



A Guide to Navigating LHON with Money in Mind

Information & Resources for the
Indiana LHON Community

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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 also many resources available that can help mitigate that financial impact.

The goal of this document is to help the Indiana 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 of agencies and programs that can create a better financial outcome for affected patients and their loved ones. Unaffected carriers can also benefit by being better prepared in case they experience LHON vision loss one day.

The organizations and services listed in this document are those that provide free or low-cost assistance. There are many other valuable fee-for-service agencies available. In some cases, those may be a better fit for you. To access them simply search blind or low-vision services in your city/region.

This document is intended as a general guide only. It was developed by LHON volunteers and is subject to change. It does not purport to provide legal, financial or tax guidance. You should check with each listed provider and your own advisors for your specific situation.

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TRAINING AND TECHNICAL RESOURCES

Indiana Vocational Rehabilitation Services

[Indiana Vocational Rehabilitation Services](#) helps individuals with disabilities achieve employment. Vocational Rehabilitation services are offered locally in 25 Area Offices throughout Indiana. Eligibility for services does not depend on income or financial resources. Counselors provide services in each county which may include helping find your first job, providing assistive technology and other services to help you keep your job, training for a new career due to factors related to your disability, and providing services for career advancement. A referral form is required and more information regarding the application process can be found on their website.

Blind and Visually Impaired Services

[Blind and Visually Impaired Services](#) is a state department, under the Family and Social Services Administration, provides statewide assistance services to eligible Hoosiers that are blind or visually impaired, aiming to achieve vocational and personal independence. Services include training, counseling, adaptive technology support, and events run by the Vision Loss Support Group.

Ability Indiana

[Ability Indiana](#) offers free and low-cost services and various programs for individuals with disabilities, including vision loss. These include job training, supported employment, and life skills. The VIBE program (Visually Impaired Blind Experience) works with people who are visually impaired and blind to maintain and remain independent in their own environments. Staff work to identify and overcome barriers through support from assistive technology, peer counseling, community programs, and more.

AccessABILITY Center for Independent Living

[AccessABILITY Center for Independent Living](#) serves the Indianapolis area, AccessABILITY provides resources and support for individuals with disabilities, including those with visual impairments. Services include advocacy, independent living skills training, and peer support empowering people with disabilities free of charge in central Indiana. This service is available for the following counties: Boone, Johnson, Hamilton, Hancock, Hendricks, Marion, Morgan and Shelby.

American Council of the Blind Indiana

[American Council of the Blind Indiana](#) (ACBI) strives for the betterment of the blind community in Indiana by increasing the independence, security, equality of opportunity, and enhancing lives of people of all ages and backgrounds with vision loss. ACBI chapters allow visually impaired people to meet other visually impaired people, share experiences, learn about the latest technologies, tips for independent living, travel, education, employment, food and other interests. Chapters include the SouthCentral Association of Visually Impaired Chapter located in Bedford, the Heartland chapter located in Bloomington, the Circle City Chapter located in Indianapolis, and the Hoosier all-state chapter.

Bosma Center for Visionary Solutions

The [Bosma Center for Visionary Solutions](#) is Indiana's largest and most comprehensive provider of rehabilitation and training for people who are blind or visually impaired. The training and rehabilitation techniques provided through this program can teach skills necessary for independent living. Located in the Indianapolis area, Bosma teaches personal management skills, such as cooking and cleaning, in addition to programs on pursuing education and career opportunities.

Easter Seals Crossroads

[Easter Seals Crossroads](#) is located in Indianapolis and provides a variety of rehabilitation services for people with disabilities, including those with vision impairments. They offer adaptive technology, mobility training, and job training for low costs or even free.

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.

Future Choices

Based in Muncie, [Future Choices](#) provides independent living services to individuals with disabilities, including those with visual impairments. They serve people living in Blackford, Delaware, Grant, Howard, Madison, Randolph, and Tipton Counties. Numerous programs and services are available to assist those living with visual impairments.

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.

Independent Living Center of Eastern Indiana

[Independent Living Center of Eastern Indiana](#) (ILCEIN) is based in Richmond, Indiana and offers services to individuals with disabilities, including vision loss. Services include independent living skills, assistive technology, information and referral, peer support, and advocacy.

