

A Guide to Navigating LHON with Money in Mind



Information and Resources for the
California LHON Community

Purpose

Individuals who carry a LHON mutation can experience sudden-onset blindness at any age. When this occurs, it is a life-changing event for the individual affected, their family, and loved ones.

There are many ways in which LHON onset can have a significant financial impact on all involved. Fortunately, there are also many resources available that can help mitigate that financial impact.

The goal of this document is to help the California LHON community become familiar with resources that can limit negative financial impacts. It provides descriptions and contact information of agencies and programs that can create a better financial outcome for affected patients and their loved ones. Unaffected carriers can also benefit by being better prepared in case they experience LHON vision loss one day.

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

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NON-PROFIT AGENCIES

In California, there is no centralized Bureau or Commission for the Blind and Visually Impaired, so support services are fragmented. A good place to start is one of the agencies throughout the state, whose mission is to provide no-cost support and information to individuals with vision loss.

LightHouse for the Blind and Visually Impaired (San Francisco): LightHouse offers a multitude of programs at their San Francisco location, including: training on accessible technology, independent living, moving effectively with a cane, social and recreational activities, health and wellness, Braille instruction, and more. Their headquarters are in downtown San Francisco, and they offer classes in Napa, Eureka, San Rafael and Berkeley. At their Enchanted Hills Camp in Napa County, LightHouse offers science and math camps for visually impaired children, teaches accessible horseback riding and music instruction, and hosts families and individuals of all ages and backgrounds. Their 6 day/5 night “*Changing Vision Changing Lives*” program is transformative and immersive, giving adults who are new to low vision/blindness an opportunity to jump-start a path to confidence, competence and independence. Participants come from all parts of California, and countries around the world.
www.lighthouse-sf.org

Society for the Blind (Sacramento): Society for the Blind is a full-service non-profit agency providing services and programs for people who are blind or have low vision. Serving 27 counties in Northern California, they are located in Midtown Sacramento.
www.societyfortheblind.org

NON-PROFIT AGENCIES

Braille Institute (Southern California): Braille Institute is a non-profit organization whose mission is to positively transform the lives of those with vision loss. Braille Institute serves more than 37,000 people through a variety of free programs, classes and services at centers and community outreach locations throughout Southern California, from Santa Barbara to San Diego counties.
www.brailleinstitute.org

San Diego Center for the Blind: The mission of the San Diego Center for the Blind (SDCB) is to help adults (ages 18 and older) with blindness or vision impairment to reach their highest level of independence. They assist individuals with vision loss to overcome challenges by focusing on capabilities, emphasizing personal strengths, encouraging participation in family life and community activities, and providing quality, comprehensive vision rehabilitation services. Their centers are in San Diego and Vista.
www.sdcb.org

Others: There are many smaller agencies throughout the state. To find one near you, search for "Blind and low vision services" followed by your city.

Hadley: Hadley offers free online learning opportunities in assistive technology and other topics.
www.hadley.edu

DEPARTMENT OF REHABILITATION (DOR)

The California Department of Rehabilitation's Blind Field Services (BFS) group works to provide services resulting in employment, independent living, and equality for individuals with vision loss. BFS staff have specialized knowledge and skills in serving individuals with vision loss. They are co-located with some DOR offices throughout the state. DOR is not a financial needs based program. Anyone at any income level can apply. DOR typically works with individuals from their late teens onward. There is no upper age cap.

Apply for services by filling out the Vocational Rehabilitation Services Application online at the DOR website www.dor.ca.gov, via regular mail, in-person at a local DOR office, or over the phone. There are offices located throughout the state. You do not need to be legally blind to initiate a case with DOR. If you are a LHON carrier and onset begins, you can immediately contact DOR and apply for services. Since it can be a lengthy process, getting started quickly is a good idea.

Once determined eligible for services, you will be assigned a DOR counselor and together you will jointly develop your Individualized Plan for Employment (IPE). The IPE is a written plan listing your job objective and the DOR services you will receive to reach your employment goal. It could be a "Job Retention" plan in which you define the tools and training required to be successful in your current job. Or it could be a plan to support you in developing the education and skills required to obtain a new job.

DOR does not have a standard "program" or set of services that everyone receives. The IPE you and your counselor create will be unique to your needs. People working with BFS/DOR counselors may receive all general vocational rehabilitation services, with the addition of vision loss counseling. Specific services include: low

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vision evaluations, low vision aids, adaptive technology assessments, adaptive technology equipment, adaptive technology training, technical support, orientation and mobility training, independent living skills training, Braille instruction, immersion services, vocational training, support through college education (at the lowest possible cost such as community college and state universities), and job placement assistance.

