



YEAR IN
2024
REVIEW

HUNTER'S HOPE FOUNDATION



HUNTER KELLY

Because of Hunter

Our lives are forever changed.

His bravery taught us to be bold.

His courage made us strong.

His humility inspired us.

His love changed us.

*And because of God's amazing grace,
our love endures forever.*

Jill Kelly

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Hunter's Hope was established in 1997 by Pro Football Hall of Fame Member and former Buffalo Bills Quarterback, Jim Kelly and his wife Jill, after their infant son, Hunter (2/14/97—8/5/05) was diagnosed with Krabbe Leukodystrophy, an inherited fatal nervous system disease. When the Kellys welcomed their only son, Hunter, into the world on February 14, 1997— Valentine's Day and Jim's birthday— they knew he was destined for something extraordinary.

God and prayer are at the core of who we are and what we do.

You can learn more about prayer [here](#).

about us

01

OUR MISSION

Hunter's Hope Foundation was established to address the acute need for information and research with respect to Krabbe Disease and related Leukodystrophies. In addition, our mission is to strive to support and encourage those afflicted and their families as they struggle to endure, adjust, and cope with the demands of these fatal illnesses.

Accordingly, our mission is four-fold:

- To broaden public awareness of Krabbe Disease and other Leukodystrophies thus increasing the probability of early detection and treatment.
- To gather and provide current functional information and service linkages to families of children with Leukodystrophies.
- To support research efforts that will identify new treatments, therapies, and ultimately, a cure for Krabbe Disease and other Leukodystrophies.
- To establish an alliance of hope that will nourish, affirm, and confront the urgent need for medical, financial, and emotional support of family members and those afflicted with Leukodystrophies.

Among the essential goals, founders Jim and Jill Kelly seek to inspire an appreciation of all children and express a thankful heart towards God for these precious gifts of life. These bedrock values are categorically and vigilantly expressed throughout all of the Foundation's programs and activities.

OUR LOGO



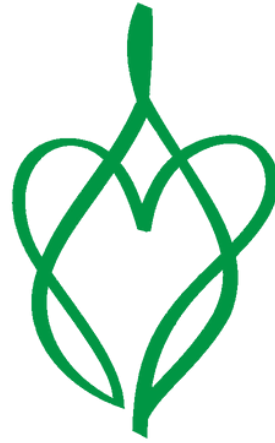
The message of the Hunter's Hope logo is at the core of the Foundation's mission and all we do.

It is green representing Hope.
It is a candle flame in a heart,
meaning the light of Christ
in our hearts.

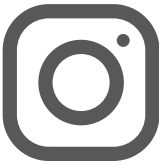
“For God, who said, ‘Let light shine out of darkness,’ made His light shine in our hearts to give us the light of the knowledge of the glory of God in the face of Christ.”

2 Corinthians 4:6

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[@huntershopefdn](#)



[Twitter \(X\)](#)
[@HuntersHopeFDN](#)



www.huntershope.org

FOLLOW US

THANK YOU!

We are deeply grateful to our families, supporters, sponsors, donors, and volunteers for standing with us in this fight.

Your unwavering commitment empowers us to continue providing critical support to hundreds of families affected by Leukodystrophy.

Equally, we owe a debt of gratitude to the researchers, medical professionals, newborn screening experts, and industry partners who don't just talk about change, but are actively working on the front lines to diagnose, treat, and ultimately find a cure for Krabbe and other Leukodystrophies. Their relentless dedication is the force that drives progress.

Thank you for being the difference maker today—for the individuals who are fighting for their futures. Together, we're not waiting for change; we're making it happen.

Our Supporters

*The Immeasurably More
Podcast*

Gifts of Love

Purpose Bear

Family Programs

*Newborn
Screening (NBS)*

*Leukodystrophy
Care Network (LCN)*

PROGRAMS

06



07

Podcast

Welcome to the "Immeasurably More" podcast, where faith and hope meet heartbreak and suffering in an uplifting journey of encouragement and perseverance. Join Erin and her mom, Jill as they delve into real stories and life-changing truths that remind us of the boundless love we can experience when we anchor our lives in who God is and who He created us to be.

