subgroups to ensure blind students can receive an equitable education.

<https://afb.org/research-and-initiatives/research/toolkits/digital-inclusion>

Nationally Available Scholarships

- NFB Scholarship Program: <https://nfb.org/programs-services/scholarships-and-awards/scholarship-program>

- College Scholarships: <https://www.collegescholarships.org/scholarships/blind.htm>
- Lighthouse Guild Scholarships: <https://lighthouseguild.org/support-services/academic-and-career-services/scholarships/>
- Christian Record Services Scholarship: <https://www.disabilityscholarships.us/disability-scholarships/unknown-blind-disability-christian-scholarship/289/>
- ACB Scholarship: <https://www.acb.org/scholarships>
- Learning Ally's National Achievement Awards: <https://learningally.org/naa>
- Financial Aid for Students with Disabilities: <https://www.bestcolleges.com/resources/students-with-disabilities-financial-aid/>
- For more information about educational resources and scholarships, visit the LHON website. www.lhon.org/living-with-lhon

Student Loan Forgiveness

A Total and Permanent Discharge (TPD) relieves you from having to repay a William D. Ford Federal Direct Loan (Direct Loan) Program loan, Federal Family Education Loan (FFEL) Program loan, and/or Federal Perkins Loan (Perkins Loan) Program loan, or complete a TEACH Grant service obligation, on the basis of your total and permanent disability. Before your federal student loans or TEACH Grant service obligation can be discharged, you must provide information to the Department of Education, Federal Student Aid Department, to show that you are totally and permanently disabled. The Department will evaluate the information and determine if you qualify for a TPD discharge.

If you think you might qualify and want to apply for a TPD discharge, you must complete a TPD discharge application and gather supporting documentation on your disability. Contact the Department to apply, either by phone: 888.303.7818 or by email: DisabilityInformation@Nelnet.net If you want to start your application online, go to:

<https://studentaid.gov/manage-loans/forgiveness-cancellation/disability-discharge>

If the Department approves your TPD discharge request, they will notify you and the holders of your loans and/or TEACH Grant service obligation of the approval. They will also instruct the loan holders to return any loan payments received after their disability date to the person who made the payments. Your “disability date” is the date they received the documentation of your SSA notice of award for SSDI or SSI benefits or the date the physician signed your discharge application, depending on the type of documentation you provided to show that you are totally and permanently disabled.

After being notified that the Department has approved your discharge request, your loan holders will transfer your loans and/or TEACH Grant service obligation to the Department for discharge. You will then be subject to a 3-year post-discharge monitoring period that begins on the date the discharge is approved. There are requirements that you must meet during the post-discharge monitoring period.

Note: The Department will reinstate your obligation to repay your discharged loans or complete your discharged TEACH Grant service obligation if at any time during the 3-year monitoring period you do not meet the requirements of the post-discharge monitoring period.

EMPLOYMENT

Disability Rights

The Americans with Disabilities Act of 1990 (ADA) is federal legislation designed to counteract bias and protect the rights of the disabled in the workplace. The ADA prohibits employers from discriminating against qualified individuals with disabilities. A disability is defined broadly as any mental or physical impairment that limits at least one major life function. Workers are deemed to be qualified to perform a job under the ADA, if they meet the educational and other requirements for the job and they can perform the job duties with or without reasonable accommodations.

Employment Assistance Programs

Many employers offer an Employee Assistance Program (EAP) that will include several visits to a mental health professional at no cost. Onset of LHON vision loss can have a significant impact on the mental health of the individual affected and their loved ones. An EAP is a valuable opportunity to try working with a mental health professional at no charge. Additional access to a therapist or counselor may be available through your health insurance, or at your local non-profit agency serving the blind and visually impaired.

Goodwill Services for People with Disabilities

Goodwill offers job placement and vocational training programs tailored to individuals with disabilities including visual impairments. Services include free career centers that assist you in searching for a job, writing a resume and building your job interview skills, rehabilitation programs that help you in your physical recovery, and assistance with your taxes through the Real Economic Impact (REI) partnership, which can provide up to \$5,000 in credits, if eligible.