Lighthouse for the Blind and Visually Impaired

[Lighthouse for the Blind and Visually Impaired](#) is a private, not-for-profit social enterprise that has provided employment, support, and training opportunities for people who are blind since 1918. They offer a multitude of programs at their various locations throughout the United States including: Training on accessible technology, independent living and moving effectively with a cane, social and recreational activities, health and wellness, and Braille instruction.

National Federation of the Blind of Indiana

The [National Federation of the Blind](#) (NFB) is the oldest and largest nationwide organization of blind Americans. Founded in 1940 and headquartered in Baltimore, the NFB consists of affiliates, chapters, and divisions in all 50 states. Through its network of blind members, it coordinates many programs, services, and resources, providing information and support to children and adults. It offers training and career mentoring, as well as scholarships and awards. Additionally, the NFB sponsors the Free White Cane Program, where any blind individual in the fifty states can request a cane for their personal use. Requests can be made as often as every six months.

Older Independent Blind Program

The [Older Independent Blind Program](#) expands independent living services for people who are age 55 and older and have a severe visual impairment. Through a grant from the Department of Education, Older Blind Program, Indiana Blind and Visually Impaired Services provide funding to contractors across the state in order to provide in-home independent living training to older individuals with significant vision loss.

Patient Advocate Foundation

The [Patient Advocate Foundation](#) (PAF) 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.

Randolph-Sheppard Business Enterprise Program

The [Randolph-Sheppard Enterprise Program](#) provides rewarding and profitable entrepreneurial opportunities for legally blind clients of Vocational Rehabilitation Services to broaden their economic opportunities and invigorate all blind people to be self-supporting, while dispelling misconceptions about people who are blind by showcasing their abilities. These blind entrepreneurs manage a wide variety of food service operations, including cafeterias, coffee shops, vending locations, and highway area vending sites. Through this program, individuals receive training and opportunities to become productive, tax-paying citizens and independent licensed managers.

Southern Indiana Center for Independent Living

[Southern Indiana Center for Independent Living](#) is a community based cross-disability, non-residential, private organization that promotes independent living. Independent Living Services provided by SICIL are FREE of charge to people with all types of disability regardless of their age. Service area includes Bartholomew, Brown, Crawford, Jackson, Lawrence, Monroe, Orange and Washington counties in Indiana.

The Blind Social Center

[The Blind Social Center](#), based in Gary, Indiana, The Blind Social Center provides a gathering place for blind and visually impaired individuals to come together in a supportive and inclusive environment. Within the social environment, patrons learn Braille training, keyboard/computer training, iPad training, personal management, homemaking, nutrition education, fitness training, as well as arts and crafts.

The Department of Veterans Affairs – Blind Rehabilitation Services

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

The League

[The League](#), based in Fort Wayne, The League offers services to people with disabilities to promote independence. Programs include assistive technology, advocacy, independent living skills and training, and community education.

The Wabash Independent Living & Learning Center

The [Wabash Independent Living & Learning Center](#) (The WILL Center), located in Terre Haute, The WILL Center is a nonprofit, community based, nonresidential organization that is run by and for people with disabilities, including visual impairments, and provides services including skills training, advocacy, peer counseling, and assistive technology assistance. The center serves the counties of Clay, Parke, Putnam, Vermillion, Owen, and Vigo in west central Indiana.

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.

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 through a live video call. It works similarly to Aira. You connect via either an iOS or an Android app on your phone. During the call, you and a volunteer can communicate directly and solve a problem. The volunteer can help guide which direction to point your camera and what to focus on. A blind or a low-vision user may need help with anything from checking expiration dates, distinguishing colors, reading instructions or navigating new surroundings.

Additionally, Be My Eyes has recently introduced Be My AI, a state-of-the-art visual assistance tool that helps vividly describe images via the use of 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, and at restaurants, vending machines, trains, and taxis.

Assistive Technology Fund

Operated by the Association of [Blind Citizens](#), the Assistive Technology Fund (ATF) will provide funds to cover 50% of the retail price of adaptive technologies for the blind and visually impaired. An individual is eligible for this fund if they are legally blind, they have a family income less than \$50,000, and the products covered are between \$200 and \$6,000.

