LHON Collective

A Guide to Navigating LHON with Money in Mind

Information & Resources for the Massachusetts LHON Community

Updated June 2026

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 many resources available to help mitigate that financial impact.

The goal of this document is to help the Massachusetts LHON community become familiar with resources that can limit negative financial impacts. It provides descriptions and contact information for agencies and programs that can help achieve better financial outcomes 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 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 for 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

Massachusetts Commission for the Blind

Upon being determined legally blind in Massachusetts, the results of your vision examination will be sent to the Massachusetts Commission for the Blind (MCB) by your doctor. Your report will be reviewed, and your eligibility will be determined. A letter of "Determination of Eligibility" will then be sent to both you and your eye care provider. You will then be registered with MCB. Once registered, an MCB staff member will contact you to provide a complete explanation of available services from the MCB, and a counselor will be assigned to you. They will also provide you with a "Legal Certificate of Blindness," which is required to access many state programs.

In general, the goal of MCB is to provide training and services for people of all ages who are blind or have low vision in the state of Massachusetts. They strive to assist individuals with vision loss in employment, independent living, and equality. MCB is not a financial needs-based program. Anyone, regardless of income level, can apply.

MCB has received state funding to work with several agencies located throughout Massachusetts, including:

The Carroll Center for the Blind
- Massachusetts Association for the Blind and Visually Impaired
- The Polus Center for Social & Economic Development
- New England Low Vision & Blindness | Low Vision Products, Software, & Training
- Lowell Association for the Blind Home

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.

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.

These organizations are located throughout the state and provide similar services, which generally include:

- Low vision evaluations and vision aids
- Adaptive technology assessments, equipment, and training
- Technical support
- Orientation and mobility training
- Independent living skills training
- Vocational training

If you have questions or need assistance, contact the Massachusetts Commission for the Blind (MCB).

American Council of the Blind

The American Council of the Blind (ACB), founded in 1961, is on a mission to increase the independence, security, equality of opportunity, and quality of life for all blind and visually impaired people. On the national level, they offer a wide variety of programs and services to help people who are blind or visually impaired and work to meet the needs of individuals, local chapters, and state and special interest affiliates.

Bay State Council of the Blind

The Bay State Council of the Blind (BSCB) is the Massachusetts affiliate of the American Council of the Blind. Their mission is to enhance the quality of life for people who are blind in the Commonwealth of Massachusetts and beyond. Their advocacy efforts focus on access to jobs, education, public transportation, health care, technology, and the arts.

National Federation of the Blind

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 a range of 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, the District of Columbia, and Puerto Rico can request a cane for their personal use. Requests can be made as often as every six months.

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 fully integrate rehabilitation services into its health benefits for patients with vision loss.

DISABILITY INSURANCE

Family Medical Leave

The Family and Medical Leave Act (FMLA) is a federal law that requires covered employers to provide eligible employees with family and medical leave. The law requires employers to provide up to 12 weeks of leave in a 12-month period for the employee's own 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.

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.

Employers are also required to continue group health insurance coverage for an employee on FMLA leave under the same terms and conditions as if the employee had not taken leave. The main benefit of FMLA is job protection, especially if your employer has a strict sick policy that could jeopardize your employment.

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 for a long period due to illness, injury, or accident. This can be devastating financially for a family. LTD insurance ensures that an employee will still receive a percentage of their income if they are unable to work for an extended period.

Some employers, if they do not provide LTD insurance, will develop a relationship with an LTD insurance company to offer an employee discount to 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 begins to assist the employee when short-term disability insurance (SDI) 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 premiums were paid by the employee themselves on an after-tax basis, are usually not taxable income. Moreover, 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 its payment by the amount of SSDI benefits. If someone collecting on an LTD policy returns to work, the insurance payout may be reduced by a percentage of the amount earned. Given the many complexities of the LTD insurance process, consider hiring a lawyer familiar with it to help navigate it.

Each LTD insurance policy has different conditions for payouts, diseases, and pre-existing conditions that may be excluded, as well as 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 he or she is capable of. In some policies, LTD payments to the employee are subject to a defined period. Others pay an employee until he or she is 65.

Keep in mind your health history and your family's history of LHON and any other diseases when you consider the amount of long-term disability insurance that you need.