<https://www.goodwill.org/goodwill-for-you/goodwills-support-and-employ-people-with-disabilities/>

Job Accommodation Network

The Job Accommodation Network (JAN) is a leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. JAN's consultants offer one-on-one guidance on workplace accommodations, the Americans with Disabilities Act (ADA) and related

legislation, and self-employment and entrepreneurship options for people with disabilities. Assistance is available both over the phone and online. JAN provides individualized consultation to assist:

- Individuals with medical conditions and disabilities seeking information about job accommodation solutions, employment rights under the ADA, and self-employment and entrepreneurship opportunities.
- Family members and rehabilitation, medical, educational, and other professionals in their effort to support successful employment outcomes for individuals with medical conditions and disabilities.
- Employers and their representatives seeking guidance on practical ways to engage in the interactive process, providing job accommodation solutions, and comply with Title I of the ADA.

www.askjan.org

MEDICAL INSURANCE

Medicare

Medicare is a national health insurance program administered by the Centers for Medicare and Medicaid Services (CMS). If you are aged 18 to 64, your eligibility for Medicare is tied to your eligibility for Social Security Disability Insurance (SSDI) benefits. You must qualify for and receive SSDI monthly income benefits to be eligible for Medicare.

Once you are approved for SSDI, you must wait 5 months for your income benefits to begin, and an additional 24 months before Medicare benefits begin.

Medicare covers only some of the healthcare expenses of those enrolled, and does not cover the cost of low vision devices. It is divided into four Parts. Medicare Part A covers hospital, skilled nursing, and hospice services, and has no cost. Part B has a cost, and covers outpatient services, outpatient hospital charges, most provider office visits, and most professionally administered prescription drugs. Your Part B cost can be deducted from your monthly SSDI and/or SSI benefit payment.

Enrollees can cover most of the remaining costs by taking additional private insurance and/or by joining a Part C Medicare health plan. Part C is an alternative to the combination of Parts A and B, called Managed Medicare or Medicare Advantage, which allows patients to choose health plans with at least the same service coverage as Parts A and B. A beneficiary must enroll in Parts A and B first before signing up for Part C. Part D covers most self-administered prescription drugs.

Medicaid

Georgia offers a state-sponsored health insurance program known as Medicaid. The program provides health coverage to people with low income and low asset levels who meet certain eligibility requirements. Many people who become affected by LHON at a young age are not eligible for Medicare benefits because they don't have the work credits to qualify for Social Security Disability Insurance (SSDI) benefits. More information can be found at the department's website:

<https://medicaid.georgia.gov/>

Genetic Testing

There are several ways to make LHON genetic testing cost-effective:

Obligate Carrier/On the Maternal Bloodline

It is first helpful to understand the genetic transmission of a LHON mutation. LHON is maternally inherited, and a woman who carries a LHON mutation usually passes that mutation to all of her children.

If someone on your maternal bloodline had genetic testing done and has a confirmed diagnosis of their LHON mutation, you can reasonably assume that you're an "obligate carrier." This means that based on genetics, you carry the same LHON mutation. You can presume you carry that LHON mutation without doing any genetic testing, which is the least expensive option. Also, there are no test results in your medical records that could impact your future insurance choices.

If you're an obligate carrier and would prefer to have your own genetic testing done to confirm your genetic status, you can save money by testing for just the specific mutation in your family. Most LHON genetic testing is a panel that tests for multiple LHON mutations at one time. However, if you have a copy of your maternal relative's LHON genetic test results, you can get testing done for that single, targeted mutation. The cost is far less expensive than the broader panel test.

First in Family

If you're the first in your extended maternal family to become affected by LHON and/or to get genetic testing done, there are ways to limit the cost, including the following:

- The Carver Lab at the University of Iowa is a non-profit lab, so the cost of a LHON panel test is usually much lower than at for-profit labs. Note that they batch their testing, so the turnaround time is slower than other labs.
<https://www.carverlab.org/>
- Athena Diagnostics offers the Athena Alliance Program. This is a financial assistance program for those with low income.
www.AthenaDiagnostics.com

- GeneDx offers a Financial Assistance Program and accepts all commercial insurance, Medicaid, Medicare and Tricare plans.
www.genedx.com/tests/billing
- Probably Genetic offers free at-home testing. www.probablygenetic

SOCIAL SECURITY

Social Security Disability Insurance (SSDI)

SSDI provides benefits to disabled persons (including those who are legally blind) who are “insured” by workers’ contributions to the Social Security trust fund. These contributions are based on your earnings (or those of your spouse or parents) as required by the Federal Insurance Contributions Act (FICA). Your dependents may also be eligible for benefits from your earnings record. Adults who have been disabled since childhood may qualify for SSDI on a parent’s record even if they never have worked.

