

A Guide to Navigating LHON with Money in Mind

Information & Resources for the
Minnesota LHON Community

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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.

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TRAINING & TECHNICAL RESOURCES

Minnesota Council for the Blind

[Minnesota Council for the Blind](#) provides a curated list of blindness and low vision support tools including accessible technology support lines, assistive tech info, and national accessibility contacts. Mainly volunteer-led support and peer mentorship resources.

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.

National Federation of the Blind of Minnesota

The [National Federation of the Blind Minnesota branch](#) (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 programs, services, and resources that provide 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.

State Services for the Blind (Living with Vision Loss- MN)

[Minnesota's state State Services for the Blind](#) agency provides training and assistive technology support for people with vision loss to live and work independently. Services include adjustment to blindness training and community referrals. You can also find assistive tech and employment tools to help customize support.

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.

Vision Loss Resources

[Vision Loss Resources](#) is a long-standing nonprofit offering training, support groups, and social connection for Minnesotans with vision loss. Programs include independent living skills, technology instruction, and community events. They can also refer people to other specialized services like DeafBlind support.

DISABILITY INSURANCE

Disability Hub MN

[Disability Hub MN](#) is a free Minnesota statewide helpline and website that provides expert assistance with understanding disability benefits, health coverage, and related options. They can walk you through Medical Assistance (Medicaid), MinnesotaCare, and other insurance programs.

Family Medical Leave

Both federal (FMLA) and some states' 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 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.

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.

Veterans Affairs — Blind Rehabilitation Service

[Veterans Affairs — VA Blind Rehabilitation Service](#) (for eligible veterans) provides intensive rehabilitation, adaptive devices, and community re-entry programs for eligible veterans with vision impairment — services are comprehensive and provided through VA medical centers. If the patient is a veteran, this is frequently free or low-cost to them.

SOCIAL SECURITY

Employment Supports

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

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 never have worked.

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

SSDI will help if you are severely disabled and can't be employed in your field of work, have a history of work, have paid into Social Security in prior work years, and have a medical issue that meets the Social Security disability guidelines (such as legal blindness). Blindness is defined as central visual acuity of 20/200 or less in the better eye with best correction, or a limitation in the field of vision in the better eye so that the widest diameter of the visual field subtends an angle of 20 degrees or less. Under SSDI, this condition 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 \(SSA\)](http://www.ssa.gov). The SSA will review your application and supporting documents and make a decision as to whether or not you qualify as disabled, and if you do, whether or not you're eligible for benefits.

You can speak with a SSDI representative by calling your local Social Security office or the national number (1-800-772-1213). Local office phone numbers can be found online with the [Social Security Office Locator](http://www.ssa.gov).

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 allowed amount, SSDI does not automatically stop sending your monthly benefit amount. They will review your case from time to time, and if they determine that you have received benefits to which you were not entitled, they will send a letter demanding repayment. This can be for a significant amount and can be an extremely unpleasant situation to be in.

Supplemental Security Income

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, including California, 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 California State

supplemental payment amounts vary based upon 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 allowed amount, or if in any month your assets exceed the maximum allowed amount, SSI does not automatically stop sending your monthly benefit amount. If you ever request to stop receiving SSI benefits, they will review your case. If they determine that you have received benefits to which you were not entitled, they will send a letter demanding repayment. This can be for a significant amount, and can be an extremely unpleasant situation to be in.

MEDICAL INSURANCE

Community Health Centers

[Community Health Centers across Minnesota](#) provide affordable primary care, dental, behavioral health, and preventive services, often on a sliding fee scale for uninsured or underinsured patients. They can also help with health insurance enrollment.

Medicare

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

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

Medicare covers only some of the healthcare expenses of those enrolled and does not cover the cost of low vision devices. It is divided into four parts. Medicare Part A covers hospital, skilled nursing, and hospice services, and has no cost. Part B has a cost, and covers outpatient services, outpatient hospital charges, most provider office visits, and

most professionally administered prescription drugs. Your Part B cost can be deducted from your monthly SSDI and/or SSI benefit payment.

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

Medicare Savings Programs

For Minnesotans enrolled in Medicare with low income, [Medicare Savings Programs](#) (MSPs) help pay Medicare premiums, deductibles, and copays, reducing the cost of Medicare coverage. There is no cost to apply, and you can use the same application that determines eligibility for other Minnesota Health Care Programs.