Computers for the Blind

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

Indiana Assistive Technology Act Project

Indiana Assistive Technology Act (INDATA) Project is operated by [Easter Seals Crossroads](#), INDATA provides assistive technology solutions, including device loans and demonstrations, to individuals with disabilities throughout Indiana. The program tries to increase access and awareness of assistive technology. This service comes at no cost to the patient.

DISABILITY INSURANCE

Family Medical Leave

In Indiana, employees are primarily protected under the federal [Family and Medical Leave Act](#) (FMLA), as the state does not have its own family and medical leave laws.

The FMLA requires covered employers to provide eligible employees with up to 12 weeks of unpaid, job-protected leave within a 12-month period for specific family and medical reasons. These reasons include the employee's serious health condition or caring for a family member with a serious health condition. This leave does not need to be taken consecutively.

To qualify for FMLA leave in Indiana, an employee must:

- Have worked for the employer for at least 12 months (not necessarily consecutive).
- Have worked at least 1,250 hours during the 12 months prior to the start of leave.
- Be employed at a location where the employer has at least 50 employees within a 75-mile radius.

Upon returning from FMLA leave, an employee is entitled to reinstatement to their original job or an equivalent position with the same pay, benefits, and other employment terms. Additionally, an employee's use of FMLA leave cannot be counted against them under a "no-fault" attendance policy.

Long-Term Disability Insurance

Long-term disability (LTD) insurance is a private insurance policy that protects an employee from loss of income if he or she is unable to work due to illness, injury, or accident for a long period of time. LTD insurance ensures that an employee will still receive a percentage of their income if they cannot work for an extended period. It can be provided and paid for by employers or individuals. Your employer may offer an LTD option. If a company doesn't offer LTD insurance or if an employee wants additional coverage, he or she has the option to purchase an individual LTD plan.

Some employers, if they do not provide LTD insurance, will develop a relationship with an LTD insurance company to offer an employee discount for their staff who choose to purchase an LTD policy.

LTD insurance provided by an employer may be inadequate to meet your needs. In this case, you might want to consider purchasing supplemental LTD insurance. Since it's expensive for an individual to purchase, LTD insurance is often available through an employee's professional associations at a discounted rate.

LTD insurance benefits usually begin when short-term disability insurance benefits end. Payments to the employee from their employer's LTD insurance (such as where the employer subsidized the premiums) are taxable income.

Payments from an employee-purchased plan, and/or where the employee paid premiums themselves on an after-tax basis, are usually not taxable income.

LTD policies sometimes have offset language. For example, a policy may require an employee to secure Social Security Disability Insurance. The insurance company will then reduce the amount of its payment by the amount SSDI is providing. If someone is collecting on an LTD policy and returns to work, the insurance payout may be reduced by some percentage of the amount earned. Since there are so many complexities to the LTD insurance process, consider hiring a lawyer familiar with LTD insurance to help navigate the process.

Each LTD insurance policy has different conditions for payout, diseases, or pre-existing conditions that may be excluded, and various other conditions that make the policy more or less useful to an employee. Some policies, for example, will pay disability benefits if the employee is unable to work in his or her current profession. Others expect the employee to take any job they are capable of doing. LTD payments to the employee, in some policies, have a defined period. Others pay an employee until he or she is 65 years old.

Consider your health history, your family's history of LHON, and any other diseases to determine the amount of long-term disability insurance that you need.

EDUCATION

Early Childhood

Early Childhood Special Education (ESCE) services are designed for young children (aged 3-5) with disabilities who need specially designed instruction or related services and whose disability causes the children to be unable to participate in developmentally appropriate typical preschool activities.

School districts are required by law to ensure that a developmentally appropriate ESCE 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.

Visually Impaired Preschool Services Indiana

[Visually Impaired Preschool Services](#) (VIPS) Indiana provides early intervention services to young children with visual impairments, including specialized education, therapy,

and family support. The organization has a network of teachers, interventionists, and Certified Orientation and Mobility Specialists who provide vision-specific early intervention services to children, birth to three, across the state. Their family resource center is located in downtown Indianapolis. They help in various areas, including early educational intervention, summer camps, and a parent empowerment program.

School Age

If someone becomes affected by LHON while in elementary, middle, or high school, it is important to contact their school district immediately. A discussion with the school principal, or Section 504 coordinator at the school district, is often the best first step to address concerns.