There is no specific time limit for a counselor to work with a client. However, services aren't considered to be open-ended either. It is more about the needs of the individual, as well as their commitment to the process. The counselor will be working toward closing the case as appropriate. If a person's needs change over time, they can return for additional services even after their case has been closed and open a new case if they experience changes in their disability, work status, job responsibilities, or accommodation needs.

If DOR provides physical items such as iPhones or computers, they are initially considered to be on loan until a person's case is closed. At that time, if the person is employed, DOR turns the items over to the individual to keep. If a person decides they do not wish to work at the time of their case closure, they have the option of either returning the items, or paying the State for them at fair market value.

www.dor.ca.gov

DISABILITY INSURANCE

California State Disability Insurance (SDI)

California has a short-term disability insurance program for employees. Most California employers are required to participate in the state's SDI program, which ensures that an employee receives a percentage of income if they cannot work due to sickness or a disabling injury.

Employees fund the short-term disability program through payroll deductions, and it is managed by California's Employment Development department (EDD). Job protection is not provided by this program, only monetary benefits.

If eligible, you can receive about 60 to 70 percent (depending on income) of wages earned 5 to 18 months before your claim start date (your base period). Benefits are payable for a maximum of 52 weeks. In order to be eligible for benefits, you must:

- Be unable to do your regular or customary work for at least eight days.
- Be employed or actively looking for work at the time your disability begins.
- Have lost wages because of your disability.
- Have earned at least \$300 from which SDI deductions were withheld during your base period.
- Serve a seven-day, non-payable waiting period.
- Be under the care and treatment of a licensed physician/practitioner or accredited religious practitioner within the first eight days of your disability.
- Complete and submit your claim form (DE 2501) no earlier than nine days after your first day of disability begins but no later than 49 days after your disability begins or you may lose benefits. You can file your claim using [SDI Online](#) or by submitting your claim form by mail.

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- Have your physician/practitioner complete the medical certification portion of your disability claim.

If the EDD determines that you are eligible for SDI, you will generally receive benefits every two weeks. Your benefit amount will depend on how much you were earning during your base period. SDI pays 60-70% of the wages you received during your highest-paid calendar quarter of the base period, depending on your income level. This amount is not subject to tax, so what you receive will be more than 60-70% of your usual take-home pay. If you receive any earnings while you are on SDI, that amount will be subtracted from your benefits.

Paid Family Leave (PFL)

California employees may receive benefits for time off spent caring for a seriously ill family member. The requirements for receiving Paid Family Leave (PFL) are similar to the rules for receiving SDI for a disability. Like SDI, your benefits will generally be 60-70% of your earnings in the highest-paid quarter of your base period. PFL is available for a maximum of six weeks.

Family Medical Leave

Both federal (FMLA) and California (CFRA) law 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.

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

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employee's use of FMLA leave cannot be counted against the employee under a "no-fault" attendance policy. Employers are also required to continue group health insurance coverage for an employee on FMLA leave under the same terms and conditions as if the employee had not taken leave. The main benefit of FMLA is job protection, especially if your employer has a strict sick policy that could jeopardize your employment.

Long-Term Disability Insurance (LTD)

Long-term disability (LTD) insurance is a private insurance policy that protects an employee from loss of income in the event that he or she is unable to work due to illness, injury, or accident for a long period of time. This can be devastating for a family financially. LTD insurance ensures that an employee will still receive a percentage of their income if they cannot work for an extended period.

California does not have a state-sponsored LTD program. However, LTD insurance can be provided and paid for by employers or individuals. Your employer may offer a LTD option. If a company doesn't offer LTD insurance or if an employee wants additional coverage, he or she has the option of purchasing an individual LTD plan.

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

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LTD insurance begins to assist the employee when short-term disability insurance (SDI) 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 premiums were paid by the employee themselves on an after-tax basis, are usually not taxable income. Moreover, 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 get help navigating 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 that the employee will take any job that the employee is capable of doing. LTD payments to the employee, in some policies, have a defined period of time. Others pay an employee until he or she is 65 years old.

Keep in mind your health history, and your family's history of LHON and any other diseases, when you consider the amount of long-term disability insurance that you need.

SOCIAL SECURITY

Social Security Disability Insurance (SSDI)

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

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

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

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

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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. Basically, if you're still able to work, and you earn over a certain amount, you aren't considered disabled.

