

A Guide to Navigating LHON with Money in Mind

Information & Resources for the
Pennsylvania LHON Community

Updated August 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 Pennsylvania 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.

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TRAINING & TECHNICAL RESOURCES

American Council of the Blind

The [American Council of the Blind](#) is a national advocacy and support organization. They offer peer support, local chapter meetings, and advocacy on issues affecting people who are blind or have low vision.

Bureau of Blindness and Visual Services (BBVS)

[BBVS](#) assists individuals with visual impairments in Pennsylvania with services that may include guidance on applying for Social Security benefits, finding work, setting up a business, independent living skills and specialized child services. There are district offices located all throughout the state.

Center for the Blind and Visually Impaired (CBVI)

[CBVI](#) provides various services such as transportation, rehabilitation therapy,

orientation & mobility training, and low cost vision exams for visually impaired individuals. They offer various youth services to assist low-vision youth with navigating education and employment.

Foundation Fighting Blindness

The [Foundation Fighting Blindness](#) drives research to provide preventions, treatments, and cures for people affected by retinal degenerative diseases such as LHON. Assistance is provided in learning about the disease and clinical trials, finding retina specialists, and connecting with others who are visually impaired.

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.

GoodWill Vision Enterprises (GVE)

[GVE](#), previously known as the Association for the Blind and Visually Impaired (ABVI), provides programs to teach and help anyone who is blind or visually impaired live an independent and meaningful life. Programs include low vision services, orientation and mobility services, and vision rehabilitation therapy all available by appointment.

National Eye Institute

The [National Eye Institute](#) explains low-vision services, rehabilitation options, and offers downloadable guides (e.g., "Living with Low Vision") that are free and evidence-based. These materials help patients and clinicians decide about vision-rehab referrals and what to expect from adaptive training. NEI also lists national rehab centers and research updates relevant to diseases like LHON.

Patient Advocate Foundation

The [Patient Advocate Foundation](#) (PFA) provides case management and

assistance to patients with chronic, life-threatening, and debilitating illnesses, including help with insurance and financial issues. PFA case managers provide free 1 on 1 management for patients and families. Case management services include helping with accessing therapies and assistive devices, paying for living expenses and treatments, finding employment, getting disability insurance, or helping with income.

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.

Pennsylvania Association for the Blind

With local agencies across the state, the [Pennsylvania Association for the Blind](#) offers various services including instruction in daily living activities, orientation and mobility instruction, summer instructional programs for children, counseling and case management, technology instruction, low vision examinations, and in-home supportive services. Check out the link below to find an agency in your area.

Pennsylvania Office of Vocational Rehabilitation (OVR)

The [PA Office of Vocational Rehabilitation](#) provides services to help individuals with disabilities prepare for, obtain, or maintain employment, including assistive technology support. The counselors provide face-to-face interviews to assist customers in achieving their vocational goals. There are district offices located across the state, serving all 67 counties.

United Mitochondrial Disease Foundation (UMDF)

As LHON is a mitochondrial disease, [UMDF](#) is a vital national resource providing disease-specific support, education, and patient registry information. They connect families with doctors and LHON-specific support groups.

VisAbility

[VisAbility](#) is a nonprofit organization dedicated to empowering individuals who are blind or visually impaired to live independently and confidently. They offer comprehensive services including low vision rehabilitation, assistive technology training, independent living skills instruction, and employment support. VisAbility also provides community-based programs such as children's vision screenings,

transportation services, and diabetes prevention initiatives. Their mission is to break down barriers and help individuals with vision loss reach their full potential. Many services are low-cost or covered by Medicare insurance.

The Sight Center of Northwest PA

The [Sight Center of Northwest PA](#) offers specialized support services to the blind community including transportation, assistance with bill-paying, mail-reading, grocery shopping, and participation in support groups.

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.

VisionCorps

[VisionCorps](#) is a nonprofit that offers rehabilitation services and training for individuals with vision loss in Pennsylvania. Residents with low vision in Adams, Chester, Lancaster, Lebanon, and York counties can depend on VisionCorps to teach and provide tools to maintain quality of life. Services are provided at no cost to clients.

Vision Resources of Central Pennsylvania (VROCP)

The [Vision Resources of Central Pennsylvania](#) is a community benefit organization that has a mission to facilitate independence, enrich the quality of life, and empower individuals who are visually impaired or otherwise disabled through prevention, employment and educational awareness programs. Programs include free vision screenings for preschool children, and assigning caseworkers to assist with bill-paying and transportation. Monthly life skills education meetings are offered in Cumberland, Dauphin and Franklin counties.

DISABILITY INSURANCE

Family Medical Leave

Both federal ([FMLA](#)) and Pennsylvania 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 for eligible veterans with vision impairment — services are comprehensive and provided through VA medical centers. If the patient is a veteran, this is frequently free or low-cost to them.

SOCIAL SECURITY

Employment Supports

There are many provisions designed to 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.