SOCIAL SECURITY

Social Security Disability Insurance

Social Security Disability Insurance (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 must have lasted or be expected to last at least 12 months.

SSDI is an earned benefit, based on your work record. 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. Basically, 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 at www.ssa.gov.

SSDI can be applied for online at the Social Security Administration (SSA). The SSA will review your application and supporting documents and decide whether you qualify as disabled and, if so, whether 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). Local office phone numbers can be found on the Social Security Office Locator website.

Note: If you receive SSDI benefits and work, it is important to pay close attention to the amount of income you earn in relation to the monthly maximum 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 an extremely unpleasant situation.

Supplemental Security Income

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 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.

SSI qualification is based on your resources. If your resources (the things you own) are worth more than $2,000 for an individual or $3,000 for a couple, you're considered to be ineligible. This amount includes most personal property, but excludes certain items, such as your primary home. There are also strict income requirements for SSI eligibility.

The maximum Federal SSI benefit tends to change yearly. Please review the Social Security website for the current amount. SSI benefit amounts and Massachusetts State supplemental payment amounts vary based on your income, living arrangements, and other factors.

To apply for SSI, you can begin the process and complete a large part of your application by visiting the Social Security website. 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.

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.

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.

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 healthcare expenses for enrolled individuals 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.

MassHealth

Massachusetts offers a Medicaid program (MassHealth) for low-income individuals and families, and for people living with disabilities who need assistance with healthcare. The program may offer benefits directly or help pay for all or part of your health insurance premiums. If you are a member, you may have access to doctor visits, dental, prescription drugs, behavioral health services, and other important health care services.

Residents across Massachusetts facing financial difficulties can apply for state health insurance and find out whether they qualify. Certain stipulations apply to those seeking approval. Blind or disabled children and adults who receive Supplemental Security Income (SSI) are eligible for MassHealth Standard. The Social Security Administration (SSA) determines eligibility.

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 who are unable to participate in developmentally appropriate, typical preschool activities due to their disability.

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 is affected by LHON while in elementary, middle, or high school, it is important to contact their school district immediately. The school district should have a Visual Impairments (VI) or Special Education department that 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 Massachusetts education system provides extensive support to students who are visually impaired through their school district and/or the Massachusetts 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 in the Massachusetts school district comes from the DOR, and affected students and their families do not have to cover the costs of educational accommodations. Keep in mind that families must provide medical documentation establishing the student's legal blindness to receive 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 can receive: Orientation and Mobility (O&M) training to develop safe travel skills; an expanded core curriculum; standardized testing to ensure appropriate grade-level expectations are met; and assessments of their vision to provide adequate assistive technology and the training associated with it. If it is determined that 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 in the VI/Special Education department in the school district (administrators, teachers, and support staff) are appropriately credentialed to ensure that the student's visual impairment needs are met and that appropriate accommodations are available to support the student's success. VI staff are also responsible for ensuring that the student meets the CA Braille reading and math standards.

Secondary Transition

For Massachusetts students receiving special education services, Secondary Transition begins when they turn 14 (or earlier if the IEP team agrees). From age 14 until they graduate or turn 22, students on IEPs receive transition services from their public school districts. Transition services are defined by federal law as a "coordinated set of activities designed to be within a results-oriented process, to facilitate the student's movement from school to post-school activities." Transition services are based on the individual student's needs, taking into account his/her strengths, preferences, and interests. These services help young adults live, work, participate in the community, and pursue further education or training as independently as possible after leaving high school.

Higher Education

If someone is affected at a college age or beyond and seeks to continue higher education, it is important to establish relationships 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 CA 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, along with its staff, works with blind or visually impaired individuals to obtain educational and employment opportunities. The services and support that BFS provides to affected individuals are unique and tailored to meet the individual's specific needs. To begin an educational path supported by the DOR/BFS, the affected individual must establish a relationship with their assigned case manager after their application is 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 on application approval and household income, shared equipment costs will be provided to affected individuals who require assistive technology for educational purposes (e.g., CCTV, laptops, 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 waiting lists for certain supports 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 understand the financial support an affected individual can receive.

