LHON Collective

A Guide to Navigating LHON with Money in Mind

Information & Resources for the New York LHON Community

Updated May 2026

Purpose

Individuals who carry a 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 California LHON community become familiar with resources that can limit negative financial impacts. 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.

We gratefully acknowledge the volunteer efforts of the student and faculty of the University of Notre Dame Patient Advocacy Initiative without whose time and energy, this document would not be possible.

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TRAINING & TECHNICAL RESOURCES

New York State Commission for the Blind

The New York State Commission for the Blind (NYSCB) aims to assist in the development of the capacities and strengths of people who are legally blind or visually impaired in New York. They provide vocational rehabilitation, educational services, and resources and assistance in areas such as employment, assistive technology, and independent living skills.

American Council of the Blind New York

American Council of the Blind New York (ACBNY) is the state affiliate of The American Council of the Blind. Its purpose is to support and promote the educational, vocational and social advancement of blind and visually impaired people. The affiliate is made up of local chapters, organized throughout the state.

Aurora of Central New York

Aurora is a non-profit organization which seeks to improve the quality of life and promote independence and opportunity for Central New Yorkers by serving people who are blind or visually impaired. They offer resources such as assistance, advocacy, and educating individuals. Individuals receive employment and vocational support, interpretation services, and emotional skill development.

Foundation Fighting Blindness

The Greater New York Chapter — 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.

GoodWill Vision Enterprises

GoodWill Vision Enterprises (GVE), previously known as the Association for the Blind and Visually Impaired (ABVI), provides programs to teach and help anyone who is blind or visually impaired live an independent and meaningful life. Programs include low vision services, orientation and mobility services, and vision rehabilitation therapy all available by appointment.

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.

Lighthouse Guild

The Lighthouse Guild offers comprehensive services for people who are blind or visually impaired, including healthcare, support, rehabilitation, and technology training. They aim to help individuals achieve their goals and lead productive, independent lives.

Lions Club International

With over 50 Lions Clubs active in New York, Lions Club has a long history of serving the blind and visually impaired. They offer services and support through vision screening, support groups, social gatherings, and grants.

National Federation of the Blind of New York

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 and low vision 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 or low vision individual in the fifty states, the District of Columbia, or Puerto Rico can request a cane for their personal use. Requests can be made as often as every six months.

New York State Preferred Source Program

New York State Preferred Source Program's mission is to create diverse employment opportunities and upward mobility for New Yorkers who are blind. NYSPSP and our network of affiliated nonprofit agencies are one of New York's top resources for employment opportunities for people who are blind.

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 expenses and treatments, finding employment, getting disability insurance, or helping with income.

The Department of Veterans Affairs

The Department of Veterans Affairs – Blind Rehabilitation Services 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.

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. Information includes: eye diseases and disorders, ways to connect with others including social media channels like Twitter and Facebook, the VisionAware blog, "Visually Impaired, Now What?" Blog by Peer Advisors as well as a searchable, free Directory of Services.

VISIONS

Vision Service Corps (Services for the Blind and Visually Impaired) is a nonprofit rehabilitation and social service organization serving blind and visually impaired individuals in New York City, Long Island, Westchester, and the Lower Hudson Valley. Their mission is to develop and implement individualized programs for the blind and visually impaired and to educate the public to understand their capabilities and needs. They provide free services including vision rehabilitation, job training, family sessions, and social work support. All legally blind and visually impaired persons sponsored by their state commission for the blind are eligible for residential short-term training at VISIONS Center on Blindness (VCB).

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 are available on-demand for almost any task, take advantage of rideshare 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. Aira Access currently comes in three forms:

- Limited and on-going promotions that provide free access to Aira agents, such as the Intuit QuickBooks Small Business Owners promotion.
- Products free to use for tasks that involve using certain products like Vispero's JAWS screen reader.
- Locations free to use while in a growing number of locations like Wegmans, Walgreens, AT&T stores, airports, and federal buildings.

