

# A Guide to Navigating LHON with Money in Mind

Information & Resources for the Oregon LHON  
Community

# Purpose

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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 Oregon 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.

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

### **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 with employment, independent living, and equality for individuals with vision loss. OCB is not a financial needs-based program. Anyone at any 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 will likely 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 over the age of 55 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, click [www.oregon.gov/blind/Pages/Request-Services.aspx](http://www.oregon.gov/blind/Pages/Request-Services.aspx) and fill in the form.

[www.oregon.gov/Blind](http://www.oregon.gov/Blind)

## **TRAINING & TECHNICAL RESOURCES**

### **The 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 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 (<https://freecane.nfb.org>) 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.

[www.nfb.org](http://www.nfb.org)

### **The Department of Veterans Affairs – Blind Rehabilitation Services (BRS)**

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

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

### **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.

[www.nwaccessfund.org](http://www.nwaccessfund.org)

## TRAINING & TECHNICAL RESOURCES

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### **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.

[www.hadley.edu](http://www.hadley.edu)

# DISABILITY INSURANCE

## **Paid Family Medical Leave Insurance (PFMLI)**

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 the employee to care for a family member with a serious health condition. However, the program is under development and no benefits are currently available. The program is anticipated to go live in 2023.

[www.oregon.gov](http://www.oregon.gov)

## **Short-Term and Long-Term Disability Insurance**

Both short-term and long-term disability insurance are private insurance policies that protect a person from loss of income if they're unable to work due to an accident, illness, or injury that lasts for a period of time or permanently. Absent such insurance, a disability can be devastating for a family financially.

Disability insurance ensures that a person will still receive a percentage of their income if they cannot work. Disability insurance can be provided and paid for by employers or individuals. Your employer may offer short-term disability, long-term disability, or both. If a company doesn't offer disability insurance or if an employee wants additional coverage, they have the option of purchasing an individual plan.

Some employers that don't provide disability insurance work with an insurance company to offer an employee discount for staff who want to purchase a policy.

The disability insurance provided by an employer may be inadequate to meet your needs. In this case, consider purchasing supplemental insurance. It's often available at a discount through employees' professional associations.



## DISABILITY INSURANCE

Long-term disability insurance usually begins to assist the employee when short-term disability insurance benefits end (most commonly after six months).

Disability 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 benefit by the amount SSDI is providing. If someone is collecting on a policy and returns to work in some capacity, the insurance payout may be reduced by some percentage of the amount earned. Since there are many complexities to the disability insurance process, consider hiring a lawyer who specializes in it to help navigate the process.

Each insurance policy has different conditions for payout, diseases, or pre-existing conditions that may be excluded, as well as other conditions that make the policy more or less useful to an employee. Some policies 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're capable of doing. In some policies, long-term disability payments have a defined period of time. 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 as you consider the amount of disability insurance that you need.

# SOCIAL SECURITY

## **Social Security Disability Insurance (SSDI)**

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

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

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

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

Qualification for SSDI is primarily based on two things: documenting a disability, and an evaluation of your work history. The Social Security Administration (SSA) looks at your recent work history, and how long

## SOCIAL SECURITY

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 on [www.ssa.gov](http://www.ssa.gov).

SSDI can be applied for online at [www.socialsecurity.gov](http://www.socialsecurity.gov). The SSA will review your application and supporting documents and make a decision as to whether or not you qualify as disabled, and if you do, whether or not you're eligible for benefits.

You can speak with an SSDI representative by calling your local Social Security office or the national number (1-800-772-1213). Local office phone numbers can be found online with the Social Security Office Locator.

[www.ssa.gov/locator](http://www.ssa.gov/locator)

*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.

# SOCIAL SECURITY

## **Supplemental Security Income (SSI)**

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

SSI 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.

To apply for SSI, you can begin the process and complete a large part of your application by visiting their website at [www.socialsecurity.gov/applyforbenefits](http://www.socialsecurity.gov/applyforbenefits). 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

## SOCIAL SECURITY

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the filing date of your application, or the month after you first meet all the eligibility requirements, whichever is later.

[www.socialsecurity.gov/applyforbenefits](http://www.socialsecurity.gov/applyforbenefits)

*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.

### **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.

[www.ssa.gov/redbook/Advice](http://www.ssa.gov/redbook/Advice)

### **Disability Rights Oregon (DRO)**

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.