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

If an affected person wishes to pursue higher education, they should consider applying for financial assistance through the "Categorical Tuition Waiver". This is a component of the "Single Tuition Waiver Program" and has the same purpose: maintaining access to the Commonwealth's public colleges and universities. The Categorical Tuition Waiver is designed to provide financial support to individuals who might not have the opportunity to achieve higher education without such assistance.

To be eligible for a Categorical Tuition Waiver, a student must:

- Be a permanent legal resident of Massachusetts for at least one year prior to the opening of the academic year.
- Be a U.S. Citizen or a non-citizen eligible under Title IV regulations.
- Not be in default of any federal or state Student Loans for attendance at any institution or owe a refund for any previous financial aid received.
- Enroll in at least three undergraduate credits per semester in a state-supported undergraduate degree or certificate program.

- Be maintaining satisfactory academic progress in accordance with institutional and federal standards.
- Be a member of an eligible category, such as being a Client of the Massachusetts Rehabilitation Commission or Commission for the Blind, as certified by the respective commission.

To apply, contact the financial aid office at an eligible institution (one within the system of public institutions of higher education, Section 5 of Chapter 15A of the General Laws: www.malegislature.gov/Laws/GeneralLaws/PartI/TitleII/Chapter15A/Section5).

You can also call the Department of Higher Education's Office of Student Financial Assistance at (617) 391-6070 to obtain more information.

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 Disability Discharge to register.

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 your 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.

Scholarships

For more information about educational resources and scholarships, visit the Living with LHON webpage.

EMPLOYMENT

Employee 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 an 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.

Disability Rights

The Americans with Disabilities Act of 1990 (“ADA”) is federal legislation that combats discrimination 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.

In Massachusetts, individuals with disabilities are further protected by Chapter 151B of the Massachusetts General Laws. Chapter 151B is similar to the ADA, but has a broader reach. Chapter 151B applies to employers with 6 or more employees, whereas the ADA applies only to employers with 15 or more employees.

The [Massachusetts Office on Disability](#) (MOD) can help you understand how disability laws and regulations may or may not apply in your situation, including your rights, responsibilities, and options for recourse.

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 from 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.

TRANSPORTATION

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, which can be used on 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 it signed by your doctor.

In Massachusetts, Regional Transit Authorities serve urban, suburban, and some rural areas across the Commonwealth from the Berkshires to the Islands. Find the transit authority that serves your area, then visit their website or call them to learn more about what they offer and how to ride.

In many cases, customers who are legally blind and have access to the [Massachusetts Bay Transit Authority]() (MBTA) can access MBTA services for free with a "Blind Access CharlieCard", which can be obtained from the CharlieCard Store. If accompanied by a guide, free travel does extend to the guide. In many locations, a white cane alone will provide access to free rides for you and your guide. However, check with your individual municipality to be sure.

To receive a [Blind Access CharlieCard](), you must have an MCB Identification Card that verifies your registration as an individual who is legally blind. This card is a Real ID, and under Massachusetts law, any person/business that accepts a driver's license for identification in granting credit or cashing checks must accept the Identification Card issued by MCB in the same way.

Certain bus and train companies grant free or reduced fares to individuals who are legally blind and traveling within the state. As these concessions are not required by law, individual companies may determine their own regulations.

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 be charged an increased fare for paratransit services, but it cannot exceed twice the regular fare.

You are eligible for paratransit service if you are 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 the time that you requested.

Within the MBTA system, paratransit is known as "The Ride". Outside of the MBTA, services can vary by town.

Disabled Person Parking Placard

A qualified permanently disabled person may obtain a Disabled Person (DP) parking placard for no fee. Placards can be moved from one vehicle to another, making them a good option for someone affected by LHON who rides in various cars. With a placard, you can park in an on-street metered parking space at no charge, along with other privileges. The placard is valid for two years and expires on June 30 of every odd-numbered year.

To apply, complete and sign an application for a Disabled Person Placard or Plates.

Have a licensed physician, surgeon, chiropractor, optometrist, physician assistant, or nurse practitioner who has knowledge of the disease and/or disability complete and sign the Medical Provider's Certification of Disability section and mail it to the address on the form.