MinnesotaCare

[MinnesotaCare](#) is a state-subsidized health insurance program for Minnesotans who make too much to qualify for Medical Assistance but still need affordable coverage. Monthly premiums are low (based on income and family size), and the plan covers doctor visits, hospital stays, medications, vision, dental, and more. You can apply year-round through MNsure.

Minnesota Health Care Programs Application Assistance

The [Minnesota Department of Human Services](#) provides step-by-step guidance on applying for Medical Assistance (MA) and MinnesotaCare, including eligibility details and how to submit a paper or online application. Assistance is also available via phone and local county offices.

Minnesota Health Information Clearinghouse

[Minnesota Health Information Clearinghouse](#) – Insurance Resources is Minnesota's health clearinghouse provides a guide to health care and insurance resources, including how to access MNsure, continuation coverage (COBRA), and general insurance information that may help you find affordable coverage or continue existing insurance.

MNsure

[MNsure](#) - Apply & Financial Help is Minnesota's official health insurance marketplace, where you can apply for Medical Assistance, MinnesotaCare, or private plans with financial help (tax credits and cost-sharing reductions). The platform guides you to no-cost or low-cost coverage options based on your income and household size, and certified helpers are available free of charge.

MN Low-Cost Health Care Directory

[MN Low-Cost Health Care Directory](#) (Bridge to Benefits) directory connects Minnesotans who are uninsured or underinsured to low-cost clinics and providers that may offer care on a sliding fee scale or help with insurance applications. It's useful for people who don't qualify for public programs but still need affordable care access.

MNsure Navigator Support & Enrollment Help

[MNsure Navigator Support & Enrollment Help](#) certified navigators offer free, personalized assistance to help Minnesotans understand their health insurance options, assess eligibility for programs like Medical Assistance or MinnesotaCare, complete applications, and enroll in coverage. This support is available statewide.

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

School-Age

If someone becomes affected by LHON while in elementary, middle, or high school, it is important to 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.

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](#).

Minnesota State Academy for the Blind

[Minnesota State Academy for the Blind](#) is a public residential school in Faribault offering individualized educational programming, assistive technology instruction, and life skills training for students up to age 21.

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 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.

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, based on 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: www.secure.disabilitydischarge.com/registration

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 [LHON website](#).

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. 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 designed to counteract bias and protect the rights of the disabled in the workplace. The ADA prohibits employers from discriminating against qualified individuals with disabilities. A disability is defined broadly as any mental or physical impairment that limits at least one major life function.

Workers are deemed to be qualified to perform a job under the ADA if they meet the educational and other requirements for the job and they can perform the job duties with or without reasonable accommodations.

Job Accommodation Network

The [Job Accommodation Network \(JAN\)](#) is a leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues.

JAN's consultants offer one-on-one guidance on workplace accommodations, the Americans with Disabilities Act (ADA) and related legislation, and self-employment and entrepreneurship options for people with disabilities. Assistance is available both over the phone and online. JAN provides individualized consultation to assist:

- Individuals with medical conditions and disabilities seeking information about job accommodation solutions, employment rights under the ADA, and self-employment and entrepreneurship opportunities.

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

Minnesota Department of Employment and Economic Development [Minnesota Department of Employment and Economic Development](#) (DEED) page outlines how Vocational Rehabilitation Services helps people with disabilities set employment goals, access training, and connect with employers. It provides contact info and step-by-step guidance for accessing services statewide.

Minnesota Disability Hub

[Minnesota Disability Hub](#) (DB101) – Work Support Information DB101’s offers free information on work incentives, employment supports, and how work interacts with benefits. It includes guidance on programs such as Vocational Rehabilitation and can help job seekers understand how to plan a job search while managing disability benefits.

State Services for the Blind

[State Services for the Blind](#) (SSB) – CareerForce is tailored for Minnesotans with significant vision loss, SSB helps with career planning, job skills training, job placement, and ongoing employment support. Services are personalized to your goals and can include assistive technology training, coaching, and access to accessible materials.

