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# **A Guide to Navigating LHON with Money in Mind**

**Information & Resources for the  
Illinois LHON Community**

*May 2025*

# Purpose

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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 Illinois 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.

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

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



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## TRAINING & TECHNICAL RESOURCES

### **Illinois Department of Human Services Division of Rehabilitation Services**

The Illinois Department of Human Services Division of Rehabilitation Services is the state's lead agency serving individuals with disabilities. The division works in partnership with people with disabilities and their families to assist them in making informed choices to achieve full community participation through employment, education, and independent living opportunities.

<https://www.dhs.state.il.us/page.aspx?item=29736>

### **Access Living - Chicago**

Access Living provides comprehensive services and support for individuals in Chicago with a variety of disabilities, aiming to help them live independently and fully participate in the community. The organization offers home and community-based services, including personal assistants, community support, cross-disability support groups, information and referral services, and money management assistance. Additional services include youth programs, peer support groups, legal assistance, consulting and training, and an Independent Living Technology Program.

<https://www.accessliving.org/our-services/>

### **Blind Service Chicago**

Blind Service Chicago is a Chicago-based service that provides the blind community with accessibility resources, and scholarships for college-aged individuals. Free resources that the organization provides include Reading and Recording services, where trained volunteers read anything that the clients need, and assist with completing forms and applications. They also host youth programs, including a summer program where kids can gain skills to assist with their independence.

<https://www.blindservicechicago.org/programs-services/>

### **Center for Independent Living (CIL) Network**

The Illinois Network of Centers for Independent Living (INCIL) supports 22 Centers for Independent Living (CILs) across the state. These organizations provide community-based, non-residential support for people with disabilities so they may achieve independence in every aspect of their lives, including home,

work, and school. CILs provide support for all people living with disabilities, regardless of their disability type, age, or economic status. CILs provide information resources, independent living skills training, peer support, advocacy, and transition support. They have a home modification program and a personal assistant training program as well.

<https://www.incil.org>

### **Central Illinois Center for the Blind and Visually Impaired**

The Central Illinois Center for the Blind and Visually Impaired offers a variety of programs, including the Uprising Technology Center, educational initiatives, social activities, and additional services such as the Assistive Technology Loaner Program, food pantry, and personal assistance. The transportation program provides free rides to events and programs within a 15-mile radius of Peoria. The website also features a comprehensive list of resources related to advocacy groups, blindness, braille, education, assistive products, and local and state services.

<https://cicbvi.org/programs-services/>

### **Chicago Lighthouse**

The Chicago Lighthouse offers 40 unique programs and services that help clients optimize remaining vision, meet developmental and educational milestones, and lead more independent lives.

<https://chicagolighthouse.org/programs-services/>

### **Hadley**

Hadley offers free online learning opportunities in assistive technology, daily living, recreation, employment, Braille, and other topics. Additionally, they offer podcasts and online discussion groups covering a wide array of topics.

<https://hadley.edu/>

### **Horizons for the Blind**

Horizons for the Blind is a non-profit organization dedicated to improving equitable opportunities through inclusion for the blind and visually impaired. They employ a dedicated staff of blind, visually impaired, and sighted professionals who deliver quality transcription services. They also provide access to special events and a full selection of tools designed for independence and accessibility.

<https://www.horizons-blind.org/>

### **Illinois Department of Human Services (IDHS)**

The Illinois Department of Human Services (IDHS) Educational Services program offers residential education for blind or low vision children at the Illinois School for the Visually Impaired. This school provides academic, vocational, and life skills training. Eligibility is based on age and disability, and services are free for qualifying Illinois residents. Referrals are made through local school districts and professionals. More information is available on the IDHS Educational Services page.

<https://www.dhs.state.il.us/page.aspx?item=29739>

### **Illinois Society for the Prevention of Blindness (ISPB)**

The Illinois Society for the Prevention of Blindness (ISPB) was founded in 1916 to reduce preventable causes of blindness, provide accessibility services to those with low vision, and give grants for research opportunities. They provide speakers and screening booths at health fairs and other events. ISPB partners with low vision clinics around the state to support Illinois residents of all ages. ISPB assists by purchasing low vision aids, scleral lenses, and glasses to those who cannot afford them.

<https://eyehealthillinois.org/>

### **Lions of Illinois Foundation**

The Lions of Illinois Foundation (LIF) provides quality programs for the detection, treatment, and rehabilitation of those with visual impairments. In the Seeing is Believing program, LIF partners with Spectrios Institute for Low Vision, the Illinois College of Optometry, and the Chicago Lighthouse for the Blind to provide a free comprehensive visual evaluation for Illinois students in grades K-12. The LIF Jacksonville Semi-Annual Low Vision Clinic provides an extensive exam to children who have severe visual impairments and supplies special low vision aids as prescribed as well as adult low vision orientation and mobility training.