SSDI is different from the Supplemental Security Income Program (SSI). SSDI is funded through FICA and Social Security taxes; SSI is financed through general tax revenues. Also, the qualifications for SSDI and SSI differ.

SSDI will help if you are severely disabled and can’t be employed in your field of work, have a history of work, have paid into Social Security in prior work years, and have a medical issue that meets the Social Security disability guidelines (such as legal blindness). Blindness is defined as central visual acuity of 20/200 or less in the better eye with best correction, or a limitation in the field of vision in the better eye so that the widest diameter of the visual field subtends an angle of 20 degrees or less. Under SSDI, this condition has to have lasted or be expected to last at least 12 months.

SSDI is an earned benefit, based on your work record. In order to qualify, you need to have worked for a minimum amount of time, depending on your age when you become disabled. Your benefit amount can be higher or lower depending on your income history and work duration.

Qualification for SSDI is primarily based on two things: documenting a disability, and an evaluation of your work history. The Social Security Administration (SSA) looks at your recent work history, and how long you’ve worked. There is also an earnings test, if you’re still working. If you’re still able to work, and you earn over a certain amount, you aren’t considered disabled.

Benefit amounts vary dramatically based on each individual’s work record. The SSA uses a weighted formula to calculate disability benefits. To get an estimate,

view your Social Security statement by creating an account on <https://www.ssa.gov/>.

SSDI can be applied for online at <https://www.ssa.gov/>. The SSA will review your application and supporting documents and make a decision as to whether or not you qualify as disabled, and if you do, whether or not you're eligible for benefits.

You can speak with an SSDI representative by calling your local Social Security office or the national number (1-800-772-1213). Specific locations can be found at <https://www.ssa.gov/locator/>.

Note: If you receive SSDI benefits and become employed, it is important to pay close attention to the amount of income you earn in relation to the maximum monthly income allowed for a blind individual to earn and to continue to receive SSDI benefits. If your monthly income exceeds the monthly allowed amount, SSDI does not automatically stop sending your monthly benefit amount. They will review your case from time to time, and if they determine that you have received benefits to which you were not entitled, they will send a letter demanding repayment. This can be for a significant amount, and can be an extremely unpleasant situation to be in.

Supplemental Security Income (SSI)

Unlike Social Security Disability Insurance (SSDI), which is based on work experience, Supplemental Security Income (SSI) is a program based on need. Eligibility for SSI does not depend on whether or not you worked and paid into the Social Security system. In order to qualify for SSI benefits, your income and resources must be below a certain amount.

SSI qualification is based on your resources and is available to people who are disabled (including legally blind), or over 65. The SSI program makes cash assistance payments to aged, blind, and disabled persons (including children) who have limited income and resources. The Federal Government funds SSI from general tax revenues. Many states pay a supplemental benefit to eligible persons in addition to their Federal benefits.

To apply for SSI, you can begin the process and complete a large part of your application by visiting their website at <https://www.ssa.gov/apply>. You can also call them toll-free at 1-800-772-1213 to set up an in-person or telephone appointment with a representative from your local Social Security office. Do not

wait to apply. If you believe you're eligible for SSI, contact SSA right away. The earliest they will pay SSI is the month after the filing date of your application, or the month after you first meet all the eligibility requirements, whichever is later.

<https://www.ssa.gov/apply>

Note: As with SSDI, if you receive SSI benefits, it is important to pay close attention to the amount of income you earn and your assets in relation to the maximum allowed. If your monthly income exceeds the monthly allowed amount, or if in any month your assets exceed the maximum allowed amount, SSI does not automatically stop sending your monthly benefit amount. If you ever request to stop receiving SSI benefits, they will review your case. If they determine that you have received benefits to which you were not entitled, they will send a letter demanding repayment. This can be for a significant amount, and can be an extremely unpleasant situation to be in.