Vocational Rehabilitation Services

[Vocational Rehabilitation Services](#) (VRS) – CareerForce Minnesota is a statewide program that helps people with disabilities prepare for, find, and keep meaningful employment. Services are provided at no cost and include vocational counseling, job skills training, job search assistance, job placement support, and workplace accommodations. VRS can also connect participants with community resources and employment specialists tailored to individual needs.

TRANSPORTATION

Air Travel

People with visual impairments are protected under the Americans with Disabilities Act (ADA) that all airlines are required to follow, however, specific methods can differ from airline to airline. While airport personnel should always accommodate requests for assistance at the airport itself, making arrangements in advance can help save time, travel headaches and delays.

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

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

Amtrak

[Amtrak](#) offers a 10% rail fare discount to adult passengers with a disability. Child passengers with a disability are eligible for the everyday 50% child discount plus an additional 10% off the discounted child's fare, regardless of the service on which they travel. Amtrak also offers a 10% discount for persons traveling with a passenger with a disability as a companion. Those designated as a companion must be capable of providing the necessary assistance to the passenger with a disability.

Just select 'Passenger with Disability' or 'Companion' for each passenger as appropriate in Fare Finder at the beginning of your search to receive the applicable discounts.

You must provide written documentation of your disability at the ticket counter and when boarding the train. Acceptable documentation includes transit system ID card for persons with a disability, membership card from a disability organization, letter from a physician, Medicare card, if under 65, or a Disabled/Accessible parking placard issued by a state Department of Motor Vehicles (photocopy is acceptable).

Arrowhead Transit

[Arrowhead Transit](#) (Dial-A-Ride) is a rural Minnesota public transit with low-fare Dial-A-Ride and volunteer driver services in the northeast region; useful for people without fixed transit access.

Disability Hub MN

[Disability Hub MN](#) — Transportation Support & Guidance is a statewide free resource network that helps Minnesota residents with disabilities understand transportation options in their area — including how to access paratransit, volunteer rides, and public transit. The Hub can also help plan trips and navigate eligibility requirements for different programs.

Disability Parking Placard - Minnesota

A qualified disabled person may obtain a Disability Parking Placard. Placards can be moved from one vehicle to another, making them a good option for someone affected by LHON who rides in various cars.

Discounted Public Transportation

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

Metro Mobility

[Metro Mobility](#) — Shared Ride Transit (Minneapolis/St. Paul) is paratransit service for riders who can't use fixed-route buses due to a disability or health condition. Certified riders receive free rides on Metro Transit buses and trains, and can schedule door-to-door service for any purpose, including medical appointments and errands. This service is especially useful for people with low vision or mobility challenges.

Metro Move

[Metro Move](#) — Shared Rides Through Waivers is a shared-ride transit service funded through Minnesota waiver programs (like CADI and DD) for people with disabilities. Eligible waiver participants can access transportation for community support, jobs, and daily activities with no fare at boarding.

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.

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 this fare cannot be more than double 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.

GoGoGrandparent

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

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

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

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.

TRAVEL AND LEISURE

Fishing License - Minnesota

Certain Minnesotans can receive [free licenses](#), such as residents who are legally blind, developmentally disabled, or receiving certain disability or supplemental income benefits — these are issued through the DNR License Center. Wildlife agencies and advocacy groups sometimes run free fishing days where anyone can fish without a license — check the Minnesota DNR events calendar for updates.

Free Minnesota State Park Days & Library Pass Program

[Minnesota's state parks](#) are normally not free, but four times each year the Minnesota Department of Natural Resources waives all entrance fees so anyone can explore trails, lakes, beaches, and picnic spots at no cost. Additionally, many local public libraries offer free 7-day state park pass checkouts — perfect for planning your own outdoor adventure without park entry fees. These passes can be found at select library systems across the state.

Minnesota Accessible Activities Calendar

[Minnesota Accessible Activities Calendar](#) is a statewide online calendar that highlights events across Minnesota with accessibility accommodations, including audio description, sensory options, and ASL interpreting. You can filter by venue, location, or accessibility feature to find performances, workshops, arts events, and community gatherings that are free or low-cost and welcoming to people with vision impairment.

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).

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.

Sports

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

[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 that may be available in your area is the [United States Association of Blind Athletes](#).