<https://lionsofillinoisfoundation.org/vision/>

### **National Federation of the Blind of Illinois**

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 Free White Cane Program | National Federation of the Blind (nfb.org) where any blind individual in the fifty states, the District of Columbia, and Puerto Rico can request a cane for their personal use. Requests can be made as often as every six months.

<https://www.nfbfillinois.org/>

<https://nfb.org/programs-services/free-white-cane-program>

### **Older Blind Program**

The purpose of the Older Blind Program is to provide services for individuals, 55 or older, whose severe visual impairment makes competitive employment difficult. Funds are used to provide independent living services, conduct activities that improve services for these individuals and improve public understanding of the challenges of these individuals.

<https://omb.illinois.gov/public/gata/csfa/Program.aspx?csfa=189>

### **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. PAF case managers provide free one-on-one management for patients and families. Case management services include help with accessing therapies and assistive devices, paying for living expenses and treatments, and finding employment or getting disability insurance or help with income.

<https://www.patientadvocate.org/>

### **Second Sense**

Second Sense provides training and support for adults with vision loss, helping them develop skills for independent living. Services include training in daily living, technology, and orientation/mobility. The organization is located in Chicago, Illinois. It offers tailored services to help clients meet their goals, with costs potentially based on need and available funding. To learn more about their programs, pricing, and locations, visit Second Sense.

<https://www.second-sense.org/>

### **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. Information includes: eye diseases and disorders, ways to connect with others including social media channels like Twitter and Facebook, the VisionAware blog, “Visually Impaired, Now What?” Blog by Peer Advisors as well as a searchable, free Directory of Services.

<https://visionaware.org>

# ASSISTIVE TECHNOLOGY

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## **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.

<https://aira.io/>

## **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.

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

## **Seeing AI**

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

- Short Text – Speaks text as soon as it appears in front of the camera

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

<http://SeeingAI.com>

### **Apple Pay**

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

[https://www.blindcitizens.org/assistive\\_tech.htm](https://www.blindcitizens.org/assistive_tech.htm)

### **Computers for the Blind (CFTB)**

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.

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

# DISABILITY INSURANCE

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## **Family Medical Leave**

Federal Family Medical Leave laws require covered employers to provide family and medical leave for eligible employees. These laws require employers to provide up to 12 weeks off 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.

In the state of Illinois, employees that are eligible for FMLA are those that:

- Have worked for the company for at least a year
- Have worked at least 1,250 hours during the previous year
- Currently work at a location with at least 50 employees within a 75-mile radius.

Upon return from FMLA leave, an employee must be restored to his or her 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.

In the state of Illinois, FMLA is unpaid. However, employees may be allowed (or required) to use their accrued paid leave during FMLA leave depending on the employer. Additionally, in the state of Illinois, the employee is entitled to continue using their health insurance at the same cost they must pay while working.

<https://www.dol.gov/general/topic/benefits-leave/fmla>

## **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 may want to consider purchasing supplemental LTD insurance. Since it is 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 are themselves, are made on an after-tax basis and 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.

# MEDICAL INSURANCE

## **Medicare**

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

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

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

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

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

## **Illinois Department of Healthcare and Family Services (HFS)**

Offers information on Medicaid services, eligibility, and application processes for individuals with disabilities. Various services are available with documents for frequently asked questions and coverage toolkits. This is the main hub for all Illinois Healthcare information.

<https://hfs.illinois.gov/medicalclients/disabled.html>

### **All Kids Program**

This is a low-cost or free health insurance program in the state of Illinois for children who need comprehensive, affordable, health insurance, regardless of immigration status or health condition. All Kids covers doctor visits, hospital stays, prescription drugs, vision care, dental care, and eyeglasses. All Kids covers regular check-ups and immunizations (shots). All Kids also covers special services like medical equipment, speech therapy, and physical therapy for children who need them.

<https://hfs.illinois.gov/medicalprograms/allkids/income.html>

### **Illinois Aid to the Aged, Blind, or Disabled (AABD)**

The Illinois Aid to the Aged, Blind, or Disabled (AABD) program provides cash and medical assistance to eligible residents who are 65 or older, blind, or disabled. Recipients may also qualify for Supplemental Nutrition Assistance Program (SNAP) benefits. Services are accessible statewide through local Family Community Resource Centers, and eligibility is based on factors such as income, assets, and citizenship status. Costs are typically covered for eligible individuals.