Aira also offers a free option to anyone who has an Aira account (regardless if they're on a plan or not) and resides in a country where Aira provides full service (USA, Canada, UK, Australia, and New Zealand). People without a monthly subscription receive one free call every twenty-four hours and people with a plan receive one free call every four hours.

Alexa

Alexa is a virtual assistant developed by Amazon, powered by artificial intelligence and voice recognition technology. It primarily operates through Amazon's Echo devices and other compatible hardware, allowing users to interact via voice commands.

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.

Blindsquare

BlindSquare is a widely used, accessible GPS app designed for blind, deafblind, and partially sighted individuals to aid with orientation and mobility. Available on iOS (and recently Android via XploreNinja), it uses GPS and compass technology to determine the user's location, gathering environmental data from Foursquare and OpenStreetMap. The app employs algorithms to prioritize relevant information, delivering it through high-quality speech synthesis (Acapela voices) or VoiceOver.

Hey Google

Hey Google is a virtual assistant developed by Google, powered by artificial intelligence and voice recognition technology. It primarily operates through Google speaker devices and other compatible hardware, allowing users to interact via voice commands.

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

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.

Computers for the Blind

Computers for the Blind (CFTB) is a non-profit 501(c)(3) organization is 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. The processing fee for a desktop or laptop with JAWS or ZoomText installed (as of October 2020) ranges from $130 to $185. Shipping is free in the US. Certain upgrades are available, and details are on the following PDF fact sheet.

Free Screen Readers

NonVisual Desktop Access (NVDA) is a free, open-source screen reader for Microsoft Windows. It's an excellent, cost-free alternative to commercial software, providing complete spoken access to a computer.

TapTapSee

TapTapSee is a free mobile application that uses a phone's camera to photograph everyday objects and speak the object's identity back to the user. It is a simple, effective, and cost-free tool for object recognition.

DISABILITY INSURANCE

New York State Paid Family Leave

In 2016, New York enacted one of the nation's strongest and most comprehensive Paid Family Leave policy so working families would not have to choose between caring for their loved ones and risking their economic security.
Paid Family Leave provides eligible employees with job-protected, paid time off to care for a family member with a serious health condition. It provides job protection, continued health insurance, and protection from retaliation or discrimination.

Family Medical Leave

Both federal (FMLA) and New York 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 Indiana, the eligibility requirements for FMLA are the following:

- Have worked for the company for at least a year
- Worked at least 1250 hours in a 12-month period immediately preceding the request or start of FML absence.
- Has not already exhausted allotment of FML for current fiscal year.

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. New York State Paid Family Leave

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

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 ESCE 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.

New York Institute for Special Education

The New York Institute for Special Education (NYISE) is a nonprofit, educational facility which provides quality programs for children who are blind or visually impaired, emotionally and learning disabled, and preschoolers who are developmentally delayed. The NYISE maintains the Blindness Resource Center which offers numerous links related to resources for people with visual impairments on braille literacy, vision support, independent living, and assistive technology.

School-Age

If someone becomes affected by LHON while in elementary, middle, or high school, it is important to immediately contact their school district. The school district should have a Visual Impairments (VI) or Special Education department who will work with the student and their family, their teacher(s), and the school to develop an Individualized Education Program (IEP) to support and accommodate the affected student.

The educational accommodations for a student affected by LHON can raise financial questions. The California education system provides extensive support to students who are visually impaired through their school district and/or the California Department of Rehabilitation (DOR). The financial costs associated with accommodations necessary for the student to be successful in the school system will generally be absorbed by the school district/DOR. Funding for VI programs within the California school district comes from the DOR and affected students and their families do not have to cover the costs associated with educational accommodations. Keep in mind that it will be necessary for families to provide medical documentation that establishes the student as being legally blind to receive the support and accommodations at no cost.

Students who are visually impaired are provided with a variety of educational options covered by the state including but not limited to, general education classes with itinerant VI teacher(s), appropriate reading material that meets their individual needs (i.e. Braille, tactile materials, recorded books, large print), and more.

