Our mission...

To revolutionize the health and quality of life of individuals affected by Leukodystrophies with proactive, innovative, and comprehensive medical care standards and specialized centers throughout the U.S., Canada and eventually the world.

“For I know the plans I have for you,” declares the Lord, “plans to prosper you, and not to harm you, plans to give you hope and a future.” Jeremiah 29:11
We are the families of a child with Leukodystrophy...

We are our child’s advocates.

We challenge you to see us, to hear us, to help us.

We are afraid, and hopeful, and sad, and brave, and we love this child with everything in us.

The goals for many of our children have changed. We are no longer dreaming of sports, and college, and weddings.

Those dreams have been dashed by the devastating diagnosis of Leukodystrophy.

We don't want our child to have pain, to die young, to be stared at, ignored or forgotten.

We want our child to live, to play, to enjoy and receive love from other people.

The medical decisions we make are with those goals in mind.

Our children are more than their disease. They are more than their limitations.

Our child has potential. Our child has impact on the world around them. Our child has love to give, and love to receive, and life to live.

Our child is worthy. Our child is worthy of our best love, and our best efforts, and yours.

We invite you to partner with us on this journey, however short or long it may be, to do our best for our child.

We challenge you to see what can be for our child, not what never will be.

We want the best for our child, the best life, the best love, the best care. And we need your help to get there.
What are Leukodystrophies?
Leukodystrophies are a group of disorders that cause deterioration of the white matter, or myelin, in the brain. There are more than 50 known Leukodystrophies, impacting 1 in 7,000 individuals throughout the U.S. and the world.

The term Leukodystrophy is derived from the prefix *leuko*, meaning white, and the word *dystrophy*, meaning imperfect growth. Therefore, Leukodystrophies are characterized by imperfect growth of the white matter in the brain.

White matter, also known as myelin, makes up the insulating sheath surrounding the nervous system. Without white matter, communication between the brain and nervous system becomes disrupted or nonexistent, resulting in a Leukodystrophy.

Most Leukodystrophies are genetic, meaning they are passed from the parents to their children. Depending on the Leukodystrophy, the manner in which a mutated gene is inherited will differ. However, recent research has also indicated that some Leukodystrophies develop sporadically, meaning it is not genetic and that neither parent is a carrier of a mutated gene.

Is there treatment?
Depending on the type of Leukodystrophy and level of progression at the time of diagnosis, some treatments may be available such as cord blood or bone marrow transplantation and gene therapy to halt the progression of the disease. In most cases, however, treatment must be administered before the disease is too far progressed.

*Though there is no cure for Leukodystrophies, they are treatable.*

An affected individual who does not qualify for the previously mentioned transplants or therapies can still receive excellence in care tailored to the ever-changing needs of the child. Comfort level and quality of life can be greatly improved with an integrated approach to care.

Through the Leukodystrophy Care Network, a team of doctors is comprised to provide various aspects of care specific to the child. Although this does not stop the progression of the disease, taking action in this proactive manner is extremely beneficial in management of symptoms.
Vision
The Leukodystrophy Care Network (LCN) is a Hunter's Hope Foundation program established in 2015. It is a network of medical providers, hospitals, Leukodystrophy organizations and affected families.

Our vision is for a world-renowned LCN to exist across the United States, Canada and eventually the world, to provide innovative therapies, treatment options, expert care and information to families affected by these diseases. The medical community will recognize the LCN and its Centers (LCC) as leaders in Leukodystrophies for patients and medical professionals. Centers will be self-sustaining, yet collaborative, networked together to ensure the highest quality groundbreaking care is available for all Leukodystrophy patients today and for generations to come.

Leadership
The LCN is led by a Steering Committee of family advocates, representing 10 different Leukodystrophy organizations, and supported by Leukodystrophy medical specialists, as well as the Hunter's Hope Foundation.

Leukodystrophy Care Centers
The Leukodystrophy Care Centers provide Early Diagnosis, Treatment, Multidisciplinary Care, Prevention, Symptom Management, and Education. There are currently 15 certified, affiliate, or candidate centers across the US.
**First, spread the word.** Your voice is a powerful tool in raising awareness of Leukodystrophies, the impact they have on families, and the complex support needed to ensure the highest quality of life for those affected. Share how the LCN is making an impact.