<https://www.dhs.state.il.us/page.aspx?item=30370>

### **Illinois Comprehensive Health Insurance Plan (ICHIP)**

This service offers health insurance to Illinois residents who are unable to obtain adequate coverage due to preexisting conditions. They provide information about eligibility and enrollment for medically vulnerable populations. This also applies to qualifying individuals who lost group health insurance coverage. You must pay premiums to participate in the plan.

<https://hfs.illinois.gov/medicalclients/health/parentorchild.html>

### **Medicaid Spend-Down Program**

Assists individuals whose income is too high to qualify for Medicaid by allowing them to “spend down” excess income on medical bills, making medical assistance more accessible. It works like an insurance deductible, where individuals pay for medical services up to a set amount each month. Once the spend-down amount is met, a medical card can be used to pay for other medical care.

The amount of your monthly spend-down depends on your income and assets. Bills or receipts for medical services or supplies can be used to meet your spend-down. These include bills or receipts for: doctor services, hospital services,

medicines, medical supplies and equipment that are prescribed by your doctor, medical or personal care in your home, Health insurance premiums, including Medicare premiums, Transportation to and from medical care and many more.

<https://hfs.illinois.gov/info/brochures-and-forms/brochures/hfs591sp.html>

### ***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.

<https://www.carverlab.org/>

- Athena Diagnostics offers the Athena Alliance Program. This is a financial assistance program for those with low income.  
[www.AthenaDiagnostics.com](http://www.AthenaDiagnostics.com)
- GeneDx offers a Financial Assistance Program and accepts all commercial insurance, Medicaid, Medicare and Tricare plans.  
[www.genedx.com/tests/billing](http://www.genedx.com/tests/billing)
- Probably Genetic offers free at-home testing. [www.probablygenetic](http://www.probablygenetic)

## SOCIAL SECURITY

### **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. These contributions are based on your earnings (or those of your spouse or parents) as required by the Federal Insurance Contributions Act (FICA). Your dependents may also be eligible for benefits from your earnings record. Adults who have been disabled since childhood may qualify for SSDI on a parent’s record even if they never have worked.

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

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

SSDI is an earned benefit, based on your work record. 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 [www.ssa.gov](http://www.ssa.gov).

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

You can speak with an SSDI representative by calling your local Social Security office or the national number (1-800-772-1213). The following is not an exhaustive list. More locations can be found at [www.ssa.gov/locator](http://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 allowed amount, SSDI does not automatically stop sending your monthly benefit amount. They will review your case from time to time, and if they determine that you have received benefits to which you were not entitled, they will send a letter demanding repayment. This can be for a significant amount, and can be an extremely unpleasant situation to be in.

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

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

SSI 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 people in addition to their Federal benefits.

To begin the process of applying for SSI, and complete a large part of your application by visiting their website at <https://secure.ssa.gov/RIL/SiView.action>. You can also call them toll-free at 1-800-772-1213 to arrange 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. [www.socialsecurity.gov/applyforbenefits](http://www.socialsecurity.gov/applyforbenefits)

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

### **Employment Supports**

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

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

### **Illinois Disability Benefits**

A comprehensive resource providing information on disability benefits, health services, and related programs in Illinois. The source provides information on laws, rights, and etiquette for citizens with disabilities.

<https://ilsrs.illinois.gov/sers/disability.html>

### **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.

<https://www.ssa.gov/work/protectionadvocacy.html>

# EDUCATION

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## **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 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.

## **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 Illinois 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:

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

## **Higher Education**

If someone becomes affected at college-age or beyond and seeks to continue higher education, it is 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.

<https://afb.org/research-and-initiatives/research/toolkits/digital-inclusion>

### **Illinois School for the Visually Impaired**

The Illinois School for the Visually Impaired (ISVI) provides accredited educational and related support services for children from birth to twenty-two years of age through preschool, elementary school, and high school.

The school focuses on providing a quality comprehensive education, helping students achieve their academic and life goals, becoming productive, self-sufficient citizens.