<https://www.ssa.gov/ssi>

Employment Supports

There are many provisions designed to assist you in becoming self-sufficient through work. The Social Security Red Book discusses each of these provisions, including Blind Work Expenses (BWE), Impairment-Related Work Expenses (IRWE), Trial Work Period (TWP) and many others.

<https://www.ssa.gov/redbook/Advice>

Protection & Advocacy for Beneficiaries of Social Security (PABSS)

Provides advocacy and legal services to help social security beneficiaries facing challenges related to employment or benefits issues. The Ticket to Work and Work Incentives Improvement Act of 1999 authorized incentives assistance program grants to the designated Protection and Advocacy (P&A) system in all 50 states.

<https://www.ssa.gov/work/protectionadvocacy.html>

TRANSPORTATION

Disabled Person Parking Permits

A qualified disabled person may obtain a Disabled Person Parking Permit. If someone is determined to be blind according to Georgia law, they are eligible for a permit. Permits can be moved from one vehicle to another, making them a good option for someone affected by LHON who rides in various cars. One is eligible for a permit in Georgia if a healthcare professional certifies that the applicant has “a severe visual impairment.” Applications can be found at

<https://dor.georgia.gov/disabled-persons-license-plates-and-parking-permits>

Discounted Public Transportation

In many municipalities, a rider with a qualifying disability, such as legal blindness, can apply for a discounted regional transportation fare card for buses, subways, streetcars or ferries, depending on local rules. In most cases, you can load a cash value on the card, which will be deducted automatically upon usage. To apply for a discounted transit card, contact your local transit authority. You will usually need to fill out a form and have your doctor sign it.

Paratransit

Paratransit is a transportation service for individuals with disabilities who are unable to use public transportation services. A transit agency must provide paratransit service within 3/4 of a mile of a bus route or rail station. This service must be available on the same days and at the same hours as regular transit services. You may have to pay a higher fare for paratransit services, but this fare cannot be more than double the regular fare. You're eligible for paratransit service if you're unable to use public transit because of your disability.

Demonstrating legal blindness is usually adequate to establish eligibility. Contact your local transit agency to request access to your local paratransit service. The transit agency may ask you to support your request for paratransit services with a letter from your doctor. Once approved, you can schedule trips by following your transit agency's scheduling process. Transit agencies are required to offer next-day service, and they must agree to pick you up within an hour of the time that you requested.

Ridesharing Services

The two largest ridesharing services are Uber (www.uber.com) and Lyft (www.lyft.com). Both utilize software and smartphone technology to assist visually impaired riders to get from place to place. Both services offer: cashless options to simplify the payment process, reducing the need for riders to worry about counting out cash or exchanging bills with a driver; on-demand transportation so riders no longer have to pre-arrange trips through dispatchers or paratransit options; upfront pricing so riders know the cost of their trip before requesting the ride; the ability to share the rider's ETA and location with friends or family members; and service animal policies which require drivers to comply with all applicable laws regarding the transportation of service animals.

Additionally, rideshare companies have been partnering with the National Federation of the Blind (NFB) and Lighthouse for the Blind to increase awareness of blind passengers' rights, advocate for effective public policies, and expand transportation options for passengers who are blind or have low vision. They are working to make their apps more accessible and inclusive.

GoGoGrandparent

Now available in all 50 states, GoGoGrandparent offers on-demand ridesharing services, as well as grocery and meal delivery for seniors and people with disabilities. GoGoGrandparent leverages the existing population of Uber and Lyft drivers but manages them within GoGo's own organization. Rides are ordered via a simple phone call to the customer service number, operated 24/7. No smartphone or computer needed.

To use GoGo, you must create an account. They offer a variety of plans and pricing levels depending on your needs.

Note: Some municipalities in the country have contracted with GoGo to offer free or discounted rides as part of their disability services, so check in the city where you live.

<https://get.gogograndparent.com>

Air Travel

People with visual impairments are protected via rules that all airlines are required to follow, however, specific methods can differ from airline to airline. While airport personnel should always accommodate requests for assistance at

the airport itself, making arrangements in advance can help save time, travel headaches and delays.