**Second, fundraise on behalf of the LCN!** The LCN is a not for profit and depends on public support to fund programs critical to making world class care and resources available to all who are affected.

- **Certified Centers** – provide innovative therapies, treatment options, expert care and information to families affected by Leukodystrophies. The Leukodystrophy Community recognizes the LCN and its Certified Centers as leaders in Leukodystrophies for patients and medical professionals.
- **Coordinating Center** – responsible for ensuring that all leading research and clinical treatment guidelines are effectively shared throughout the network, and that the LCN and its Certified Centers are accessible to all affected individuals.
- **Clinical Practice Guidelines** – establish a published, peer-reviewed standard of care to ensure that individuals with Leukodystrophy have the best possible medical care, improving length and quality of life. Care Centers provide a standard of Leukodystrophy care with guidelines based on the latest research, medical evidence and consultation with experts on best practices.
- **Family Support** – helping families obtain the resources and services they need to maximize quality of life for those affected
- **Education and Awareness** – publishing the most current educational resources and making them easily accessible for families, caregivers, and physicians within the network and beyond.
- **Data Registry** – optimize intake, maintenance, and application of data related to natural history of disease, CPG effectiveness, outcome monitoring, clinical trial readiness, and quality of care.

### PROGRAM EXPENSES

- **Certified Centers** 47%
- **Clinical Practice Guidelines** 15%
- **Coordinating Center** 4%
- **Data Registry** 17%
- **Family Support** 10%
- **Education and Awareness** 7%
## FUNDRAISING IDEAS

<table>
<thead>
<tr>
<th><strong>Peer to Peer:</strong></th>
<th><strong>Restaurant Benefit Nights:</strong></th>
<th><strong>Raffle/Auction:</strong></th>
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<tr>
<td>Share your story on social media. Share why the LCN is important to you. Share your link to a personal fundraising page! The more people you reach the more likely you are to find donors! Additional details on the next page.</td>
<td>Many restaurants offer dates where a portion of proceeds can benefit your cause. Ask around and you may be surprised which ones participate.</td>
<td>Raffling or auctioning off prizes can be an exciting way to fundraise. Auctions can be silent, or quite the opposite, depending on your preference!</td>
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<tr>
<th><strong>Walk/Run:</strong></th>
<th><strong>Gala:</strong></th>
<th><strong>Golf Tournament:</strong></th>
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<tr>
<td>A walk or a run can be a fun way for people to get behind your cause. In person events are also a great opportunity to share your message!</td>
<td>Ticketed dinners or concerts with a portion of proceeds benefitting your cause are a great way to fundraise! These are also great opportunities to share your story with potential donors face to face. Enhance the experience, and your fundraising potential, with raffles or auctions at the event.</td>
<td>This may be a great way to engage corporate sponsors!</td>
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<th><strong>Garage Sale:</strong></th>
<th><strong>Exercise Class:</strong></th>
<th><strong>Bake Sale:</strong></th>
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<td>Make that unused pile of stuff have an impact in more ways than one! This could be coordinated with neighbors, on your own, or held at a local school or church.</td>
<td>What better way to invigorate the mind, body, and soul than to work up a sweat for a good cause? A local gym or personal trainer can help you get started.</td>
<td>It's hard to pass up a baked goodie. It's even harder to pass up a baked goodie when the proceeds are going to a good cause! Dates and locations can also be pretty flexible for this type of event.</td>
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<th><strong>Dress Down Days:</strong></th>
<th><strong>Special Occasions:</strong></th>
<th><strong>Local Businesses:</strong></th>
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<tr>
<td>How about turning your $5 jeans day into a fundraiser? Supporting a cause near and dear to a co-worker’s heart can be very fulfilling!</td>
<td>Requesting donations in lieu of gifts can be a meaningful way to share your special day. This may be birthdays, weddings, or other holidays.</td>
<td>Many businesses have allocated funds for charitable giving. You may never know which ones are still looking for a meaningful cause unless you ask!</td>
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<th><strong>Class/Department Competitions:</strong></th>
<th><strong>Matching Gifts:</strong></th>
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<tr>
<td>A little healthy competition between groups may drive your fundraising to the next level!</td>
<td>Don't forget to have donors check with their employers. Many business sponsor charitable match programs.</td>
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**Step 1: Choose what you want to do** – there are so many ways to fundraise! Asking for donations can be uncomfortable, but you may quickly realize that donors find it very rewarding to support a meaningful cause and the volunteers who are passionate about it. Start where you are comfortable, and branch out as you gain experience!