To apply, you will need to fill out an Application for Disabled Parking. Your healthcare provider will need to complete a section to verify your disability status. The RMV is also the organization that supplies Identification Cards to non-drivers who are residents of Massachusetts.

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 to 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 online when making a 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 (photocopy is acceptable).

TRAVEL & LEISURE

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, who 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 copy 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).

Audiobooks and Periodicals

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.

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.

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.

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 U.S. Department of Education, Office of Special Education Programs (OSEP), 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.

Perkins Library

In Massachusetts, both BARD and Newsline are administered by the Perkins Library. Perkins circulates more than half a million accessible books, newspapers, and publications in braille, large print, and digital audio formats annually to thousands of registered patrons with print disabilities in New England and beyond.

Members can borrow books and magazines in a variety of formats and languages, and access free services like Newsline. Newsline allows users to listen to newspapers and magazines via synthetic voice output in their internet browser or on any touch-tone telephone. It is free for registered users.

Theatre Discounts

Many theatres in Massachusetts offer discounts and often special seating for the blind. Many also offer special performances with a live Audio Describer. Examples include the Opera House, Huntington Theatre, and the Hanover Theatre in Boston. A listing of performances with audio description is available by email from the Perkins Library.

SPORTS

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

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.

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

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

ASSISTIVE TECHNOLOGY

Braille and Talking Book Library Assistive Technology Lending Program

The Braille and Talking Book Library (BTBL) of the Massachusetts State Library System offers the following assistive technology devices free of charge to eligible patrons.

The HumanWare Explore 5 is a compact, lightweight device with a 5-inch LCD screen, a camera, an image gallery, large tactile keys, and a retractable handle. The Explore 5 has a magnification range between 2X and 22X. This handheld magnifier can connect to an external display, such as a TV or computer monitor, to enlarge text or images. Loan period: one-year; renewable

The Orbic Speed Mobile Hotspot is an Internet access tool. The device has a default 2.4 GHz Wi-Fi setting and supports up to 5 Wi-Fi-enabled devices with unlimited data. Patrons requesting a Wi-Fi hotspot must consent to the CSL Wi-Fi Agreement. Loan period: one-year; renewable

HumanWare's Victor Reader Stream 2 is a handheld audio player. Users can listen to books, magazines, newspapers, Internet radio, music, and podcasts, available online or offline. The Victor Reader Stream can connect directly to the following libraries: NFB Newsline, Bookshare, and NLS BARD. Patrons must have a valid email address and an active BARD account prior to borrowing this device. Loan period: one-year; renewable.

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

Aira also offers a free option to anyone with an Aira account (regardless of plan status) who 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 24 hours, while those with a plan receive one free call every 4 hours.

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 via live video calls. 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 low-vision user may need help with anything from checking expiration dates to distinguishing colors to reading instructions to navigating new surroundings.

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, as well as at restaurants, vending machines, trains, and taxis.

Computers for the Blind

Computers for the Blind (CFTB) is a non-profit 501(c)(3) organization 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; details are in the following PDF fact sheet.

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 deduct a larger standard 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.

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 printer, eyeglasses, eye exams, eye surgery, Guide dog and all related costs, and home modifications.

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.

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.

Real Estate Tax Exemption

Individuals who are legally blind may be eligible for a property tax exemption on a home they own and reside in. As the amount of the exemption varies, contact the local assessor's office for further details. A current Certificate of Blindness must be submitted.

Automobile Excise Tax Exemption

Individuals who are legally blind may be eligible for an excise tax exemption on one vehicle registered in his/her name. Application for this exemption should be made through the local assessor's office. A current Certificate of Blindness is required for this exemption, and the forms must be completed each year.

MISCELLANEOUS

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 their loved ones have lost time from work for these appointments and have spent money traveling to a range of specialists in an effort 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 on the Genealogy page 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.

Genetic Testing

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

Obligate Carrier/On the Maternal Bloodline

It's first helpful to understand the genetic transmission of an LHON mutation. LHON is maternally inherited, and a woman who carries a LHON mutation passes that mutation to all her children. If someone on your maternal bloodline has 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 currently $140; 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.
- If you're in the SF Bay Area, the Little Zebra Fund offers financial support to those needing assistance with the cost of genetic testing in some instances.

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.