Protection & Advocacy for Beneficiaries of Social Security (PABSS)

[PABSS](#) Provides advocacy and legal services to help social security beneficiaries facing challenges related to employment or benefits issues. The Ticket to Work and Work Incentives Improvement Act of 1999 authorized incentives assistance program grants to the designated Protection and Advocacy (P&A) system in all 50 states.

MEDICAL INSURANCE

Medicare

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

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

Medicare covers only some of the healthcare expenses of 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.

NeedyMeds

[NeedyMeds](#) is a national nonprofit database that helps people find patient assistance programs, drug discount cards, and low-cost clinics. It's free to use and particularly useful to locate manufacturer patient assistance programs (PAPs) and local low-cost health centers when insurance is limited. They also publish state-specific resources.

Pennsylvania Health Access Network (PHAN)

[PHAN](#) is an advocacy organization with a long history of successful campaigns to improve health equity across Pennsylvania. They also work on an individual level by helping people navigate the healthcare system.

Pennsylvania Medicaid for Children with Special Needs (PH95)

The [PH95 program](#) provides full Medical Assistance coverage to children with disabilities, regardless of parental income. Designed for parents who make too

much money to qualify for traditional Medicaid categories, benefits include emergency and physician services, prescriptions, medical supplies, mental health treatment, and rehabilitation services. Children must be under the age of 18, hold a valid social security number, and are considered disabled according to Social Security standards.

Genetic Testing

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

Obligate Carrier/On the Maternal Bloodline

It is first helpful to understand the genetic transmission of a LHON mutation. LHON is maternally inherited, and a woman who carries a LHON mutation usually passes that mutation to all of her children.

If someone on your maternal bloodline had genetic testing done and has a confirmed diagnosis of their LHON mutation, you can reasonably assume that you're an "obligate carrier." This means that based on genetics, you carry the same LHON mutation. You can presume you carry that LHON mutation without doing any genetic testing, which is the least expensive option. Also, there are no test results in your medical records that could impact your future insurance choices.

If you're an obligate carrier and would prefer to have your own genetic testing done to confirm your genetic status, you can save money by testing for just the specific mutation in your family. Most LHON genetic testing is a panel that tests for multiple LHON mutations at one time. However, if you have a copy of your maternal relative's LHON genetic test results, you can get testing done for that single, targeted mutation. The cost is far less expensive 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 usually much lower than at for-profit labs. Note that they batch their testing, so the turnaround time is slower than other labs.

[Athena Diagnostics](#) offers the Athena Alliance Program. This is a financial assistance program for those with low income.

[GeneDx](#) offers a Financial Assistance Program and accepts all commercial insurance, Medicaid, Medicare and Tricare plans.

[Probably Genetic](#) offers free at-home testing.

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 Pennsylvania education system provides extensive support to students who are visually impaired through their school district and/or the [Pennsylvania Vocational Rehabilitation Services](#). 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 Pennsylvania 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 [Pennsylvania Vocational Rehabilitation Services](#) 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.

American Foundation for the Blind Digital Inclusion Toolkit

The [American Foundation for the Blind](#) offers many resources for navigating educational advocacy as a blind student, parent of a blind student, or teacher. They provide digital inclusion toolkits for each of these subgroups to ensure blind students can receive an equitable education.

Children's Hospital of Pittsburgh – Vision Enhancement Center

The [VEC](#) is a collaboration of health care providers, educators, social workers, and other specialists located throughout Allegheny County. They provide information on organizations and support services for children with vision impairments, aiding in educational planning. This center provides information from summer opportunities to expert medical care.

Learning Ally

[Learning Ally](#) is a national non-profit offering a large library of human-narrated audiobooks, providing K-12 and college-level textbooks and literature in an accessible format for students with visual or learning disabilities. There is a low-cost subscription, often covered by schools.

Parent Education & Advocacy Leadership (PEAL) Center

The [PEAL Center](#) works with families, youth, and young adults with disabilities to help them understand their rights and advocate for themselves in the educational setting.

PaTTAN – Assistive Technology

The [Pennsylvania Training and Technical Assistance Network \(PaTTAN\)](#) offers resources and training on assistive technology for educators and families, focusing on enhancing learning for students with disabilities. Week-long summer institutes, ongoing professional development series, webinars, on-site assistance, and individual student or teacher support are some of the means by which PaTTAN provides support to schools.

Western Pennsylvania School for Blind Children (WPSBC)

Located in Oakland, [WPSBC](#) provides specialized education and services for individuals with visual impairments, offering programs from early childhood through adulthood. Approximately 200 children are enrolled in the school every year. WPSBC hopes to nurture the unique abilities of individuals with blindness and visual impairment through educational excellence and a lifetime of learning.

Nationally Available Scholarships

- [AFB Scholarship](#)
- [NFB Scholarship Program](#)
- [College Scholarships](#)
- [Lighthouse Guild Scholarships](#)
- [Christian Record Services Scholarship](#)
- [Learning Ally's National Achievement Awards](#)
- [Financial Aid for Students with Disabilities](#)

For more information about educational resources and scholarships, visit the LHON website. 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, 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 designed to combat discrimination and protect 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 to be qualified to perform a job under the ADA if they meet the educational and other requirements for the job, and they can perform the job duties with or without reasonable accommodations.