Three Rivers Park District

The [Three Rivers Park District](#) offers free entrance and parking at its many parks and trails around the Twin Cities. Visitors can hike, explore nature, and enjoy picnics at no cost, and there are low-cost equipment rentals (like snowshoes, sleds, disc golf discs, and bocce gear) for those who want active outdoor fun without breaking the bank.

Vision Loss Resources

[Vision Loss Resources](#) is a Minnesota-based organization that provides monthly recreational and social activities for people who are blind or have low vision — many with low or no fees. These events focus on community, recreation, arts, and learning, offering accessible opportunities to engage and have fun with peers.

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.

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

Learning Ally

[Learning Ally](#) offers low-cost, human-narrated audiobooks focused on education and literature for people with print disabilities. While geared toward students and learners, they also have a wide catalog of adult fiction and nonfiction. A membership allows unlimited access to audio titles.

Libby by OverDrive

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

LibriVox

[LibriVox](#) volunteers record free public-domain audiobooks that are available to download or stream. This is a completely free resource with a large catalog of classics, historical works, and some lesser-known titles — ideal if cost is a barrier.

Minnesota Braille and Talking Book Library

[Minnesota Braille and Talking Book Library](#) offers free audio and braille books mailed or downloadable for leisure reading, including travel and leisure topics.

National Library Service for the Blind and Print Disabled

[National Library Service for the Blind and Print Disabled](#) (NLS) – Library of Congress provides free audio and Braille materials to eligible U.S. residents, including audiobooks and magazines. Patrons get access to a large catalog of downloadable books and periodicals and can receive materials by mail or digital download via the BARD app. This is one of the most comprehensive free audio resources in the U.S.

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.

Project Gutenberg

[Project Gutenberg](#) (Audio Editions) offers free public-domain ebooks and some human-narrated or computer-generated audio editions of classic literature. While not

Minnesota-specific, it's a great low-cost resource for accessible audio classics and periodicals in the public domain.

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.

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.

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.

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, and [details are on the following PDF fact sheet](#).

ConnectAbility of MN

[ConnectAbility of MN's Adaptive Equipment Connection](#) offers financial assistance or grants to help people with disabilities purchase adaptive devices, including assistive technology not covered by insurance. While not fully free, this program can dramatically reduce costs for required AT devices and equipment.

Eligible participants must meet financial and disability criteria.

Eye-Link Foundation

The [Eye-Link Foundation](#) (Minnesota Adaptive Tech Grants) provides adaptive and assistive devices at no cost to eligible residents of Minnesota, Wisconsin, and North Dakota who are blind or have significant vision loss. Devices include screen magnifiers, Braille displays, OCR (optical character recognition) readers, and software like JAWS or ZoomText, all aimed at increasing independence in daily activities. This is a grant-based technology resource that can make high-cost equipment far more accessible.

Minnesota Guide to Assistive Technology

[Minnesota Guide to Assistive Technology](#) is a statewide resource hub that offers information about assistive technology options, funding sources, and how to access technology that can support daily living, communication, education, and employment. It's designed for Minnesota residents of all ages with disabilities, plus families and professionals who support them. The website also links to programs that loan equipment, provide training, or help fund purchases.

Minnesota STAR Program

The [Minnesota STAR Program](#) (A System of Technology to Achieve Results) is Minnesota's federally funded Assistive Technology Act Program, helping people with disabilities access the technology they need to live, learn, work, and play. This includes device demonstrations, short- and long-term loans, device reuse and exchange listings, and technical assistance, often at no cost or low cost to users. It's a great first stop for finding equipment or trying a device before purchasing.

Southeast Minnesota Center for Independent Living

The [Southeast Minnesota Center for Independent Living](#) – Assistive Technology Services (SEMCIL) offers assistive technology demonstrations and short-term loans at no cost, allowing individuals to try devices before deciding whether to obtain them. Their AT Lab includes a wide range of technology for vision, hearing, mobility, computers, and daily living and staff can help guide users through features and benefits. This is particularly helpful for people who need to compare technologies firsthand.

Technology for HOME

[Technology for HOME](#) – Assistive Tech Links provides a curated list of assistive technology resources that include services, products, and funding options relevant to Minnesota residents. Their directories cover items like AT funding sources, device loan programs, and home-adaptation technologies, a helpful starting point for identifying tools that support vision, communication, and daily tasks.