From personal testimonies to thought-provoking and sometimes challenging discussions with special guests, each episode offers encouragement and a reminder of the immeasurably MORE that God has planned for our lives...a MORE that ultimately transcends the challenges we face in life.



PODCAST HOSTS



Erin is our podcast host. She is the oldest daughter of Jim and Jill Kelly. Erin attended Liberty University, where she earned a Bachelor degree in Digital Media and Strategic Communications. While at Liberty Erin met her husband, Parker Bean. The two got married in 2018 and recently moved back to Buffalo.

Jill Kelly is Erin's co-host. Each week they have real, honest, open conversations about life, faith, family, hope, mental health, and so much more!

We trust that God can and will do immeasurably more than all we could ever ask or imagine (Ephesians 3:20). Our hope and prayer is that as you listen to these episodes God would do just that... immeasurably more!



08

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MENTAL HEALTH

Erin and Jill are passionate about talking about mental health and sharing their own personal stories. They've found that these conversations really resonate with our listeners. During Mental Health Awareness Month, Erin and Jill shared their stories as well as what God has walked them through and what they've learned along the way.

"I share my story because I want others to feel the freedom to share their own story. I believe that there is so much power and healing in [sharing what we've walked through.](#)"

erin

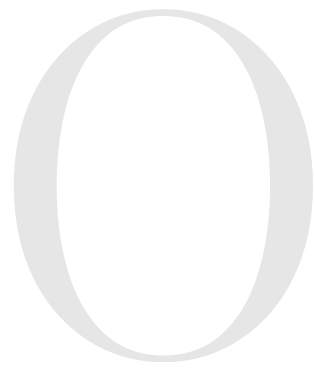
"God is God. He is good and faithful. We have both found Him to be the [ultimate answer](#) in our mental health struggles."

Jill

[Here are the Mental Health episodes shared this year:](#)

Recap of Erin & Jill's Mental Health Stories & Evidence of Healing
How to Help Someone with Depression & Anxiety
Climbing out of the Depths of Depression & Anxiety
How to Overcome the Fear of Falling Back into Depression & Anxiety
Your Story Isn't Over
Highlights & Takeaways from Mental Health Awareness Month
Keep Going Part 1 & Part 2
World Mental Health Day 2024
How do you cope with anxiety?

MOM'S & SIBLINGS EPISODES



At this year's Symposium we had the opportunity to talk to some of our amazing mom's and siblings! We talk about life, faith, pain, prayer, and more. We are so thankful for our families willingness to share their stories and the hope that they have!



**YOUR STORY
MATTERS!**

MOM'S & SIBLINGS EPISODES

CHRISTIN
WEBB

“



We were going to make it through
as long as we **put our trust in Him...**

The Hunter's Hope Mom's Session (Part 2)

“

THE SIBLING SESSION - PART 1

I would ask God to give me the
ability to talk with my sister or
communicate with her.
We gotta have the **girl talk**,
all of that kind of stuff.

ABBY SMITH

“

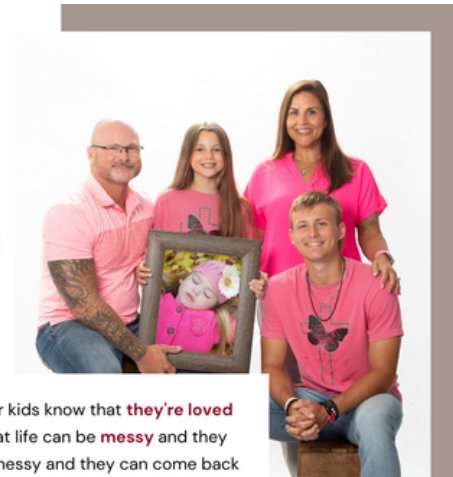
THE SIBLING SESSION - PART 2

My favorite quote is,
“I am not afraid.
I was born to do this.”
Marshall was literally born to
do this and fight for himself
and for me. I say this a lot, but
he truly did save my life.

MICHAEL WILSON

“

KRISTAL
ABNER



Let your kids know that **they're loved**
and that life can be **messy** and they
can be messy and they can come back
to you with their mess and **feel safe**.