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

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 a SSDI representative by calling your local Social Security office or the national number (1-800-772-1213). Local office phone numbers can be found online with the Social Security Office Locator. www.ssa.gov/locator

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

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Supplemental Security Income (SSI)

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

SSI is available to people who are disabled (including legally blind), or over 65. The SSI program makes cash assistance payments to aged, blind, and disabled persons (including children) who have limited income and resources. The Federal Government funds SSI from general tax revenues. Many states, including California, pay a supplemental benefit to eligible persons in addition to their Federal benefits.

SSI qualification is based on your resources. If your resources (the things you own) are worth more than \$2,000 for an individual or \$3,000 for a couple, you're considered to be ineligible. This amount includes most personal property, but excludes certain items, such as your primary home. There are also strict income requirements for SSI eligibility.

The maximum Federal SSI benefit tends to change yearly. Effective January 1, 2020, the Federal benefit rate is \$783 for an individual and \$1,175 for a couple. SSI benefit amounts and California State supplemental payment amounts vary based upon your income, living arrangements, and other factors.

To apply for SSI, you can begin the process and complete a large part of your application by visiting their website at www.socialsecurity.gov/applyforbenefits. You can also call them

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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.

www.socialsecurity.gov/applyforbenefits

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

Employment Supports

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

www.ssa.gov/redbook/Advice

Disability Rights California (DRC)

DRC is California's protection and advocacy system, helping people with disabilities. DRC provides information, advice and support regarding Social Security and other matters.

www.disabilityrightscalifornia.org

MEDICAL INSURANCE

Medicare

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

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

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

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

www.medicare.gov

MEDICAL INSURANCE

Medi-Cal

Medi-Cal is the Medicaid program in California. It provides health coverage to people with low income and low asset levels who meet certain eligibility requirements. If you are blind or have a disability and receive Supplemental Security Income (SSI), you are automatically eligible for and enrolled in Medi-Cal.

Many people who become affected by LHON at a young age are not eligible for Medicare benefits because they do not have the work credits to qualify for Social Security Disability Insurance (SSDI) benefits. These people are only covered by Medi-Cal, not Medicare, if they are eligible based on low income and low assets.

Some people are eligible for both Medicare and Medi-Cal. When medical benefits are covered by both Medicare and Medi-Cal, Medicare is the primary payer and Medi-Cal is the secondary payer. When services such as dental care or long-term care are covered only by Medi-Cal, it is the sole payer. If you have both Medicare and Medi-Cal, be sure the medical providers you choose accept both sources of payment for your care. Otherwise, you may face billing delays or be required to pay unexpected medical costs.

When you first qualify for Medi-Cal you are covered under Fee-for-Service (also called Regular Medi-Cal). Within 45 days you will be mailed information explaining your health plan options. You must choose a health plan within 30 days of receiving your health plan information mailer. If you do not choose a plan within 30 days, Medi-Cal will choose a plan for you. The health plans available to you depend on the county where you live.

www.medi-cal.ca.gov

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School-Age

If someone becomes affected by LHON while in elementary, middle, or high school, it is important to immediately contact their school district. The school district should have a Visual Impairments (VI) or Special Education department who will work with the student and their family, their teacher(s), and the school to develop an Individualized Education Program (IEP) to support and accommodate the affected student.

The educational accommodations for a student affected by LHON can raise financial questions. The California education system provides extensive support to students who are visually impaired through their school district and/or the California Department of Rehabilitation (DOR). The financial costs associated with accommodations necessary for the student to be successful in the school system will generally be absorbed by the school district/DOR. Funding for VI programs within the California school district comes from the DOR, and affected students and their families do not have to cover the costs associated with educational accommodations. Keep in mind that it will be necessary for families to provide medical documentation that establishes the student as being legally blind to receive the support and accommodations at no cost.

Students who are visually impaired are provided with a variety of educational options covered by the state including but not limited to, general education classes with itinerant VI teacher(s), appropriate reading material that meets their individual needs (i.e. Braille, tactile materials, recorded books, large print), and more.

Affected students are able to receive: Orientation and Mobility (O&M) training to develop safe travel skills, an expanded core curriculum, standardized testing assessments to ensure that

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appropriate grade-level expectations are being met, and assessments of their vision to provide adequate assistive technology and the training associated. If it is determined the student needs specific assistive technology such as a CCTV, ZoomText, JAWS, Braille Note, and more, the school district will cover the costs associated with the technology. As the equipment evolves and upgrades become available, the student will be eligible to receive the updated/upgraded equipment and tools.