[www.droregon.org](http://www.droregon.org)

# MEDICAL INSURANCE

## Medicare

Medicare is a national health insurance program administered by the Centers for Medicare and Medicaid Services (CMS). If you are age 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.

[www.medicare.gov](http://www.medicare.gov)

## MEDICAL INSURANCE

### **Oregon Health Plan**

Oregon Health Plan (OHP) is Oregon's Medicaid program. It provides health coverage to people with low income and low asset levels 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 who become affected by LHON at a young age are not eligible for Medicare benefits because they don't have the work credits to qualify for Social Security Disability Insurance (SSDI) benefits. 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](https://www.oregon.gov/oha) and create an account. You can then use the online Oregon Eligibility (ONE) system to apply or renew your OHP and report changes.

<https://www.oregon.gov/oha>

## EDUCATION

### **Elementary through High School**

If someone becomes affected by LHON while in elementary, middle, or high school, it's important to contact their school district immediately. In Oregon, special education staff within Oregon Department of Education ([www.oregon.gov/ode/students-and-family/SpecialEducation](http://www.oregon.gov/ode/students-and-family/SpecialEducation)) have the primary responsibility for assuring that young children and students with disabilities receive an appropriate education program in the least restrictive environment. This happens through collaboration with families, districts, agencies, and programs to ensure quality services.

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

Under Section 504, students with disabilities can access the accommodations, aids, and services they need to access and benefit from education. Section 504 requires that public schools provide a "free appropriate public education" (FAPE) to every student with a disability—regardless of the nature or severity of the disability.

A counselor or coordinator works with the student and their family, their teacher(s), and the school to develop an Individualized Education Program (IEP) to support and accommodate the affected student.

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

<https://www2.ed.gov/about/offices/list/ocr/docs/504-resource-guide-201612.pdf>



# EDUCATION

## Higher Education

If someone is affected at college age or beyond and seeks to continue higher education, it's important to establish a relationship with 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. Many also have Accessible Technology Programs (ATP) as part of their Accessible Education Center. These programs actively promote technology access by directly helping disabled students use assistive technology or managing alternative format services.

Students who are blind or have reduced vision often encounter barriers with printed text. They may need it converted to e-text or formatted for Braille output. Students with low vision may also need enlarged paper texts or computer documents formatted for screen enlargement.

The ATP provides conversion of paper texts and inaccessible electronic texts into materials usable by students with reading disabilities. The output ranges from searchable PDF files to Braille documents.

For those interested in higher education, scholarship opportunities are available to those with visual impairments. Some are listed here: [www.lhon.org/living-with-lhon](http://www.lhon.org/living-with-lhon)

## Student Loan Forgiveness

A Total and Permanent Discharge (TPD) relieves you from having to repay a William D. Ford Federal Direct Loan (Direct Loan) Program loan, Federal Family Education Loan (FFEL) Program loan, and/or Federal Perkins Loan (Perkins Loan) Program loan, or complete a TEACH Grant service obligation, on the basis of your total and permanent disability. Before your federal student loans or TEACH Grant service obligation can be discharged, you

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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](mailto:DisabilityInformation@Nelnet.net)

If you want to start your application online, go to: [www.secure.disabilitydischarge.com/registration](http://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.

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*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.

[www.lhon.org/living-with-lhon](http://www.lhon.org/living-with-lhon)

# TRANSPORTATION

## **Discounted Public Transportation**

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

## **Paratransit**

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

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

## **TriMet (Portland Metro Area)**

TriMet offers reduced fares for people with disabilities through an "Honored Citizens" program. To receive this service, contact the Commission for the

## TRANSPORTATION

Blind for an application. TriMet also offers a notebook of large numbers, which allows the bus driver to see what 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.

[www.trimet.org](http://www.trimet.org)

### **Disability Parking Permit**

A qualified permanently disabled person may obtain a Disability Parking Permit for no fee. Permits can be moved from one vehicle to another, 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 it allows the holder to park in a public parking zone that has a limit of more than 30 minutes. It also allows parking in any space reserved for disabled parking in Oregon except for "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](http://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 that they have a 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.

# TRANSPORTATION

## Ridesharing Services

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

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

## Air Travel

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

When making your reservation, contact the airline's disability support desk; they often have a dedicated phone number. Your reservation can be marked to let the ground staff and onboard personnel have all the information they need to facilitate any special arrangements you may require such as

## TRANSPORTATION

transportation to your gate and upon arrival at your destination, as well as assistance regarding your baggage and ground transportation. This information can also be entered into a reservation online.