The Hunter's Hope Mom's Session (Part 2)

BECKY
BOURASSA

“



Surround yourself with **love** and
people that are gonna **support you**.
You got this. **You can do it.**

The Hunter's Hope Mom's Session (Part 1)

“

THE SIBLING SESSION - PART 1

When I'm ever feeling down I kind
of look at it like, I made it
past another day and **one day**
closer to the best time of the year,
Hunter's Hope, is easily the best
time of the year for a lot of us.

STANLEY BOURASSA

WHAT PEOPLE ARE SAYING

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“I love listening to these podcasts. Erin and Jill, you have definitely helped me in my walk with Jesus. Your honesty and just true understanding and compassion for others is so inspiring. Thank you for what you do!” - Nannie

“My son deals with severe social anxiety. He always thought no one could know what he was feeling or experiencing. After listening to Erin describe how she felt on one of the podcasts, I had him listen to it. He had tears in his eyes saying, “Wow, she is describing exactly what I’m feeling. I’m not alone.” Thank you so much for sharing, you have no idea how much it helps.” - Sue

“Your mission is helping thousands.” - Lynnette

“Thank you so much for taking the time to allow us to see freedom and joy in suffering. Thank you Jesus!” - Auntie

“I just wanted to let you and your beautiful mother know that because of your podcast and such godly lives, I can 100% say I believe in Jesus now more than ever.” - Maria

“Thank you for sharing your heart and for being real. I can relate to so much of what you guys talk about. I have been encouraged so many times. Thank you, thank you, thank you! Please keep doing what you’re doing.” - Kelly

THANK YOU TO OUR LISTENERS!

PODCAST STATISTICS AS OF 1/2/25

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Social Media

Over **32,000 accounts** were reached
in the last 90 days.

We currently have **2,606 followers** on Instagram and
have recently become active on Twitter.

Podcast Platform Buzzsprout Statistics

147 Episodes published, and
70,929 downloads since launching the podcast two
years ago. The podcast has been listened to in
79 different countries.

Thank you so much to our listeners!

[Learn more here.](#)

keep going

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your story isn't over.
HH x MH collection



booklet

Over the last four years we have created booklets to share the hope that we have found in God. This year Erin designed the Keep Going booklet during Mental Health Awareness Month in order to encourage others with the hope that she's found in the midst of her own healing journey.

Our hope is that this booklet encourages you to Keep Going and that you're reminded that your story isn't over! This booklet is also a great gift to give someone who needs this encouragement too.

To learn more about this year's booklet, click [here](#).

To download a digital copy of the booklet, click [here](#).

To view all of our booklets, click [here](#).

GIFTS OF LOVE



We feel incredibly blessed to have the opportunity to share over 1,500 of our Gifts of Love (special bears) with special people throughout Western NY. We have visited 17 wonderful organizations to meet the amazing individuals they serve.

You can learn more about Gifts of Love [here](#).



PURPOSE BEAR

My name is "Purpose."

I am a personalized Boyds Bear created for the Hunter's Hope Foundation. Hunter knew God and trusted His promises. He knew that God created him for a greater purpose.

You can learn more about the Purpose Bear [here](#).

FAMILY PROGRAMS

Family Care

LCN Family Collection

Wall of Fame

Wish Gift

Equipment Exchange

Symposium

Newborn Screening

*Leukodystrophy Care
Network*



FAMILY CARE

Our Family Care program sends cards and care packages to Leukodystrophy families in a variety of meaningful ways. These include when they register with the Foundation, celebrate a birthday, honor a child's heaven date, or simply need a moment of encouragement and prayer. In 2024, over 1,000 cards and over 50 care packages were sent to affected children and their families.



BIRD FAMILY

The Bird Family registered with Hunter's Hope this year. Joseph is 10 years old and Jesse is seven. They are both affected by Pelizaeus Merzbacher Disease (PMD), a Leukodystrophy.



JARRIN FAMILY

The Jarren Family is one of many families who registered with Hunter's Hope this year. Tessa is one year old and is affected by Tubb4A Leukodystrophy.

LCN FAMILY COLLECTION



The LCN Family Collection honors families affected by Leukodystrophy, raising awareness and support for those impacted. Each family has a unique product line in our Shop featuring items with their personalized logo, designed by the families themselves. These logos symbolize the strength and unity of their journey. The collection fosters a sense of community and solidarity while helping fund research and support initiatives for Leukodystrophy.

