A Guide to Navigating LHON with Money in Mind

Information & Resources for the Oregon LHON Community

Updated May 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 Oregon LHON community become familiar with resources that can limit negative financial impacts. While designed for the LHON community, some of the information may be of value to others with vision loss. It provides descriptions and contact information 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.

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

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TRAINING & TECHNICAL RESOURCES

Oregon Commission for the Blind

The Oregon Commission for the Blind (OCB) provides training and services for people of all ages who are blind or have low vision. The goal is to assist individuals with vision loss in employment, independent living, and equality. OCB is not a financial needs-based program. Anyone, regardless of income level, can apply.

Vocational Rehabilitation Services are free to Oregonians age 14 or older who want to obtain or retain employment and are either legally blind or have a condition that is likely to lead to blindness. The entire vocational rehabilitation process is about helping you obtain employment, so you must be actively involved in every step of the process.

Independent living services are free to Oregonians age 55 and older who experience vision loss.
Specific services may include:

- Low vision evaluations and aids
- Adaptive technology assessments, equipment
- Technology training
- Technical support and training
- Orientation and mobility training
- Independent living skills training, immersion services, and vocational training

To apply, visit the Oregon State Commission for the Blind website.

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.

Northwest Access Fund – Oregon and Washington

The Northwest Access Fund offers visually impaired people customized loans, financial coaching, and other resources to promote access to assistive technology, independence, financial resilience, and life opportunities.

VisionAware

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

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

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 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, which allows any blind individual in the 50 states, the District of Columbia, and Puerto Rico to request a cane for personal use. Requests can be made every 6 months.

DISABILITY INSURANCE

Paid Family Medical Leave Insurance

The Oregon Paid Family and Medical Leave Insurance (PFMLI) program will eventually serve Oregonians by providing paid leave for an employee’s own serious health condition or for caring for a family member with a serious health condition.

Family Medical Leave

Both federal (FMLA) and state laws require covered employers to provide family and medical leave to eligible employees. These laws require 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 their 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 they are unable to work for a long period due to illness, injury, or accident. LTD insurance ensures that an employee will still receive a percentage of their income if they are unable to work for an extended period.
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, where the employee paid premiums themselves on an after-tax basis, are usually not taxable income.

LTD policies sometimes include offset language requiring an employee to secure SSDI benefits. Each LTD policy has different payout conditions. 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.

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SOCIAL SECURITY

Disability Rights Oregon

Disability Rights Oregon (DRO) is Oregon’s state disability protection and advocacy system, helping people with disabilities. DRO provides information, advice, and support regarding Social Security and other matters.

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.

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. 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.

Benefit amounts vary dramatically based on each individual's work record. 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). 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, pay close attention to the monthly income maximum allowed for a blind individual. If your monthly income exceeds the allowed amount, SSDI does not automatically stop — they may later demand repayment of overpaid benefits.

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 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.

MEDICAL INSURANCE

Oregon Health Plan

Oregon Health Plan (OHP) is Oregon's Medicaid program. It provides health coverage to people with low income and limited assets who meet eligibility requirements. If you are blind or have a disability and receive Supplemental Security Income (SSI), you're automatically eligible for and enrolled in OHP Plus.

Many people affected by LHON at a young age are not eligible for Medicare benefits because they don't have the work credits required to qualify for Social

Security Disability Insurance (SSDI). These people are only covered by OHP, not Medicare, if they're eligible based on low income and low assets.

Some people are eligible for both Medicare and OHP. When medical benefits are covered by both Medicare and OHP, Medicare is the primary payer, and OHP is the secondary payer. When services such as dental care or long-term care are covered only by OHP, it is the sole payer. If you have both Medicare and OHP, be sure the medical providers you choose accept both sources of payment for your care. Otherwise, you may face billing delays or be required to pay unexpected medical costs.

To apply for OHP, go to ONE.Oregon.gov and create an account. You can then use the online Oregon Eligibility (ONE) system to apply or renew your OHP and report changes.

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, 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.

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.

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 Oregon education system provides extensive support to students who are visually impaired through their school district. 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. Funding for VI programs within the [STATE] school district comes from the state, and affected students and their families generally do not have to cover the costs associated with 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 (e.g., Braille, tactile materials, recorded books, large print), and more. Affected students may receive: Orientation and Mobility (O&M) training to develop safe travel skills; an expanded core curriculum; standardized testing; and assessments of their vision to provide adequate assistive technology and training. 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.

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 vocational rehabilitation agency 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 Oregon is to complete and sign the Vocational Rehabilitation Services Application and provide supporting documentation to begin the assessment, which will determine eligibility and priority status. To begin an educational path supported by the vocational rehabilitation agency, 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.

For those interested in higher education, there are scholarship opportunities for individuals with visual impairments on the Living with LHON webpage.

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, which allows any blind or low-vision individual in the 50 states, the District of Columbia, or Puerto Rico to request a cane for 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 at 888-303-7818 or by email at DisabilityInformation@Nelnet.net. If you want to start your application online, go to www.disabilitydischarge.com.

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. 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 educational and other requirements for the job and 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 are working 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.

Goodwill

Goodwill Industries International offers a variety of employment and training programs, including job training, employment placement services, and other community-based programs for people with disabilities and disadvantaged individuals.

TRANSPORTATION

TriMet

TriMet (Portland Metro Area) offers reduced fares for people with disabilities through an “Honored Citizens” program. To receive this service, contact the Commission for the Blind for an application. TriMet also offers a large-number notebook, which allows the bus driver to see which bus you are waiting for. This notebook is in large print with large-cell Braille numbers on each card.