Job Accommodation Network

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

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

- Individuals with medical conditions and disabilities seeking information about job accommodation solutions, employment rights under the ADA, and self-employment and entrepreneurship opportunities.
- Family members and rehabilitation, medical, educational, and other professionals are in their effort 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.

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 Placard — Pennsylvania

A qualified disabled person may obtain a [Disability Parking Placard](#). Placards can be moved from one vehicle to another, making them a good option for someone affected by LHON who rides in various cars. In the state of Pennsylvania, a permanent placard may be obtained if a person is blind or is the parent or spouse of a blind person. To apply, either visit the Riverfront Office Center in Harrisburg (1101 S Front St, Harrisburg, PA 17104) or mail the form to PennDot in Harrisburg. Applications must be certified by a health care personnel.

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

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

Braille and Audio Reading Download (BARD)

[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 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.

Library of Accessible Media for Pennsylvanians (LAMP)

The [Library of Accessible Media for Pennsylvanians](#) is dedicated to providing a wide-set of services for those with visual impairments. Their various libraries offer Braille and large-print literature as well as audiobooks. LAMP also provides technical assistance in person and over the phone, especially assisting patrons with BARD. For those under 21 years old, they offer various activities to engage with the blind community at a young age.

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.

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.

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.

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

[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.

National Ability Center

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

United in Stride

[United in Stride](#) is an online resource to unite blind/visually impaired runners and sighted guides across North America. It is free to register and individuals can pair up with someone of similar athletic ability or goals including walking, hiking, jogging or running.

United States Association of Blind Athletes

A good source of information on sports available in your area is the [United States Association of Blind Athletes](#).

Traveleyes International

[Traveleyes](#) offers guided group tours specifically designed for blind and visually impaired travelers, where sighted travelers act as guides in exchange for a

discounted trip. While international, the model can make travel affordable and accessible.

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.

Alexa

[Alexa](#) is a virtual assistant developed by Amazon, powered by artificial intelligence and voice recognition technology. It primarily operates through Amazon's Echo devices and other compatible hardware, allowing users to interact via voice commands.

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.

Blindsquare

[BlindSquare](#) is a widely used, accessible GPS app designed for blind, deafblind, and partially sighted individuals to aid with orientation and mobility. Available on iOS (and recently Android via XploreNinja), it uses GPS and compass technology to determine the user's location, gathering environmental data from Foursquare and OpenStreetMap. The app employs algorithms to prioritize relevant information, delivering it through high-quality speech synthesis (Acapela voices) or VoiceOver.

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.

Early Intervention Technical Assistance (EITA) – Assistive Technology

[EITA](#) provides guidance on integrating assistive tools into daily routines for children with disabilities, supporting decision-making on appropriate technology use. Working on behalf of the Bureau of Early Intervention Services, EITA provides training for local infant/toddler and preschool agencies in providing support for children with disabilities. They work on supporting kids from birth until school age.

Free Screen Readers (NVDA)

[NonVisual Desktop Access \(NVDA\)](#) is a free, open-source screen reader for Microsoft Windows. It's an excellent, cost-free alternative to commercial software, providing complete spoken access to a computer.

Hey Google

Hey Google is a virtual assistant developed by Google, powered by artificial intelligence and voice recognition technology. It primarily operates through Google speaker devices and other compatible hardware, allowing users to interact via voice commands.

Pennsylvania Assistive Technology Foundation (PATF)

[PATF](#) is a nonprofit statewide organization that offers resources and financial assistance for acquiring assistive technology in Pennsylvania. Assistive technology encompasses any device that helps a person achieve a more independent life. Examples of assistive technology include computers, adapted sports equipment, adapted vehicles, and many more.

TapTapSee

[TapTapSee](#) is a free mobile application that uses a phone's camera to photograph everyday objects and speak the object's identity back to the user. It is a simple, effective, and cost-free tool for object recognition.

TechOWL (Technology for Our Whole Lives)

[TechOWL](#), operated by Temple University, assists Pennsylvanians with disabilities in exploring and acquiring assistive technology. They offer device demonstrations, loans, and a used equipment exchange program through ten Assistive Technology Resource Centers across the state. TechOWL also provides free presentations and training for Pennsylvania organizations, universities, schools, groups, and more. Pre-recorded and asynchronous learning opportunities can be found on their website.

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.

ABLE Account Tax-Benefit

Pennsylvania supports [ABLEnow accounts](#), which allow people with disabilities to save up to a specified amount without jeopardizing eligibility for public benefits. Contributions may qualify for a Pennsylvania state tax deduction under “other deductions”, where contributors to ABLEnow accounts may subtract contributions. While Virginia doesn’t list a “blind” deduction exactly like the IRS, use of ABLE accounts or itemized medical cost deductions (federal) may interact with PA state filing.

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.

IRS Accessible Tax Forms

The IRS provides [tax forms and publications](#) in various accessible formats, including Braille, large print, text-only, and audio formats, ensuring all necessary documentation can be reviewed independently.

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](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](#) 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

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.