Affected students are able to receive: Orientation and Mobility (O&M) training to develop safe travel skills, an expanded core curriculum, standardized testing assessments to ensure that appropriate grade-level expectations are being met, and assessments of their vision to provide adequate assistive technology and the training associated. If it is determined the student needs specific assistive technology such as a CCTV, ZoomText, JAWS, BrailleNote, and more, the school district will cover the costs associated with the technology. As the equipment evolves and upgrades become available, the student will be eligible to receive the updated/upgraded equipment and tools.

Staff who belong to the VI/Special Education department in the school district (administrators, teachers, and support staff) are appropriately credentialed to make sure that the student's visual impairment needs are met and those appropriate accommodations are available for the student to excel. VI staff are also responsible for ensuring that the CA Braille reading and math standards are met by the student.

NYC Department of Education

The NYC Department of Education – Blindness and Low Vision Support provides educational support and resources for students who are blind or have low vision, ensuring they receive appropriate accommodations and services within the school system.

Higher Education

If someone is affected at a college-age or beyond and seeks to continue higher education, it is important to establish a relationship with your local DOR and the Disability/Accessibility center at your campus. Most colleges and universities offer low vision assistance and resources such as notetakers and priority registration, as well as other support services.

The first step to request services and support from the MI DOR is to complete and sign the Vocational Rehabilitation Services Application and provide the DOR with any pertinent information to begin the assessment which will determine eligibility and priority status. The Blind Field Services (BFS) department at DOR and its staff work with blind or visually impaired persons to obtain educational and employment opportunities. The services and support that BFS provides to affected individuals is unique and tailored to meet the individual's specific needs. In order to begin an educational path supported by the DOR/BFS, the affected individual must begin a relationship with their assigned case manager after their application has been approved. The individual's case manager will work closely with the affected individual to determine what accommodations are necessary to receive educational support. The affected individual will share their higher education goals with their case manager to best determine the support and services they will need from DOR to become academically successful.

First, the case manager and affected individual will work together to determine what assistive technology and equipment are necessary for academic success. Based upon application approval and household income, the amount for shared costs for equipment will be provided for affected individuals who require assistive technology for educational purposes (i.e. CCTV, laptop, SenseView, accessibility software, and more). Regardless of household income, training for necessary assistive technology and vocational training is provided.

Further educational support from the DOR ranges from tuition support to textbook fee assistance, and the shared cost amount is determined based on the individual's household income. It is imperative to establish a relationship with the DOR as quickly as possible as there may be a waiting list for some types of support that are necessary for educational success.

The support that the DOR/BFS can provide varies from student to student based on their educational needs, goals, and financial status. It is crucial to develop a relationship with the assigned case manager to be aware of the financial support an affected individual is able to receive.

For those interested in higher education, it should be noted that there are scholarship opportunities available to those with visual impairments on the Living with LHON webpage.

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.

Learning Ally

Learning Ally is a national non-profit offering a large library of human-narrated audiobooks, providing K-12 and college-level textbooks and literature in an accessible format for students with visual or learning disabilities. There is a low-cost subscription, often covered by schools.

Nationally Available Scholarships

- NFB Scholarship Program
- College Scholarships
- Lighthouse Guild Scholarships
- Christian Record Services Scholarship
- ACB Scholarship

- Learning Ally's National Achievement Awards
- Financial Aid for Students with Disabilities
- LHON.org

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. Start an application online.

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 that addresses bias and protects the rights of people with disabilities 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 qualified to perform a job under the ADA if they meet the job's educational and other requirements and can perform the job's 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. The 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.

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 professionals in rehabilitation, medical, educational, and other fields are working to support successful employment outcomes for individuals with medical conditions and disabilities.
- Employers and their representatives seek guidance on practical ways to engage in the interactive process, provide job accommodation solutions, and comply with Title I of the ADA.

MEDICAL INSURANCE

Coordinated Care Services

The Coordinated Care Services Facilitated Enrollment for Aged, Blind & Disabled is a state-sponsored insurance application assistance program, educating and assisting New Yorkers with navigating public health insurance programs. They assist with applying for various Medicare and Medicaid programs. This organization can help apply for Medicaid, Medicare Savings Programs, Medicaid Excess Income Programs, and Medicaid Buy–In for Working People with Disabilities through one-on-one private counseling about public health options.