**Step 2: Choose a date and location** – based on the type of event, consider weather and venue availability if applicable. Consider your audience and select dates where competing priorities are limited if possible.

**Step 3: Set your fundraising target** – the key to a successful fundraiser is to have clear goals. This may be a dollar amount you want to raise, or it may be the number of people that you want to reach with your message through a particular event. Not only is this motivating to you and those that are helping you, but also potential donors who want to help you reach those targets.

**Step 4: Create a fundraising page** – this is the easiest step! Visit the LCN support page: [https://www.classy.org/campaign/leukodystrophy-care-network/c121075](https://www.classy.org/campaign/leukodystrophy-care-network/c121075) and follow the steps to join as an individual, part of an existing team, or to setup your own new team.

**Step 5: Spread the word** – word of mouth, flyers, local media outlets, and social media can help your spread the message about your cause and your fundraising efforts.

**Step 6: Collect your fundraising materials** – this may include supplies depending on the nature of your event. Enlist volunteers to help organize and manage your event. Materials may also include information that you want to share about your cause, contact information, and next steps for potential donors that want to continue supporting. If you have any questions don't hesitate to contact LCN support.

**Step 7: Have fun** – if you've come this far you are doing something that's really important to you. Let that shine through! Your story, and your passion for the Leukodystrophy Community might just be what inspires a donor to come alongside you on this journey.

**Step 8: Collect Donations** – if you chose to hold an event, just contact an LCN representative once concluded to complete the donation process! Online donations through your personal fundraising page are seamless. You won't need to take any additional action!

**Step 9: Thank Your Supporters** – let anyone who supported your fundraising efforts, whether volunteer or donor, know that they are an important part of the team that's revolutionizing the care for all who are affected by Leukodystrophies!
Start Early – often times taking the first step is the most difficult. Once you've committed to fundraise, make sure to start the planning process early. As you work through planning there are likely to be additional details or new ideas that you discover along the way that need to be incorporated. Leaving plenty of time to work through these is important not only to the overall success of your efforts, but also in minimizing the stress that comes with last minute planning. This varies by the type of fundraising you are doing. For example, creating an online fundraiser is very quick and requires no lead time. Other events may require you to coordinate between multiple parties and schedule a venue well in advance. There are plenty of resources available to help you through any effort. If you are ever unsure contact the LCN for support.

Ask Everyone – you never know who may have a connection to your cause unless you ask. Everyday encounters could be a perfect opportunity to share your story. Consider friends, family, neighbors, doctors, dentists, or staff at your local coffee shops or restaurants to name a few. Social media has also made it possible to easily reach a very broad audience. You have an important story to tell, and asking for support is merely an invitation for people to be a part of that story.

Send Reminders – people are busy! It's completely appropriate to send follow up requests to potential donors you have connected with. It can be a much-appreciated reminder. If you have an event planned, send reminders for key information such as dates, times, and locations. Your attendees will appreciate the extra effort put into the organization and communication surrounding your event.

Say Thank You – the LCN is critical to the future care of individuals affected by Leukodystrophy. Let your donors know how much their contributions are appreciated either with immediate acknowledgement or follow up thank you notes, letters, or emails. You can never thank them too much for supporting your mission.

Connect – a wide range of resources are available, from fundraising help to additional information about the Leukodystrophy Care Network. Stay up to date with the latest developments at the overall LCN level or at regional Care Centers that you have a connection with. Contact LCN representatives with any additional questions or need for support.

HELPFUL TIPS

huntershope.org  facebook.com/huntershope  @HuntersHopeFD  @HuntersHopeFD
The Leukodystrophy Care Network (LCN) Certified Centers provide innovative therapies, treatment options, expert care and information to families affected by Leukodystrophies. The Leukodystrophy Community recognizes the LCN and its Certified Centers as leaders in Leukodystrophies for patients and medical professionals. Certified Centers are self-sustaining, yet collaborative, networked together to ensure the highest quality, groundbreaking care is available for all Leukodystrophy patients.

LCN Certified Centers adhere to LCN requirements established by the LCN Steering Committee and other Family Advocates. To learn more about Certified Center requirements, click here – LCN Certified Center Requirements.

