

A Guide to Navigating LHON with Money in Mind

Information & Resources for the
Texas 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 Texas 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

Texas Workforce Solutions-Vocational Rehabilitation Services

[Texas Workforce Solutions-Vocational Rehabilitation Services \(TWS-VRS\)](#) supports people with disabilities in preparing for, obtaining, maintaining, and advancing in meaningful employment. VR counselors work closely with job seekers to determine an employment goal, then identify and arrange for high-quality services. TWS-VRS is part of the Texas Workforce Commission and a statewide network of 28 Workforce Development Boards.

Services include: referrals for visual and other examinations; medical and psychological assessments; college education or trade certification; on-the-job training; vocational adjustment training; rehabilitation teachers; orientation & mobility training; Braille instruction; and supported employment.

To locate a TWS-VRS office, visit the following website:

www.twc.texas.gov/find-locations

Criss Cole Rehabilitation Center

[Criss Cole Rehabilitation Center \(CCRC\)](#) is a state-of-the-art adult residential training facility located in Austin, Texas, the largest vocational training facility in the United States. CCRC provides training in orientation & mobility, daily living skills, Braille, technology, career guidance, industrial arts, and adjustment to blindness. CCRC offers three training paths: Proficiency Training, Career Focus Training, and the Deafblind Training Program. To participate, customers must be legally blind or meet the definition

of deafblind and be referred by a VR counselor. Phone: 512-377-0300 | Email: ccrc.admissions@twc.state.tx.us

National Federation of the Blind of Texas

The [National Federation of the Blind Texas branch](#) (NFB) is the oldest and largest nationwide organization of blind Americans. Founded in 1940 and headquartered in Baltimore, the NFB consists of affiliates, chapters, and divisions in all 50 states. Through its network of blind members, it coordinates programs, services, and resources that provide information and support to children and adults. It offers training and career mentoring, as well as scholarships and awards. Additionally, the NFB sponsors the [Free White Cane Program](#), 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 as often as every six months.

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.

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.

DISABILITY INSURANCE

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.

Veterans Affairs — Blind Rehabilitation Service

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

SOCIAL SECURITY

Employment Supports

There are many provisions designed to 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.

Disability Rights Texas (DRTx)

[Disability Rights Texas \(DRTx\)](#) is Texas's state disability protection and advocacy system, helping people with disabilities. Disability Rights Texas (DRTx) provides information, advice, and support regarding Social Security and other matters.

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 SSDI, which is based on work experience, Supplemental Security Income (SSI) is a program based on need. Eligibility does not depend on whether or not you worked and paid into Social Security. SSI is available to people who are disabled (including legally blind) or over 65, with limited income and resources.

To apply for SSI, visit the [Social Security website](#) or call 1-800-772-1213. Do not wait to apply. The earliest SSI payment is made the month after your application is filed.

MEDICAL INSURANCE

Medicare

[Medicare](#) is a national health insurance program. If you are aged 18 to 64, your Medicare eligibility is tied to your SSDI eligibility. Once approved for SSDI, you must wait 5 months for income benefits to begin, and an additional 24 months before Medicare benefits begin.

Medicare Part A covers hospital, skilled nursing, and hospice services at no cost. Part B covers outpatient services, most provider office visits, and most professionally administered prescription drugs. Part C (Medicare Advantage) is an alternative to Parts A and B. Part D covers most self-administered prescription drugs.

Medicaid in Texas

[Medicaid in Texas](#) provides health coverage to people with low income and limited assets who meet certain eligibility requirements. If you are blind or have a disability and receive SSI, you are eligible for Medicaid.

Many people affected by LHON at a young age are not eligible for Medicare because they don't have the work credits to qualify for SSDI. These people are only covered by Medicaid, not Medicare, if they are eligible based on low income and low assets. Some people are eligible for both Medicare and Medicaid; Medicare is the primary payer, and Medicaid is the secondary payer. To apply: visit www.yourtexasbenefits.com and choose "Apply for new benefits." Note: Approval may take up to 45 days.

Community Health Centers in Texas

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

EDUCATION

Early Childhood

[Early Childhood Special Education \(ECSE\)](#) services are designed for young children (aged 3–5) with disabilities. School districts are required by law to ensure that a developmentally appropriate ECSE program is available and that all children with disabilities have a free and appropriate public education (FAPE).

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 to develop an Individualized Education Program (IEP).

The Texas education system provides support to students who are visually impaired through their school district and/or the [Texas Workforce Solutions-Vocational Rehabilitation Services \(TWS-VRS\)](#). 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 comes from the state, and families generally do not have to cover the costs of educational accommodations. Medical documentation establishing legal blindness is required.

Higher Education

If someone is affected at a college-age or beyond, it is important to establish a relationship with [Texas Workforce Solutions-Vocational Rehabilitation Services \(TWS-VRS\)](#) and the Disability/Accessibility center at your campus. A TWS-VRS counselor assists with determining educational needs based on the student's chosen career field, FAFSA guidance, assistive technology evaluation, and financial support. Students must complete FAFSA every year at studentaid.gov/h/apply-for-aid/fafsa. FAFSA approval can take up to four months. For those interested in higher education, there are scholarship opportunities on the [Living with LHON webpage](#).