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

Under Section 504, students with disabilities are entitled to accommodations, aids, and services to access and benefit from education. Section 504 requires that public schools provide a "free appropriate public education" to every student with a disability, regardless of the nature or severity of the disability. A counselor or coordinator works with the student and their family, teacher(s), and the school to develop an Individualized Education Program (IEP) to support and accommodate the student's needs.

For detailed information on Section 504, please see the [Parent and Educator Resource Guide to Section 504](#) in Public Elementary and Secondary Schools.

Indiana School for the Blind and Visually Impaired

The [Indiana School for the Blind & Visually Impaired](#) is one of the largest schools for the blind and visually impaired in the country and is nationally recognized for its excellence. ISBVI educates and invests in many children that, due to blindness/low vision or blindness/low vision and additional handicapping conditions, other schools cannot or have difficulty serving. ISBVI's vision is to provide diverse and salient opportunities for students, educators, and families to access and benefit from these resources. Recognized nationally for its excellence, the school also offers outreach services to support families and educators statewide.

Sightless Children Club

[Sightless Children Club](#) is a non-profit organization for parents of, or students with, significant vision loss specializing in training and equipment to enhance educational endeavors of children with vision loss and providing parent support.

Higher Education

If someone becomes affected at college-age or beyond and seeks to continue higher education, it's important to establish a relationship with the disability/accessibility center on campus. Most colleges and universities offer low-vision assistance and resources such as notetakers and priority registration, as well as other support services.

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.

Indiana Education Scholarship Account

The [Indiana Education Scholarship Account](#) (INESA) will provide students with disabilities and their siblings throughout the state of Indiana access to the educational environment that best meets their learning needs. Parents of eligible students have the opportunity to spend dedicated scholarship money on approved educational programs, therapies, services, tuition and fees, and other expenses related to the students' education.

Nationally Available Scholarships

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

Student Loan Forgiveness

A Total and Permanent Discharge (TPD) relieves you from having to repay a William D. Ford Federal Direct Loan (Direct Loan) Program loan, Federal Family Education Loan (FFEL) Program loan, and/or Federal Perkins Loan (Perkins Loan) Program loan, or complete a TEACH Grant service obligation, on the basis of your total and permanent disability. Before your federal student loans or TEACH Grant service obligation can be discharged, you must provide information to the Department of Education, Federal Student Aid Department, to show that you are totally and permanently disabled. The Department will evaluate the information and determine if you qualify for a TPD discharge.

If you think you might qualify and want to apply for a TPD discharge, you must complete a TPD discharge application and gather supporting documentation on your disability. Contact the Department to apply, either by phone: 888.303.7818 or by email: DisabilityInformation@Nelnet.net. Start your application online at the [Student Aid Government website](#).

If the Department approves your TPD discharge request, they will notify you and the holders of your loans and/or TEACH Grant service obligation of the approval. They will also instruct the loan holders to return any loan payments received after their disability date to the person who made the payments. Your "disability date" is the date they received the documentation of your SSA notice of award for SSDI or SSI benefits or the date the physician signed your discharge application, depending on the type of documentation you provided to show that you are totally and permanently disabled.

After being notified that the Department has approved your discharge request, your loan holders will transfer your loans and/or TEACH Grant service obligation to the Department for discharge. You will then be subject to a 3-year post-discharge monitoring period that begins on the date the discharge is approved. There are requirements that you must meet during the post-discharge monitoring period.

Note: The Department will reinstate your obligation to repay your discharged loans or complete your discharged TEACH Grant service obligation if at any time during the 3-year monitoring period you do not meet the requirements of the post-discharge monitoring period.

EMPLOYMENT

Disability Rights

The Americans with Disabilities Act of 1990 (ADA) is federal legislation designed to counteract bias and protect the rights of the disabled in the workplace. The ADA prohibits employers from discriminating against qualified individuals with disabilities. A disability is defined broadly as any mental or physical impairment that limits at least one major life function. Workers are deemed to be qualified to perform a job under the ADA, if they meet the educational and other requirements for the job and they can perform the job duties with or without reasonable accommodations.

Employment Assistance Programs

Many employers offer an Employee Assistance Program (EAP) that will include several visits to a mental health professional at no cost. Onset of LHON vision loss can have a significant impact on the mental health of the individual affected and their loved ones. An EAP is a valuable 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.