<https://www.dhs.state.il.us/page.aspx?item=87427>

### **Nationally Available Scholarships**

- NFB Scholarship Program: <https://nfb.org/programs-services/scholarships-and-awards/scholarship-program>
- College Scholarships: <https://www.collegescholarships.org/scholarships/blind.htm>
- Lighthouse Guild Scholarships: <https://lighthouseguild.org/support-services/academic-and-career-services/scholarships/>
- Christian Record Services Scholarship: <https://www.disabilityscholarships.us/disability-scholarships/unknown-blind-disability-christian-scholarship/289/>
- ACB Scholarship: <https://www.acb.org/scholarships>
- Learning Ally's National Achievement Awards: <https://learningally.org/naa>

- Financial Aid for Students with Disabilities:  
<https://www.bestcolleges.com/resources/students-with-disabilities-financial-aid/>
- For more information about educational resources and scholarships, visit the LHON website. [www.lhon.org/living-with-lhon](http://www.lhon.org/living-with-lhon)

### **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 If you want to start your application online, go to: <https://studentaid.gov/manage-loans/forgiveness-cancellation/disability-discharge>

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

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

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

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## **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 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.

<https://www.goodwill.org/goodwill-for-you/goodwills-support-and-employ-people-with-disabilities/>

## **Illinois Workforce Development System**

The Illinois Workforce Development System provides a variety of employment opportunities and related services for individuals with disabilities. Services include job training and placement, career counseling, and job search assistance.

<https://www.illinoisworknet.com>

## **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 seeking guidance on practical ways to engage in the interactive process, providing job accommodation solutions, and comply with Title I of the ADA.

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

# TRANSPORTATION

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## **Disability Parking Placard**

A qualified disabled person may obtain a Disability Parking Placard. If someone is determined to be blind according to Illinois law, they are eligible for a 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.

[https://www.ilsos.gov/services/persons\\_with\\_disabilities/disabilities.html](https://www.ilsos.gov/services/persons_with_disabilities/disabilities.html)

[https://www.ilsos.gov/publications/pdf\\_publications/vsd62.pdf](https://www.ilsos.gov/publications/pdf_publications/vsd62.pdf)

## **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.

## **Chicago Transit Authority (CTA) Accessibility**

The CTA provides information on accessible public transportation options in Chicago for people with disabilities. The CTA has an All Stations Accessibility Program (ASAP) that has made 100% of Chicago's buses and rail cars accessible and over 70% of the rail stations accessible

<https://www.transitchicago.com/accessibility/>

## **Regional Transportation Authority (RTA)**

The Regional Transportation Authority (RTA) coordinates public transit in the Chicago area, including the CTA, Metra, and Pace systems. It ensures accessible, affordable, and efficient transit for commuters, seniors, and people with disabilities. Services include trip planning, fare discounts, and mobility assistance. RTA operates throughout northeastern Illinois, covering six counties. Pricing varies by transit provider and eligibility for fare reductions. For more details on services, locations, and costs, visit the RTA website.

<https://www.rtachicago.org>

## **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 are eligible for paratransit service if you are 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.

### **Pace's Rideshare Access Program (RAP)**

RTA-certified ADA paratransit riders are eligible to enroll in RAP if their ADA certification will not expire within the next three months, not enrolled in Pace's Taxi Access Program, and they have an account with Uber or UZURV: The Adaptive Transportation Network Company. Eligible riders will pay the first \$2.00 of the cost of a trip taken with Uber or UZURV if the origin and destination of the trip is within 3/4 of a mile from any PACE or CTA fixed bus route.

<https://www.pacebus.com/rap>

### **Pace's Taxi Access Program (TAP)**

TAP provides eligible riders with the option of using Chicago taxi providers at a reduced rate for same-day trips. Eligible riders are RTA-certified ADA paratransit riders are eligible for TAP if they are not enrolled in RAP and will pay the first \$2.00 of a trip taken with a Chicago taxi provider if the origin of the trip is within the city of Chicago.

<https://www.pacebus.com/tap>

## **Pace Paratransit**

Pace provides ADA Paratransit in and around Chicago to people with disabilities who have been certified for ADA Paratransit by the RTA. Pace also provides other transportation options and services in the city of Chicago and the Suburbs. Pace also offers free rides on Pace Fixed Routes for ADA Certified Riders.

<https://www.rtachicago.org/riders/accessible-transit>

### **Ridesharing Services**

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

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

### **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.

<https://get.gogograndparent.com>

### **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 for children aged 17 and under. Miracle Flights also assists individuals with flights to retrieve or train a service dog.

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

### **Amtrak**

Amtrak offers a 10% rail fare discount to adult passengers with a disability. Child passengers with a disability are eligible for the everyday 50% child discount plus an additional 10% off the discounted child's fare, regardless of the service on which they travel. Amtrak also offers a 10% discount for persons traveling with a passenger with a disability as a companion. Those designated as a companion must be capable of providing the necessary assistance to the passenger with a disability. Just select 'Passenger with Disability' or 'Companion' for each passenger as appropriate in Fare Finder at the beginning of your search to receive the applicable discounts.