Staff who belong to the VI/Special Education department in the school district (administrators, teachers, and support staff) are appropriately credentialed to make sure that the student's visual impairment needs are met and those appropriate accommodations are available for the student to excel. VI staff are also responsible for ensuring that the CA Braille reading and math standards are met by the student.

Higher Education

If someone is affected at a college-age or beyond and seeks to continue higher education, it is important to establish a relationship with your local DOR and the Disability/Accessibility center at your campus. Most colleges and universities offer low vision assistance and resources such as notetakers and priority registration, as well as other support services.

The first step to request services and support from the CA DOR is to complete and sign the Vocational Rehabilitation Services Application and provide the DOR with any pertinent information to begin the assessment which will determine eligibility and priority status. The Blind Field Services (BFS) department at DOR and its staff work with blind or visually impaired persons to obtain educational and employment opportunities. The services and support that BFS provides to affected individuals is unique and



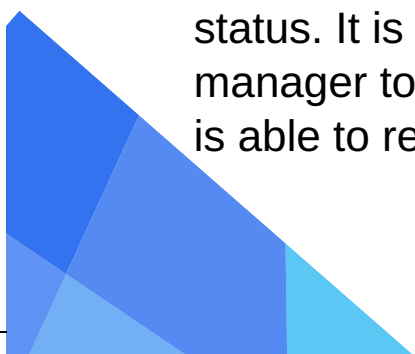
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tailored to meet the individual's specific needs. In order to begin an educational path supported by the DOR/BFS, the affected individual must begin a relationship with their assigned case manager after their application has been approved. The individual's case manager will work closely with the affected individual to determine what accommodations are necessary to receive educational support. The affected individual will share their higher education goals with their case manager to best determine the support and services they will need from DOR to become academically successful.

First, the case manager and affected individual will work together to determine what assistive technology and equipment are necessary for academic success. Based upon application approval and household income, the amount for shared costs for equipment will be provided for affected individuals who require assistive technology for educational purposes (i.e. CCTV, laptop, Senseview, accessibility software, and more). Regardless of household income, training for necessary assistive technology and vocational training is provided.

Further educational support from the DOR ranges from tuition support to textbook fee assistance, and the shared cost amount is determined based on the individual's household income. It is imperative to establish a relationship with the DOR as quickly as possible as there may be a waiting list for some types of support that are necessary for educational success.

The support that the DOR/BFS can provide varies from student to student based on their educational needs, goals, and financial status. It is crucial to develop a relationship with the assigned case manager to be aware of the financial support an affected individual is able to receive.



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For those interested in higher education, it should be noted that there are scholarship opportunities available to those with visual impairments. Some are listed here:

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:

www.secure.disabilitydischarge.com/registration

If the Department approves your TPD discharge request, they will notify you and the holders of your loans and/or TEACH Grant service obligation of the approval. They will also instruct the loan holders to return any loan payments received after your disability date to the person who made the payments. Your “disability date” is the date they received the documentation of your SSA notice of

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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.

TRANSPORTATION AND TRAVEL

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 which can be used on 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 it signed by your doctor.

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 be charged an increased 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 must agree to pick you up within an hour of the time that you requested.

TRANSPORTATION AND TRAVEL

Ridesharing Services

The two largest ridesharing services are Uber (www.uber.com) and Lyft (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 hoping to make their apps more accessible and inclusive.

Disabled Person Parking Placard

A qualified permanently disabled person may obtain a Disabled Person (DP) parking placard for no fee. Placards can be moved from one vehicle to another, making them a good option for someone affected by LHON who rides in various cars. With a placard, you can park in an on-street metered parking space at no charge, along with other privileges. The placard is valid for two years and expires on June 30 of every odd-numbered year.

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To apply, complete and sign an Application for Disabled Person Placard or Plates:

www.dmv.ca.gov/portal/uploads/2020/06/reg195.pdf

Have a licensed physician, surgeon, chiropractor, optometrist, physician assistant, or nurse practitioner that has knowledge of the disease and/or disability complete and sign the Medical Provider's Certification of Disability section and mail to the address on the form.

Air Travel

People with visual impairments are protected under the Americans with Disabilities Act (ADA) 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 you may have traveling with you to provide assistance. Check with your airline to see what specific services they provide.