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

### **Miracle Flights**

Some people affected by LHON want to travel to a distant location to see a LHON specialist, but find the travel cost prohibitive. One option to consider is Miracle Flights, the nation's leading medical flight charity and one of the only national non-profits. They arrange more than 600 flights every month to medical facilities across the country.

[www.miracleflights.org](http://www.miracleflights.org)

### **Amtrak**

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

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

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

[www.amtrak.com/passengers-with-disabilities-discounts](http://www.amtrak.com/passengers-with-disabilities-discounts)



## TRAVEL & LEISURE

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### **National Parks Access Pass**

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

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

If you apply for an Access Pass at a Federal recreation site you do NOT need to fill out an application. Upon arrival, the officer will verify your documentation of disability and that you are a U.S. citizen or permanent resident by checking your ID. You will then be issued the Pass. The Pass is free if obtained in person, and there is no processing fee. Before making a trip to obtain a Pass, be sure to contact the site to ensure that they have Passes available. To obtain an Access Pass through the mail or online, you must complete an application, provide a photocopy of proof of citizenship or residency, documentation of disability, and pay the processing fee. The cost of obtaining an Access Pass through the mail or online is \$10 for application processing (the Pass is free).

[store.usgs.gov/access-pass](https://store.usgs.gov/access-pass)

## TRAVEL & LEISURE

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### ***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.

[www.loc.gov/nls](http://www.loc.gov/nls)

#### **Libby by OverDrive**

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

[www.overdrive.com](http://www.overdrive.com)

#### ***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.

[www.sfl.org](http://www.sfl.org)

## TRAVEL & LEISURE

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

[www.discovernac.org](http://www.discovernac.org)

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

[www.challengedathletes.org](http://www.challengedathletes.org)

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

[www.usaba.org](http://www.usaba.org)

## ASSISTIVE TECHNOLOGY

### **Aira**

Aira delivers instant access to visual information. Aira's trained, professional agents remotely assist people who are blind or 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. 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.

[www.aira.io/free-access](http://www.aira.io/free-access)

### **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

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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.

[www.bemyeyes.com](http://www.bemyeyes.com)

### Seeing AI

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

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

<http://SeeingAI.com>

### Apple Pay

Once set up, Apple Pay is easy and works with your Apple devices. You can make contactless, secure purchases in stores, apps, and on the web. You can also send and receive money from friends and family. Apple Pay is safe, helping you avoid touching buttons or exchanging cash. For many people with low vision, it is often simpler and more secure than using a physical

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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 (CFTB)**

CFTB is a non-profit 501(c)(3) organization located in Richardson, Texas, devoted to providing refurbished computers with assistive technology to persons who are blind or visually impaired, at very low cost. There are no income or age requirements. There is a processing fee for a desktop or laptop with JAWS or ZoomText installed. Shipping is free in the US. Certain upgrades are available, and details are on this fact sheet: <https://www.computersfortheblind.org/src/documents/CFTBPriceSheet.pdf>

[www.computersfortheblind.org](http://www.computersfortheblind.org)

## MISCELLANEOUS

### **Avoiding Unnecessary Medical Care**

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

[www.LHON.org/living-with-LHON](http://www.LHON.org/living-with-LHON)

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.

### **Employee Assistance Programs (EAP)**

Many employers offer an Employee Assistance Program 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 Program 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.

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### **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 of 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



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testing done for that single, targeted mutation. The cost is far less than the broader panel test.

### **First in Family**

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

The Carver Lab at the University of Iowa is a non-profit lab, so the cost of 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.

[www.CarverLab.org](http://www.CarverLab.org)

Athena Diagnostics offers the Athena Alliance Program. This is a financial assistance program for those with low income.

[www.AthenaDiagnostics.com](http://www.AthenaDiagnostics.com)

GeneDx offers a Financial Assistance Program.

<https://www.genedx.com/tests/billing>

### **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.

### **Bigger Standard Deduction**

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

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from your adjusted gross income. Married filers also benefit from this deduction when their spouse is visually impaired. If you're blind and over age 65, your savings increase.

### **Medical Deductions for the Blind**

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

### **Impairment-Related Work Expenses**

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

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.