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, that allows patients to choose health plans with at least the same level of 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.

New York State Medicaid

[New York's Medicaid program] provides comprehensive health coverage to more than 7.5 million New Yorkers. Medicaid pays for a wide-range of services, depending on your age, financial circumstances, family situation, or living arrangements. These services are provided through a large network of health care providers that you can access directly using your Medicaid card or through your managed care plan if you are enrolled in managed care. Some services may have small co-payments, which can be waived if you cannot afford them.

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 an 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 performed as a panel that simultaneously tests for multiple LHON mutations. 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 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 an 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 that of other labs.
- Athena Diagnostics offers the Athena Alliance Program. This is a financial assistance program for low-income individuals.
- GeneDx offers a Financial Assistance Program and accepts all commercial insurance, Medicaid, Medicare, and Tricare plans.
- Probably Genetic offers free at-home testing.

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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 have never worked.

SSDI differs from the Supplemental Security Income (SSI) program. 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 www.socialsecurity.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 limit, SSDI does not automatically reduce your monthly benefit. 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.

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 those who are 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 limit, or if in any month your assets exceed the maximum allowed amount, SSI does not automatically stop sending your monthly benefit. 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.
https://www.ssa.gov/ssi

Employment Supports

There are many provisions designed to help you become 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.

Protection & Advocacy for Beneficiaries of Social Security

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. The Ticket to Work and Work Incentives Improvement Act of 1999 authorized grants to the designated Protection and Advocacy (P&A) system in all 50 states for an incentive assistance program.

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 Indiana 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. To receive a parking placard, you and your healthcare provider must complete the "Application for a Parking Permit or License Plates, for Persons with Severe Disabilities" and bring it to your local issuing agency (traditionally the office of the city clerk). Please note that the DMV does not issue parking permits. There is no fee for a permit. Metered parking fee waivers can also be obtained by completing the "Application for Meter Parking Waiver for Persons with Severe Disabilities."

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 cash value onto the card, which will be deducted automatically upon use. 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 it cannot exceed twice 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 must agree to pick you up within an hour of your requested time.

Ridesharing Services

The two largest ridesharing services are Uber and Lyft. 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 hoping 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 options to suit 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.

Air Travel

People with visual impairments are protected under the Americans with Disabilities Act (ADA) that all airlines follow; however, specific methods can differ from airline to airline. While airport personnel should always accommodate requests for assistance, making arrangements in advance can help avoid time-consuming 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 provide ground staff and onboard personnel with 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 with your baggage and ground transportation. This information can also be entered into an online reservation.

Additionally, some airlines' disability support desks can waive seat assignment fees, and/or provide a lower cost fare for a companion you may have 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.

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 fare, regardless of the service they travel on. 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 able to provide 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, a membership card from a disability organization, a letter from a physician, a Medicare card (if under 65), or a Disabled/Accessible parking placard issued by a state Department of Motor Vehicles (a photocopy is acceptable).

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 membership fee. To qualify, you will need to provide a proof of disability form signed by a qualified expert, such as an ophthalmologist.

Braille and Audio Reading Download

Braille and Audio Reading Download (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.

Braille and Talking Book Library

The Florida Bureau of Braille and Talking Book Library provides information and reading materials in Braille and recorded audio formats to Florida residents who are unable to use standard print due to visual, physical, or reading disabilities.

Libby by OverDrive

The Libby app is a free downloadable audiobook 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.

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.

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).

Fishing License

Florida residents with a valid Florida Driver's License or ID can apply online for a Resident Persons with Disabilities License, which includes saltwater fishing, freshwater fishing, and hunting licenses. If the applicant does not have a Florida driver's license or ID card, they may provide proof of residency documentation at a local tax collector’s office.

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.