Goodwill Services for People with Disabilities

[Goodwill Services for People with Disabilities](#) offers job placement and vocational training programs tailored to individuals with disabilities including visual impairments. Services include free career centers that assist you in searching for a job, writing a resume and building your job interview skills, rehabilitation programs that help you in your physical recovery, and assistance with your taxes through the Real Economic Impact (REI) partnership, which can provide up to \$5,000 in credits, if eligible.

Job Accommodation Network

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

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

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 those enrolled, and does not cover the cost of low vision devices. It is divided into four parts. Medicare Part A covers hospital, skilled nursing, and hospice services, and has no cost. Part B has a cost, and covers outpatient services, outpatient hospital charges, most provider office visits, and most professionally administered prescription drugs. Your Part B cost can be deducted from your monthly SSDI and/or SSI benefit payment.

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

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

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.

SOCIAL SECURITY

Social Security Disability Insurance (SSDI)

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

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

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

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

Qualification for SSDI is primarily based on two things: documenting a disability and an evaluation of your work history. The Social Security Administration (SSA) looks at your recent work history and how long you’ve worked. There is also an earnings test if you’re still working. If you’re still able to work, and you earn over a certain amount, you aren’t considered disabled.

Benefit amounts vary dramatically based on each individual’s work record. The SSA uses a weighted formula to calculate disability benefits. To get an estimate, view your Social Security statement by creating an account on <https://www.ssa.gov/>.

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

You can speak with an SSDI representative by calling your local Social Security office or the national number (1-800-772-1213). Specific locations can be found at <https://www.ssa.gov/locator/>.

Note: If you receive SSDI benefits and become employed, it is important to pay close attention to the amount of income you earn in relation to the maximum monthly income allowed for a blind individual to earn and to continue to receive SSDI benefits. If your monthly income exceeds the monthly limit, SSDI does not automatically reduce your monthly benefit. They will review your case from time to time, and if they determine that you have received benefits to which you were not entitled, they will send a letter demanding repayment. This can be for a significant amount and can be an extremely unpleasant situation.

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 qualification is based on your resources and 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.

To apply for SSI, you can begin the process and complete a large part of your application by visiting their website at <https://www.ssa.gov/apply>. 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.

<https://www.ssa.gov/apply>

Note: As with SSDI, if you receive SSI benefits, it is important to pay close attention to the amount of income you earn and your assets in relation to the maximum allowed. If your monthly income exceeds the monthly allowed amount, or if in any month your assets exceed the maximum allowed amount, SSI does not automatically stop sending your monthly benefit amount. If you ever request to stop receiving SSI benefits, they will review your case. If they determine that you have received benefits to which you were not entitled, they will send a letter demanding repayment. This can be for a significant amount, and can be an extremely unpleasant situation to be in.

<https://www.ssa.gov/ssi>

Employment Supports

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

Protection & Advocacy for Beneficiaries of Social Security

[Protection & Advocacy for Beneficiaries of Social Security](#) (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.

TRANSPORTATION

Disabled Person Parking Permits

A qualified disabled person may obtain a [Disabled Person Parking Permit](#). If someone is determined to be blind according to Indiana law, they are eligible for a permit. Permits can be moved from one vehicle to another, making them a good option for someone affected by LHON who rides in various cars. One can apply for a permanent disability parking placard by completing a form sent to the Indiana Bureau of Motor Vehicles Winchester.

Commuter Connect

[Commuter Connect](#) offers free alternative transportation in central Indiana with van pool and carpool opportunities.

Discounted Public Transportation

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

Paratransit

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

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

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 levels depending on your needs.

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

Air Travel

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

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

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

Miracle Flights

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

Amtrak

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

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

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

TRAVEL & LEISURE

Audiobooks and Periodicals

Allen County Public Library Audio Reading Service

[Allen County Public Library's Audio Reading Service](#) is specifically designed for and directed to people who have visual, physical, learning or language challenges to reading traditional printed materials because of blindness in the Fort Wayne area. Through this free service, you can take advantage of the broadcasting of local and national readings, which are accessible through free radio receivers, web streaming, Mobile Sero App, Alexa-enabled devices. The service broadcasts 24 hours a day, 7 days a week.

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

[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.