Certificate of Blindness Tuition Waiver — Texas

Texas residents who are legally blind are eligible for a Certificate of Blindness Tuition Waiver. This waiver is valid for any public college in Texas and waives all tuition and fees (except refundable deposits) when presented to the college's registrar. Private and out-of-state colleges will not honor the waiver. TWS-VRS will issue the waiver upon the student presenting a current eye exam report that shows legal blindness. Contact your local TWS-VRS counselor to obtain the waiver.

National Federation of the Blind

The [National Federation of the Blind](#) (NFB) offers training and career mentoring, as well as scholarships and awards. 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 federal student loans based on total and permanent disability. Contact the Department of Education by phone: 888-303-7818, email: disabilityInformation@Nelnet.net, or online at: www.disabilitydischarge.com.

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.

Disability Rights

The Americans with Disabilities Act of 1990 ("ADA") is federal legislation that prohibits employers from discriminating against qualified individuals with disabilities. Workers are deemed qualified if they meet the job's educational requirements and can perform the job duties, with or without reasonable accommodations.

Texas Workforce Solutions-Vocational Rehabilitation Services

[Texas Workforce Solutions-Vocational Rehabilitation Services \(TWS-VRS\)](#) supports people with disabilities in preparing for, obtaining, maintaining, and advancing in meaningful employment through personalized vocational counseling, job skills training, job placement, and assistive technology support.

Job Accommodation Network

The [Job Accommodation Network](#) (JAN) is a leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. JAN's consultants offer one-on-one guidance on workplace accommodations, the Americans with Disabilities Act (ADA) and related legislation, and self-employment and entrepreneurship options for people with disabilities. Assistance is available both over the phone and online. JAN provides individualized consultation to assist:

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

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

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.

Disability Parking Placard — Texas

A qualified permanently disabled person may obtain a Disabled Parking Placard that can be transferred from one vehicle to another. With a placard, you can park in on-street metered spaces at no charge and in spaces designated for people with disabilities. The placard is valid for four years.

Apply at your local Texas tax collector's office using Form VTR-214 ([Application for Persons with Disabilities Parking Placard and/or License Plate](#)). Required: Form VTR-214, a medical certification signed by your doctor or optometrist, and a copy of your Texas driver's license or ID card.

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.

Paratransit

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

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

Ridesharing Services

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

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

GoGoGrandparent

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

To use GoGo, you must create an account. They offer a variety of plans and pricing options to suit your needs.

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

TRAVEL AND LEISURE

Fishing License — Texas

A Special Resident All-Water Fishing License is available to any Texas resident who is legally blind — endorsements are not required for this license. For information, visit: [Texas Parks and Wildlife — Fishing Licenses](#).

Texas Parklands Passport

[Texas Parklands Passport](#) provides persons with permanent disabilities a 50% discount on the entry fee to Texas state parks (rounded to the next whole dollar). For example, if the entry fee is \$3, you and a companion each pay \$2.

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

Audiobooks and Periodicals

Bookshare

[Bookshare](#) is an ebook library where members can access a collection of over 1,109,245 titles. It includes books for school, career, and reading pleasure, as well as titles in over 34 languages. Thanks to funding from the Office of Special Education Programs (OSEP) in the U.S. Department of Education, Bookshare is free for all qualified U.S. students and schools. Qualified individuals who are not students pay a nominal annual membership fee. To qualify, you will need to provide a proof of disability form signed by a qualified expert, such as an ophthalmologist.

Braille and Audio Reading Download

[Braille and Audio Reading Download](#) (BARD) is a free online service run by The National Library Service for the Blind and Print Disabled (NLS) that allows you to download books and magazines instantly.

To use BARD, you must be an NLS patron and fill out an application. Once approved, you can download the BARD mobile app for either iOS or Android at no cost.

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.

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.

LibriVox

[LibriVox](#) offers free public-domain audiobooks available for download or streaming — a great, low-cost resource for accessible audio classics.

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 audio editions of classic literature.

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 desktops or laptops 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.

Deduction for the Legally Blind

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

Impairment-Related Work Expenses

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

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

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.

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.

Texas State Tax — Note

Texas has no personal state income tax, so there is no state-level blind deduction. Federal tax deductions for the legally blind (larger standard deduction, IRWE) still apply. Check with your tax preparer for details.

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](https://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](https://carverlab.org) 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](https://athena-diagnostics.com) offers the Athena Alliance Program. This is a financial assistance program for low-income individuals.
- [GeneDx](https://genedx.com) offers a Financial Assistance Program and accepts all commercial insurance, Medicaid, Medicare, and Tricare plans.
- [Probably Genetic](https://probablygenetic.com) 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.

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.

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.