When making your reservation, contact the airline's disability support desk; they often have a dedicated phone number. Your reservation can be marked to let the ground staff and onboard personnel have all the information they need to facilitate any special arrangements you may require such as transportation to your gate and upon arrival at your destination, as well as assistance regarding your baggage and ground transportation. This information can also be entered into a reservation online.

Additionally, some airlines' disability support desks can waive seat assignment fees, and/or provide a lower cost fare for a companion who may be traveling with you to provide assistance. Check with your airline to see what specific services they provide.

Miracle Flights

Some people affected by LHON want to travel to a distant location to see a LHON specialist, but find the travel cost prohibitive. One option to consider is Miracle Flights, the nation's leading medical flight charity and one of the only national non-profits. They arrange more than 600 flights every month to medical facilities across the country for children aged 17 and under. Miracle Flights also assists individuals with flights to retrieve or train a service dog.

www.miracleflights.org

Amtrak

Amtrak offers a 10% rail fare discount to adult passengers with a disability. Child passengers with a disability are eligible for the everyday 50% child discount plus an additional 10% off the discounted child's fare, regardless of the service on which they travel. Amtrak also offers a 10% discount for persons traveling with a passenger with a disability as a companion. Those designated as a companion must be capable of providing the necessary assistance to the passenger with a disability. Just select 'Passenger with Disability' or 'Companion' for each passenger as appropriate in Fare Finder at the beginning of your search to receive the applicable discounts.

You must provide written documentation of your disability at the ticket counter and when boarding the train. Acceptable documentation includes a transit

system ID card for persons with a disability, membership card from a disability organization, letter from a physician, Medicare card (if under 65), or a Disabled/Accessible parking placard issued by a state Department of Motor Vehicles (photocopy is acceptable).

www.amtrak.com/passengers-with-disabilities-discounts

TRAVEL & LEISURE

Audiobooks and Periodicals

Bookshare

Bookshare is an ebook library where members can access a collection of over 1,109,245 titles. It includes books for school, career, and reading pleasure, as well as titles in over 34 languages. Thanks to funding from the Office of Special Education Programs (OSEP) in the U.S. Department of Education, Bookshare is free for all qualified U.S. students and schools. Qualified individuals who are not students pay a nominal annual fee for their membership. To qualify, you will need to provide a proof of disability form signed by a qualified expert such as an ophthalmologist.

www.bookshare.org/cms/get-started/sign

Braille and Audio Reading Download (BARD)

BARD is a free online service run by The National Library Service for the Blind and Print Disabled (NLS) that allows you to download books and magazines instantly.

To use BARD, you must be an NLS patron and fill out an application. Once approved, you can download the BARD mobile app for either IOS or Android at no cost.

www.loc.gov/nls

Georgia Library Service for the Blind and Print Disabled

Georgia Library Service for the Blind and Print Disabled (GLS), a division of the Georgia Public Library Service, is a free library service for Georgia residents of any age who are unable to read standard print due to a visual, physical, or reading disability. Although physically located in Atlanta, GLS serves the entire state, offering books and magazines in Braille or audio formats through postage-free mail or via download.

<https://gls.georgialibraries.org>

Georgia Radio Reading Services (GaRRS)

Every month GaRRS broadcasts and streams hundreds of programs including local and national newspapers, books, magazines, events, employment

opportunities, and shopping ads for individuals who are visually or print impaired. The programming is broadcast 24 hours a day, 7 days a week and accessed by using an Amazon Alexa Dot, special radio, through our online web stream, by telephone, or by using a mobile app.

<https://garrs.org/>

Libby by OverDrive

The Libby app is a free downloadable audio book borrowing service that works with any public library using OverDrive. Over 90% of public libraries in North America have OverDrive. To utilize Libby, you need a library card from your local OverDrive-enabled library. Once downloaded, the Libby app works with Windows 10, IOS, or Android. The app can be downloaded from your preferred app store.

www.overdrive.com

NFB-Newsline

Anyone who cannot read printed publications due to vision loss is eligible to receive NFB-NEWSLINE; a free audio news service offering access to more than 500 publications, emergency weather alerts, job listings, and more.

www.nfb.org/programs-services/nfb-newsline

Georgia State Parks Accessibility

All Georgia State Parks can be accessed through a \$5 a day parking pass. All lodges have accessible rooms, meeting areas, and restaurants. The Will-A-Way Recreation Area at Fort Yargo State Park, operated by Camp Twin Lakes, is a fully accessible group camp accommodating up to 250 people. More popular hard-surface trails can be found at Amicalola Falls, Tallulah Gorge, Panola Mountain, and Red Top Mountain.