The LCN is committed to providing patient-centered, multidisciplinary, expert care to all individuals affected by Leukodystrophies. LCN Certified Centers are staffed with a Care Coordinator to help ensure the best possible care. To learn more about the Care Coordinator, click here – LCN Care Coordinator.

**LCN Certified Centers**
The following LCN Certified Centers meet the LCN Certified Center requirements.
For more information and contact information for each center, please click on the links below.
- Ann & Robert H. Lurie Children’s Hospital of Chicago
- Children’s Healthcare of Atlanta
- Duke Children’s Hospital
- Golisano Children’s Hospital
- Kennedy Krieger Institute
- Massachusetts General Hospital
- Monroe Carell Jr. Children’s Hospital at Vanderbilt
- Primary Children’s Hospital

**LCN Candidate and Affiliate Centers**
The following LCN Centers are either working toward meeting the LCN requirements for Certification or are Affiliate Centers working in collaboration with the LCN. For more information and contact information for each Center, please click on the links below.
- Children’s National Health System
- Lucile Packard Children’s Hospital at Stanford
- Texas Children’s Hospital
- The Children’s Hospital of Philadelphia
- UF Health Shands Hospital
- University of Minnesota Masonic Children’s Hospital
- Weill Cornell Medicine
Leukodystrophy Clinical Practice Guidelines (CPGs) will establish a published, peer-reviewed standard of care to ensure that individuals with Leukodystrophy have the best possible medical care, improving length and quality of life. The LCN helps its accredited Centers provide a standard of Leukodystrophy care with guidelines based on the latest research, medical evidence and consultation with experts on best practices. The CPG focus areas were determined through the LCN’s Clinical Issues Survey, which had over 300 participants affected by Leukodystrophies.

**Krabbe Newborn Screening:**
*Guidelines: Consensus guidelines for newborn screening, diagnosis and treatment of infantile Krabbe disease*
- Lead Author: Dr. Jennifer M. Kwon
- Family Co-Lead: Phil May

**Neurology:**
*Guidelines: Defining Leukodystrophy categories to establish a framework for recommendations, neurologic monitoring, symptom management and care coordination.*
- Lead Author: Dr. Florian Eichler, Massachusetts General Hospital, Harvard Medical School
- Family Co-Lead: Elisa Seeger

**Treatment:**
*Guidelines: Role of hematopoietic stem cell transplantation in the treatment of Leukodystrophy patients, newer emerging therapies that have potential to treat Leukodystrophy patients and designate the optimal supportive care measures needed to optimize the quality of life of Leukodystrophy patients.*
- Lead Author: Dr. Joanne Kurtzberg, Duke Children’s Hospital
- Family Co-Leads: Matt & Lauren Hammond

**Diagnosis:**
*Guidelines: Newborn screening applications, clinical utility of next generation sequencing, practitioner education in diagnosis, MRI and clinical phenotype guided diagnosis and family counseling after a diagnosis.*
- Lead Author: Dr. Adeline Vanderver, The Children’s Hospital of Philadelphia
- Family Co-Lead: Bob Rauner

**Musculoskeletal:**
*Guidelines: Maximize functional capabilities of affected children, pain & sleep management, management of hypertonia, bone health and medical equipment.*
- Lead Author: Dr. Sally Evans, Children’s National Hospital
- Family Co-Leads: Phil & Amy May

**Respiratory:**
*Guidelines: Pulmonary consultation referrals, prevent/reduce risk of pneumonia and mechanical ventilation.*
- Lead Author: Dr. Richard Kravitz, Duke Children’s Hospital
- Family Co-Leads: Chad & Lisa Borodychuk
APPENDIX C: LCN CONTACTS

The LCN Steering Committee is comprised of family members affected by Leukodystrophy and provides leadership, direction and oversight for the LCN. Click on the Steering Committee names to read their stories: Chad & Lisa Borodychuk, Matt & Lauren Hammond, Robert & Kristen Malfara, Phil & Amy May, David & Lindey McIntyre, Bob Rauner, Elisa Seeger, Kaprice Shullanberger, Sarai Taylor, Mike & Jenna Wallace, and Christin Webb.

Hunter’s Hope Support Team (LCN Coordinating Center)
Jacque Waggoner, CEO, LCN Executive Director
Anna Grantham, Programs Director, LCN Director
Kaitlin Brunner, Development Director
Laura Egan, Finance and Administration Assistant

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