Geva Theater

Located in Rochester, the Geva Theater provides tickets that can be purchased for a Sunday matinee performance. These productions are Audio-Described by a live narrator for patrons who are blind or visually impaired. The pre-performance description of sets and costumes begins after Prologue, at approximately 20 minutes prior to curtain, and visual details are verbalized during the performance. Audio-description receivers and Braille programs are available in the lobby.

SPORTS

Challenged Athletes Foundation

Challenged Athletes Foundation (CAF) offers grants to athletes with any disability, including vision loss, to support their athletic activities.

Dare2Tri

Dare2Tri provides opportunities for people with physical disabilities and/or visual impairments to develop skills in Para triathlon.

Ski for Light is an all-volunteer, non-profit organization whose mission is to teach visually- and mobility-impaired adults the sport of classic cross-country skiing.

Facilities like the National Ability Center provide adaptive sports opportunities, often at low/no cost to the vision impaired.

A good source of information on sports available in your area is the United States Association of Blind Athletes.

Double H Ranch

Double H Ranch is a free camp in Lake Luzerne, New York, for children with serious illnesses. Founded in 1992 by Charles R. Wood and actor Paul Newman, it offers fun and safe activities like swimming, skiing, and ropes courses, all adapted to each child's needs. The camp runs year-round and has served over 80,000 kids. It's part of the SeriousFun Children's Network and runs entirely on donations so families never have to pay.

InTandem Cycling

InTandem Cycling is a non-profit organization whose mission is to provide tandem cycling programs to people who are blind, have low vision, or cannot ride independently due to other disabilities. It offers an accessible opportunity to exercise and socialize in NYC. On the two seater bike, users will be the stoker in the back seat and the rider in front is the captain. Call and ask to be matched to a sighted captain. Members are matched with riders of the same skill level.

Third Eye Insight

Third Eye Insight is a 501(c)(3) nonprofit organization based in West Islip, New York, dedicated to empowering individuals who are blind or visually impaired through adaptive fitness programs. Founded in 2010 by Sensei Devin Fernandez and his sister Kim Fernandez, the organization offers a range of physical activities designed to promote independence, self-confidence, and overall well-being.Programs and Activities

Third Eye Insight provides specialized classes and events tailored to the needs of the visually impaired community:

- Martial Arts/Self-Defense: Training that enhances flexibility, strengthens the immune system, and provides stress management tools to improve mental focus and emotional control.
- Yoga and Meditation: Practices that unite mind, body, and spirit, promoting energy flow, relaxation, and increased body awareness.
- Recreational Activities: Including archery, horseback riding, skiing, kayaking, surfing, tandem bike riding, fishing, hiking, white water rafting, sailing, and blind soccer.

TAX TIPS

Several aspects of federal tax law apply specifically to individuals who are legally blind (vision is 20/200 or worse in the better 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.

The minimum dollar amount requirements 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 (VITA) program, sponsored by the IRS. Taxpayers can find a nearby IRS office location by calling 1-800-906-9887.

MISCELLANEOUS

Guide Dog Users of the Empire State

Guide Dog Users of the Empire State (GDUES) serves as a voice, supporting and advocating for all guide dog users living in New York State. They also offer a network of educational information, social support, and resources to guide dog handlers. Information on Guide Dog Applications available.

Guiding Eyes for the Blind

Guiding Eyes for the Blind is a non-profit organization based in Yorktown Heights, New York which trains, raises, and provides guide dogs for people with vision loss completely free of charge.

Leader Dogs for the Blind

Leader Dogs is an organization that aims to enhance the mobility, independence, and quality of life of people with vision impairment through services ranging from matching with a Leader Dog to white cane training. Through their guide dog training services, clients can train with their guide dog in a variety of situations to meet 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.

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 select specialty retailers, including Cardenas Markets, Rite Aid, Pet Food Express, and Mission Wine & Spirits.

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 an 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 identify maternal relatives and prepare 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 patients to pay to participate. Legitimate trials will not require patient payment.

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, particularly Lions Clubs, which have a specific mission to serve people 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 crowdsource 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.