<https://gastateparks.org/>

National Parks Access Pass

The National Parks Access Pass is a free, lifetime pass available to U.S. citizens or permanent residents, regardless of age, that have a permanent disability. It can be used at over 2,000 Federal recreation sites across the nation, including National Parks, National Wildlife Refuges, and many National Forest lands. Discounts offered by the Pass vary widely across the many different types of recreation sites. Pass owners are encouraged to check with sites they plan to

visit before obtaining a Pass to verify that their Pass will be accepted. Any time a Pass is used, photo identification will be requested to verify Pass ownership.

The Pass may be obtained at certain federal recreation sites, through the mail, or online. To obtain a Pass you must have identification to verify that you are a U.S. citizen or permanent resident as well as documentation that you have a permanent disability. Showing a state motor vehicle department disability sticker, license plate or placard is not acceptable documentation.

If you apply for an Access Pass at a Federal recreation site you do NOT need to fill out an application. Upon arrival, the officer will verify your documentation of disability and that you are a U.S. citizen or permanent resident by checking your ID. You will then be issued the Pass.

The Pass is free if obtained in person, and there is no processing fee. Before making a trip to obtain a Pass, be sure to contact the site to ensure that they have Passes available. To obtain an Access Pass through the mail or online, you must complete an application, provide a photocopy of proof of citizenship or residency, documentation of disability, and pay the processing fee. The cost of obtaining an Access Pass through the mail or online is \$10 for application processing (the Pass is free).

<https://www.nps.gov/subjects/accessibility/interagency-access-pass.htm>

Fishing License

Georgia residents with a valid Georgia Driver License or ID can apply online for a Resident Persons with Disabilities License, which includes saltwater fishing, freshwater fishing, and hunting licenses. To apply online, visit the fishing license website at:

<https://georgiawildlife.com/licenses-permits-passes/disability>

Sports

There are many ways to save money while participating in sports with LHON vision. For instance, many ski areas provide a free pass to a guide for a visually impaired skier. Check with your local ski area for more information.

Challenged Athletes Foundation (CAF)

Offers grants to athletes with any disability including vision loss to support their athletic activities. www.challengedathletes.org

Dare2Tri

Provides opportunities for people with physical disabilities and/or visual impairments to develop skills in the sport of Para triathlon.

<http://www.dare2tri.org/>

Georgia Lions Camp

Provides a transformative outdoor experience for individuals living with a visual impairment to foster independence, self-confidence, and lifelong friendships while cultivating a spirit of adventure, personal growth, and inclusion in an empowering, supportive environment. They run summer youth and adult programs. Individuals participate in various outdoor pursuits such as biking, swimming, and horseback riding, all within a secure and nurturing setting.

<https://glcb.org/>

National Ability Center

Provides adaptive sports opportunities, often at low/no cost to the vision impaired. www.discovernac.org

Ski for Light

An all-volunteer, non-profit organization whose mission is to teach visually- and mobility-impaired adults the sport of classic cross-country skiing. www.sfl.org

United States Association of Blind Athletes

A good source of information on sports that may be available in your area is the United States Association of Blind Athletes. www.usaba.org

Theatre Discounts

Many theatres throughout the country offer discounts and often special seating for the blind. Many also offer special performances with a live AudioDescriber. Check with the theatres in your area.

TAX TIPS

Several aspects of federal tax law apply specifically to individuals considered to be legally blind (vision is 20/200 or less in the best eye). Some of those deductions are described below, but check with the IRS or your local tax preparer for comprehensive information.

Deduction for the Legally Blind

Legally blind federal tax filers can claim unique deductions. This translates into a larger tax break, allowing you to subtract a bigger standard tax deduction from your adjusted gross income. Married filers also benefit from this deduction when their spouse is visually impaired. If you're blind and over age 65, your savings increase.