Indiana Reading and Information Services

[Indiana Reading and Information Services](#) (IRIS) is a free audio reading service for anyone with a condition that affects reading traditional print. Listeners can stay informed, inspired, and engaged with the central Indiana community by tuning to hear articles from area newspapers, popular magazines, public service announcements, chapter books, and more. IRIS delivers audio readings of many different types of publications to individuals with visual impairments within 50 miles of Indianapolis. Services are available through no-cost special radios and online streaming. The live broadcast is streamed everyday from 6am - 10pm.

Indiana Talking Book and Braille Library

The [Indiana Talking Book and Braille](#) provides free library services to residents of Indiana who are unable to read standard printed material due to visual, physical, or reading disability. Those eligible can borrow braille books, digital audio books, large print books, audio magazines, and special playback equipment from the library. Materials can be mailed directly to homes. Braille and audio books are also available to download.

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.

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.

National Parks Access Pass

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

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

If you apply for an Access Pass at a Federal recreation site, you do NOT need to fill out an application. Upon arrival, the officer will verify your documentation of disability and that you are a U.S. citizen or permanent resident by checking your ID. You will then be issued the Pass. The Pass is free if obtained in person, and there is no processing fee. Before making a trip to obtain a Pass, be sure to contact the site to ensure that they have Passes available.

To obtain an Access Pass through the mail or online, you must complete an application, provide a copy of proof of citizenship or residency, documentation of disability and pay the processing fee. The cost of obtaining an Access Pass through the mail or online is \$10 for application processing (the Pass is free).

Fishing License

Legally blind residents of Indiana are exempt from needing a fishing license when fishing in public waters within the state. Proof of being legally blind is not required while fishing.

SPORTS

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

Challenged Athletes Foundation

Organizations like the [Challenged Athletes Foundation \(CAF\)](#) provide 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 the sport of Para triathlon.

Indianapolis Bowling League for the Blind

Indianapolis Bowling League for the Blind meets weekly beginning in August at Eastgate's All Star Bowl. A guide rail is available for those who find it helpful. If interested, please contact Mrs. Jeanette Schaefer via email at jazs@comcast.net and put "Bowling" in the subject line.

National Ability Center

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

Rehabilitation Hospital of Indiana

[Rehabilitation Hospital of Indiana](#) organization specializes in serving youths and adults with various disabilities including visual impairments. Specifically designed equipment is available to enable participants to enjoy activities comfortably and safely. Sports clinics are offered year-round with education regarding adaptive equipment and community resources. Sports programs are also available on a competitive and noncompetitive recreational level.

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

All Kids Included

[Accessible Arts Experiences for Kids](#) (AKI) promotes inclusive arts and cultural programs in school settings and throughout the community so that kids of all abilities and their families can participate fully in the arts.

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.

TAX TIPS

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

Deduction for the Legally Blind

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

Impairment-Related Work Expenses

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

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

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

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 Program (VITA) sponsored by the IRS. Taxpayers can find a nearby IRS office location by calling 1-800-906-9887.

MISCELLANEOUS

Leader Dogs for the Blind

[Leader Dogs](#) is an organization that aims to enhance the mobility, independence, and quality of life for the visually impaired through their services that range from matching with a Leader Dog to white cane training. Through their guide dog training services, clients have the opportunity to train with their guide dog in a variety of situations to fit current and future lifestyle needs. Their services are provided at no cost and their program will cover expenses for training, room and board, and travel to their campus.

Low-Cost Grocery Delivery

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

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 trying to get the correct diagnosis. If LHON vision loss begins when an individual knows they carry a LHON mutation, they can avoid all of these costs, and go directly to a LHON specialist for care. This is one of many reasons why people in the LHON community tell their maternal relatives about LHON. While it can be difficult information to share, there can be great value. There are several videos and links in the Genealogy section of the [LHON.org](https://lhon.org) website that can help in identifying maternal relatives, and preparing to share the information.

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

General Financial Support

Many in the LHON community have been creative in finding financial support. Local service organizations are often willing to assist those in need, in particular Lions Clubs which have a specific mission to serve those with vision loss. College fraternities and sororities often do fundraising and are willing to provide support, especially the Delta Gamma (DG) sorority whose philanthropy is Service for Sight. GoFundMe.com is a fundraising platform on which individuals can describe their financial hardship or need, then share the link with family and friends to crowd source donations.

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.