TAX TIPS

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

AARP Foundation Tax-Aide Minnesota

[AARP Foundation Tax-Aide Minnesota](#) is a national program that provides free in-person and virtual tax preparation help to anyone, with a focus on taxpayers over 50 or with low-to-moderate income. Volunteers are IRS-certified and can prepare federal and state returns; multiple service models are offered (in-person, scan/drop-off, or virtual).

Deduction for the Legally Blind

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

Impairment-Related Work Expenses

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

Minimum requirements for the dollar amount do not apply to blind filers.

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

Deduction for the Legally Blind

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Minnesota Department of Revenue

The [Minnesota Department of Revenue](#) — Free Tax Preparation Sites maintains a searchable list of free tax preparation sites (VITA and AARP Tax-Aide) across Minnesota, including in-person and virtual options. These sites help eligible taxpayers prepare and file both federal and Minnesota income tax returns at no charge; volunteers are IRS-certified and can assist with common credits and deductions. This page also offers an interactive site finder.

Minnesota Volunteer Income Tax Assistance & Tax Counseling for the Elderly

[Minnesota Volunteer Income Tax Assistance & Tax Counseling for the Elderly](#)

(VITA/TCE) programs offer free tax help to eligible Minnesotans (people with low to moderate income, persons with disabilities, limited English speakers, and seniors). Volunteers help prepare federal and state returns and answer questions about tax credits you may qualify for.

Tax Preparation Assistance

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

MISCELLANEOUS

American Council of the Blind of Minnesota

[American Council of the Blind of Minnesota](#) (ACB) – Resource Page maintains a comprehensive list of support organizations and services statewide, including transit resources, talking book services, vision loss support centers, and volunteer braille services. This is a helpful starting point for connecting with community partners and specialized services throughout Minnesota.

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 trying to get the correct diagnosis. If LHON vision loss begins when an individual

knows they carry a LHON mutation, they can avoid all of these costs, and go directly to a LHON specialist for care. This is one of many reasons why people in the LHON community tell their maternal relatives about LHON. While it can be difficult information to share, there can be great value. There are several videos and links in the [Genealogy page of the LHON.org website](#) that can help in identifying maternal relatives and preparing to share the information.

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

First in Family

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

- The [Carver Lab at the University of Iowa](#) is a non-profit lab, so the cost of a LHON panel test is currently \$140; much lower than at for-profit labs. Note that they batch their testing, so the turnaround time is slower than other labs.
- [Athena Diagnostics](#) offers the Athena Alliance Program. This is a financial assistance program for those with low income.
- 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.

General Financial Support

Many in the LHON community have been creative in finding financial support. Local service organizations are often willing to assist those in need, in particular Lion's Clubs which have a specific mission to serve those with vision loss. College fraternities and sororities often do fundraising and are willing to provide support, especially the Delta Gamma (DG) sorority whose philanthropy is Service for Sight. GoFundMe.com is a fundraising platform on which individuals can describe their financial hardship or need, then share the link with family and friends to 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 a 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 a panel that tests for multiple LHON mutations at one time. However, if you have a copy of your maternal relative's LHON genetic test results, you can get testing done for that single, targeted mutation. The cost is far less than the broader panel test.

Leader Dogs for the Blind

[Leader Dogs](#) is an organization that aims to enhance the mobility, independence, and quality of life for individuals who are blind or have low vision through their services that range 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 fit current and future lifestyle needs. Their services are provided at no cost and their program will cover expenses for training, room and board, and travel to their campus.

Low-Cost Grocery Delivery

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

Minnesota DeafBlind Project

While focused on combined hearing and vision loss, the [Minnesota DeafBlind](#) project offers free workshops, mentoring, and family support services that can benefit people with complex vision diagnoses or those whose vision loss overlaps with other challenges. Services are free for Minnesota families and include resource sharing and community connections. Even if not deafblind, the networking and educational resources can be useful for families navigating vision loss.

Vision Loss Resources

[Vision Loss Resources](#) (Minnesota) is a long-standing nonprofit based in the Twin Cities that offers free and low-cost support groups, training programs, social events, and technology help for people with vision loss. They also connect people with emotional support, adaptive skills training, and peer mentoring opportunities. Events range from online support groups to in-person activities tailored to blind or low-vision adults and youth.