You must provide written documentation of your disability at the ticket counter and when boarding the train. Acceptable documentation includes a transit system ID card for persons with a disability, membership card from a disability organization, letter from a physician, Medicare card (if under 65), or a

Disabled/Accessible parking placard issued by a state Department of Motor Vehicles (photocopy is acceptable).

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

## TRAVEL & LEISURE

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### ***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.

[www.bookshare.org/cms/get-started/sign](http://www.bookshare.org/cms/get-started/sign)

#### **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.

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

#### **Libby by OverDrive**

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

<https://libbyapp.com/interview/welcome#doYouHaveACard>

#### **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.

[www.nfb.org/programs-services/nfb-newsline](http://www.nfb.org/programs-services/nfb-newsline)

### **Talking Book and Braille Service**

The Illinois State Library offers the Talking Book and Braille Service (TBBS), providing audiobooks and braille to Illinois residents with permanent or temporary visual and physical disabilities. These materials are distributed via mail or digital download. Additionally, in Illinois, nine radio stations provide current information from local newspapers. This service allows patrons to listen to broadcasts of local news, grocery ads and other information not available through the Talking Book Program.

<https://www.ilbph.org>

### **Adaptive Adventures Illinois**

Adaptive Adventures is an organization that provides free outdoor adventures to individuals with physical disabilities and their families, regardless of location, equipment needs or economic status. Their diverse range of adaptive activities are designed to empower all individuals with physical disabilities and promote health, independence, and community. Participants can join an adaptive program by visiting the website and registering for the program that interests them, and the team will provide all necessary information and support.

<https://adaptiveadventures.org>

### **Illinois Fishing License**

The state of Illinois will exempt you from a fishing license if you are blind or disabled. You are not exempt from a Habitat Stamp, and you will still have to apply and pay for your permits.

<https://www.fishing.org/licenses>

### **National Parks Access Pass**

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

The Pass may be obtained at certain federal recreation sites, through the mail, or online. To obtain a Pass you must have identification to verify that you are a U.S.

citizen or permanent resident as well as documentation that you have a permanent disability. Showing a state motor vehicle department disability sticker, license plate or placard is not acceptable documentation.

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

<https://www.nps.gov/subjects/accessibility/interagency-access-pass.htm>

## ***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 (CAF)**

Offers grants to athletes with any disability including vision loss to support their athletic activities.

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

### **Dare2Tri**

Provides opportunities for people with physical disabilities and/or visual impairments to develop skills in the sport of Para triathlon.

<http://www.dare2tri.org/>

### **National Ability Center**

Provides adaptive sports opportunities, often at low/no cost to the vision impaired.

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

### **Ski for Light**

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

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

### **United States Association of Blind Athletes**

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

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

### **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

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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.

### **Illinois Department of Revenue Disability-Related Tax Information**

The Illinois Department of Revenue Disability-Related Tax Information offers state-specific tax information and benefits for those with disabilities, including tax exemptions and credits.

<https://tax.illinois.gov/>

### **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 printer, 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.

### **Internal Revenue Service (IRS) Tax Guide for the Disabled**

The IRS Tax guide for the Disabled provides a comprehensive tax guide detailing tax credits, deductions, and tips applicable to individuals with disabilities and those who take care of them. The guide highlights information about income, itemized deductions, household employers, business tax incentives, and ABLE accounts.

[www.irs.gov/publications/p907](http://www.irs.gov/publications/p907)

## MISCELLANEOUS

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### **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.

<https://www.leaderdog.org/>

### **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.

<https://www.amazon.com/dp/B0CJ9DGD6N/>

### **Penny Forward**

Penny Forward is a nonprofit organization dedicated to empowering blind individuals to navigate personal finances. They provide a Seven Steps to Financial Fitness guide, podcast, and financial calculator for free. Additionally, they provide financial services for as little as \$99 a year and distribute paid-for blind resources.

[www.pennyforward.com/courses-home/](http://www.pennyforward.com/courses-home/)

### **Avoiding Unnecessary Medical Care**

The diagnostic odyssey for LHON can be extremely expensive, including many tests to rule out other, more common causes of sudden vision loss. Many individuals have spent thousands of dollars on tests and treatments for diseases they did not have (Brain Tumor, Optic Neuritis, MS, NMO, etc.). They and their loved ones have lost time from work for these appointments and have spent money traveling to a range of specialists trying to get the correct diagnosis. If

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

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

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

### **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 fundraise 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.

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*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.*