To obtain this notebook, call TriMet’s Honored Citizen office at 503-962-8200.

Air Travel

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

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

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

Amtrak

Amtrak offers a 10% rail fare discount to adult passengers with a disability. Child passengers with a disability are eligible for the everyday 50% child discount plus an additional 10% off the discounted child fare, regardless of the service they travel on. Amtrak also offers a 10% discount for persons traveling with a passenger with a disability as a companion. Those designated as a companion must be able to provide the necessary assistance to the passenger with a disability.

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

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

Paratransit

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

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

Disability Parking Permit

A qualified permanently disabled person may obtain a Disability Parking Permit for no fee. Permits can be transferred between vehicles, making them a good option for someone affected by LHON who rides in various cars.

The Individual Parking Permit is available to people with severe visual disabilities and allows the holder to park in a public parking zone for more than 30 minutes. It also allows parking in any disabled parking space in Oregon, except "wheelchair user only" spaces.

The permit is valid for eight years, and you can renew it by submitting a new application and certificate of disability.

To apply, you will need to fill out the "Application for Parking Permit for an Individual with a Disability" 735-265 (www.oregon.gov).

The applicant will need a valid Oregon driver's license or ID card, as well as a doctor's signature on the application certifying the need for the permit.
You may submit your handicap parking application via mail or in person at any Oregon Driver and Motor Vehicle Services Division.

Discounted Public Transportation

In many municipalities, a rider with a qualifying disability, such as legal blindness, can apply for a discounted regional transportation fare card for buses, subways, streetcars, or ferries, depending on local rules. In most cases, you can load cash value onto the card, which will be deducted automatically each time you use it. 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.

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.

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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.

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

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 photocopy of proof of citizenship or residency, documentation of disability, and pay the processing fee. The cost of obtaining an Access Pass through the mail or online is $10 for application processing (the Pass is free).

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 offer a free guide for a visually impaired skier. Check with your local ski area for more information.

Challenged Athletes Foundation

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

Dare2Tri

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

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

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

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

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.

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 Office of Special Education Programs (OSEP) in the U.S. Department of Education, Bookshare is free for all qualified U.S. students and schools. Qualified individuals who are not students pay a nominal annual membership fee. To qualify, you will need to provide a proof of disability form signed by a qualified expert, such as an ophthalmologist.

Learning Ally

Learning Ally offers low-cost, human-narrated audiobooks focused on education and literature for people with print disabilities. A membership allows unlimited access to audio titles.

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.

LibriVox

LibriVox volunteers record free, public-domain audiobooks available for download or streaming. 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.

National Library Service for the Blind and Print Disabled

The 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, accessible via mail or the BARD app.

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. This is a great, low-cost resource for accessible audio versions of classic works 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 on demand for almost any task, take advantage of ride-share integration to get you where you need to be, and use one of the ever-growing list of free Aira Access offers to save you money while doing it. To discover all available free Aira Access offers, just tap on the "Search & Apply a Free Offer" button on the home screen of your Aira app.

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 an iOS or 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.

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

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.

Assistive Technology Fund

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

Computers for the Blind

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

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.

AARP Foundation Tax-Aide

AARP Foundation Tax-Aide provides free in-person and virtual tax preparation assistance to anyone, with a focus on taxpayers age 50+ or with low-to-moderate income. Volunteers are IRS-certified and can prepare federal and state returns.

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.

Impairment-Related Work Expenses

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

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

Medical Deductions for the Blind

The law allows you to deduct what you spend to prevent, diagnose, or treat illness, as well as any costs related to your blindness or visual impairment. As with any taxpayer, the total of both types of medical expenses must be more than 10% of your adjusted gross income before you can claim a deduction. Transportation to and from a doctor's office, prescriptions, insurance premiums, and tests are examples of accepted medical deduction expenses, as are disability-associated items such as Braille magazines and books (costs that exceed regular print versions), Braille printers, eyeglasses, eye exams, eye surgery, guide dog, and all related costs and home modifications.

Tax Preparation Assistance

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

MISCELLANEOUS

Avoiding Unnecessary Medical Care

The diagnostic odyssey for LHON can be extremely expensive, including many tests to rule out other, more common causes of sudden vision loss. Many individuals have spent thousands of dollars on tests and treatments for diseases they did not have (Brain Tumor, Optic Neuritis, MS, NMO, etc.). They and/or their loved ones have lost time from work for these appointments and have spent money traveling to a range of specialists 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 in the Genealogy section of the LHON.org website that can help identify maternal relatives and prepare to share the information.

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

First in Family

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

- The Carver Lab at the University of Iowa is a non-profit lab, so the cost of an LHON panel test is usually much lower than at for-profit labs. Note that they batch their testing, so the turnaround time is slower than that of other labs.
- Athena Diagnostics offers the Athena Alliance Program. This is a financial assistance program for low-income individuals.

- GeneDx offers a Financial Assistance Program and accepts all commercial insurance, Medicaid, Medicare, and Tricare plans.
- Probably Genetic offers free at-home testing.

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

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 confirmed genetic testing for an LHON mutation, you can reasonably assume that you're an "obligate carrier" and can presume you carry that LHON mutation without doing any genetic testing. If you prefer to confirm your genetic status, you can save money by testing for just the specific mutation in your family.

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 a panel that tests for multiple LHON mutations simultaneously. 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 of people with vision impairment through services ranging from matching with a Leader Dog to white cane training. Through their guide dog training services, clients can train with their guide dog in a variety of situations to meet current and future lifestyle needs. Their services are provided at no cost, and their program will cover expenses for training, room and board, and travel to their campus.

Low-Cost Grocery Delivery

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

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.