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Miracle Flights

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

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 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

TRANSPORTATION AND TRAVEL

National Parks Access Pass

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

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

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

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

store.usgs.gov/access-pass

ASSISTIVE TECHNOLOGY

Aira

Aira delivers instant access to visual information. Aira's trained, professional agents remotely assist people who are blind or low vision with virtually any task, all without a sighted assistant nearby. Through an app on your smartphone, you can connect with a trained Aira agent. Pick the plan that makes the most sense for you, sign up in a couple of minutes, and download the Aira app to your smartphone. Access agents on-demand for almost any task, take advantage of rideshare integration to get you where you need to be, and use one of the ever-growing list of free Aira Access offers to save you money while doing it. To discover all available free Aira Access offers, just tap on the "Search & Apply a Free Offer" button on the Home screen of your Aira app. Aira Access currently comes in three forms:

- Limited and on-going promotions that provide free access to Aira agents, such as the Intuit QuickBooks Small Business Owners promotion.
- Products free to use for tasks that involve using certain products like Vispero's JAWS screen reader.
- Locations free to use while in a growing number of locations like Wegmans, Walgreens, AT&T stores, airports, and federal buildings.

www.aira.io/free-access

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

Computers for the Blind (CFTB)

CFTB is a non-profit 501(c)(3) organization located in Richardson, Texas, devoted to providing refurbished computers with assistive technology to persons who are blind or visually impaired, at very low cost. There are no income or age requirements. The processing fee for a desktop or laptop with JAWS or ZoomText installed (as of October 2020) ranges from \$130 to \$185. Shipping is free in the US. Certain upgrades are available, and details are on this fact sheet:

www.computersfortheblind.org/src/documents/CFTBFactSheet.pdf

For more information:

www.computersfortheblind.org

MISCELLANEOUS

Avoiding Unnecessary Medical Care

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

www.LHON.org/living-with-LHON

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.

CalABLE

CalABLE is a savings and investment plan offered by the State of California to individuals with disabilities. You can pay for a range of qualified disability expenses (including basic living expenses, health and wellness, housing, financial management, transportation, education and training, and assistive technology) with your optional CalABLE Visa Prepaid Card. Earnings grow free from federal and California state taxes, and generally, funds in a

MISCELLANEOUS

CalABLE account are disregarded when determining eligibility for certain means-tested benefits programs such as Medicaid and Supplemental Security Income (SSI).

CalABLE accounts are available to eligible U.S. citizens and legal residents, regardless of state residency. An “Eligible Individual” is someone who developed the onset of their disability before age 26, and is entitled to benefits like Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) based on blindness or disability or self-certifies that they have a condition listed on the Social Security Administration’s List of Compassionate Allowances Conditions and have a signed qualifying disability diagnosis from a qualified physician.

The enrollment process is entirely online. You will not need to produce a copy of your diagnosis in order to open a CalABLE account. However, a record of your eligibility or diagnosis must be readily available for verification.

www.calable.ca.gov

Employee Assistance Programs (EAP)

Many employers offer an Employee Assistance Program that will include several visits to a mental health professional at no cost. Onset of LHON vision loss can have a significant impact on the mental health of the individual affected and their loved ones. An EAP Program is an opportunity to try working with a mental health professional at no charge. Additional access to a therapist or counselor may be available through your health insurance, or at your local non-profit agency serving the blind and visually impaired.

MISCELLANEOUS

General Financial Support

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

Genetic Testing

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

Obligate Carrier/On the Maternal Bloodline: It's first helpful to understand the genetic transmission of a LHON mutation. LHON is maternally inherited, and a woman who carries a LHON mutation passes that mutation to all of her children. If someone on your maternal bloodline has had genetic testing done and has a confirmed diagnosis of their LHON mutation, you can reasonably assume that you're an "obligate carrier." This means that based on genetics, you carry the same LHON mutation. You can presume you carry that LHON mutation without doing any genetic testing, which is the least expensive option. Also, there are no test results in your medical records that could impact your future insurance choices.

If you're an obligate carrier and would prefer to have your own genetic testing done to confirm your genetic status, you can save money by testing for just the specific mutation in your family. Most

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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 than the broader panel test.

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

The Carver Lab at the University of Iowa is a non-profit lab, so the cost of a LHON panel test is currently \$140; much lower than at for-profit labs. Note that they batch their testing, so the turnaround time is slower than other labs.

www.CarverLab.org

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

www.AthenaDiagnostics.com

If you're in the SF Bay Area, the Little Zebra Fund offers financial support to those needing assistance with the cost of genetic testing in some instances.

www.LittleZebraFund.org

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

www.discovernac.org

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

www.challengedathletes.org

Tax Tips

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

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

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

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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.



www.LHON.org

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