Impairment-Related Work Expenses

You may require special equipment or accommodations as an employee or self-employed individual. The tax code allows you to subtract expenses for things you must have in order to work. Called impairment-related work expenses, they appear as unreimbursed employee expenses on the Schedule A form used for itemizing.

Minimum requirements for the dollar amount do not apply to blind filers. Impairment-related work expenses you might have, provided you don't count them under medical expenses, include the following: computer attachments for Braille display and typing, electronic visual aids, high-speed Internet connection, modifications to your home, software that provides synthetic voice description, and reader services.

Medical Deductions for the Blind

The law allows you to deduct what you spend to prevent, diagnose, or treat illness, as well as any costs related to your blindness or visual impairment. As with any taxpayer, the total of both types of medical expenses must be more than 10% of your adjusted gross income before you can claim a deduction.

Transportation to and from a doctor's office, prescriptions, insurance premiums, and tests are examples of accepted medical deduction expenses, as are disability-associated items such as Braille magazines and books (costs that

exceed regular print versions), Braille printers, eyeglasses, eye exams, eye surgery, guide dog, and all related costs and home modifications.

Tax Preparation Assistance

Blind or low vision people are eligible for tax preparation assistance from their local IRS office, or through the Volunteer Income Tax Assistance Program (VITA) sponsored by the IRS. Taxpayers can find a nearby IRS office location by calling 1-800-906-9887.

MISCELLANEOUS

Leader Dogs for the Blind

Leader Dogs is an organization that aims to enhance the mobility, independence, and quality of life for the visually impaired through their services that range from matching with a Leader Dog to white cane training. Through their guide dog training services, clients have the opportunity to train with their guide dog in a variety of situations to fit current and future lifestyle needs. Their services are provided at no cost and their program will cover expenses for training, room and board, and travel to their campus.

<https://www.leaderdog.org/>

Low-Cost Grocery Delivery

Amazon offers an unlimited grocery delivery service in conjunction with Amazon Fresh and Whole Foods. The service costs \$10 a month for Prime members and \$5 a month for those with a registered SNAP/EBT card. The program includes free unlimited grocery deliveries on orders over \$35 from Amazon Fresh, Whole Foods, and a select number of specialty retailers including Cardenas Markets, Rite Aid, Pet Food Express, and Mission Wine & Spirits.

<https://www.amazon.com/dp/B0CJ9DGD6N/>

Avoiding Unnecessary Medical Care

The diagnostic odyssey for LHON can be extremely expensive, including many tests to rule out other, more common causes of sudden vision loss. Many individuals have spent thousands of dollars on tests and treatments for diseases they did not have (Brain Tumor, Optic Neuritis, MS, NMO, etc.). They and/or their loved ones have lost time from work for these appointments, and have spent money traveling to a range of specialists trying to get the correct diagnosis. If LHON vision loss begins when an individual knows they carry a LHON mutation, they can avoid all of these costs, and go directly to a LHON specialist for care. This is one of many reasons why people in the LHON community tell their maternal relatives about LHON. While it can be difficult information to share, there can be great value. There are several videos and links in the Genealogy section of the LHON.org website that can help in identifying maternal relatives, and preparing to share the information.

Since there are no approved treatments for LHON, patients and their families can be vulnerable to unproven, experimental and expensive “treatments”. It’s important to avoid clinics that claim to offer “clinical trials” that require payment by the patient to participate. Legitimate trials will not require patient payment.

<https://www.lhon.org/living-with-lhon>

General Financial Support

Many in the LHON community have been creative in finding financial support. Local service organizations are often willing to assist those in need, in particular Lions Clubs which have a specific mission to serve those with vision loss. College fraternities and sororities often do fundraising and are willing to provide support, especially the Delta Gamma (DG) sorority whose philanthropy is Service for Sight. GoFundMe.com is a fundraising platform on which individuals can describe their financial hardship or need, then share the link with family and friends to crowd source donations.

This document is intended as a general guide only. It was developed by LHON volunteers and is subject to change. It does not purport to provide legal, financial or tax guidance. You should check with each listed provider and your own advisors for your specific situation.