LCN FAMILY CHALLENGE Congratulations to our Winners!


| Top 3 | LCN Family Collection Family Lines | Total Products |
|-------|------------------------------------|----------------|
| 1 | SB Line | 146 |
| 2 | GC Line | 144 |
| 3 | NS Line | 137 |

| Top 3 | LCN Family Collection Family Lines | Total Sales |
|-------|------------------------------------|-------------|
| 1 | SB Line | \$3,620 |
| 2 | NS Line | \$3,072 |
| 3 | GC Line | \$2,141 |




Grujic Family - NS Line

43012



Schmiedel Family - Maddy Effect Line

22115



Feldt Family - Dawson Strong Line

15111

Learn More [here](#).

WALL OF FAME



Tessa Jarrin



Ella Fox



Arturo Beltran



Lucy Johnson

The Wall of Fame gives families an opportunity to honor their loved ones. These are just a few of the children added to the Wall of Fame this year.

To learn more, please click [here](#).

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WISH GIFT

Brandon and
Nathan Mederios



Families face tremendous stress and financial hardship as they care for a child with a Leukodystrophy. Hunter's Hope assists families with these diseases so they can focus on what matters most – caring for their child.

Brandon and Nathan are identical twins with Late Onset Krabbe Leukodystrophy. They needed a wheelchair van that can fit two wheelchairs, making travel to activities like the movies, beach, shopping, and doctor's appointments much easier. Their mom says that both boys love riding in their new van, especially going over bumps.

In 2024, Hunter's Hope fulfilled 8 Wish Gifts totaling nearly \$150,000.

To learn more, please click [here](#).

EQUIPMENT & SUPPLY EXCHANGE

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LEO CAYER

Children affected by a Leukodystrophy require equipment and supplies that can cost thousands of dollars. Insurance companies do not always cover these items and a lot of families can't afford to purchase them on their own.

This program facilitates the donation of equipment and supplies from families who no longer need them to bless other families in need. Hunter's Hope pays for the equipment to be shipped from the donating family to the family in need.

Leo is two years old and has a leukodystrophy.

"The Stander is working great for our little Leo! We appreciate all that you and your organization does for families!" ~ Leo's mom

To learn more, please click [here](#).

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FAMILY SYMPOSIUM

We were blessed to be together again in person for this year's 2024 Family Symposium! Over 50 families joined us at Holiday Valley Resort. Hunter's Hope covers all costs for families to attend. Families were also able to join us from all over the world virtually for sessions throughout the week.

Sessions were provided that inspired, uplifted, gave hope, and shared God's love for all. This week provides community, friendship, and understanding for all who attend. Hunter's Hope provides hotel accommodations, meeting expenses, and all meals so that families can truly relax and enjoy the week.

There were many special events for families: Prayer Room, Welcome Dinner, Kid Kamp, Photo Shoot with Brody, Siblings Challenge, Balloon Release, Family Walk, Morgan's Legacy Sensory Room Experience, LCN Family Collection Fashion Show, Stars of Hope Talent Show, and more.

It was a great week filled with HOPE!



We look forward to continuing to provide in-person and virtual access to the Symposium next year, July 16-20, 2025.

You can learn more about this year's family symposium on the Hunter's Hope website - click [here](#).

BALLOON RELEASE



SEE YOU AGAIN

Every year we write the names of our loved ones on balloons and release them to Heaven. We pray...

Then we play the Carrie Underwood song *See You Again*.

*Sometimes I feel my heart breaking
But I stay strong, and I hold on 'cause I know
I will see you again, oh
This is not where it ends
I will carry you with me...*

24 Learn more about this year's family symposium [here](#).

MEDICAL SYMPOSIUM

Thank you to our amazing medical professionals!



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MEDICAL SYMPOSIUM

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At the 2024 Hunter's Hope Medical Symposium, over 120 medical and scientific professionals joined us both in-person and virtually. This year's event was filled with hope and a shared commitment to improving the lives of individuals with Leukodystrophies.

Day 1 focused on Nationwide Newborn Screening (NBS) for Leukodystrophies, including updates on Krabbe disease, which has been added to the Recommended Uniform Screening Panel (RUSP). Discussions highlighted the readiness of NBS programs to screen for Krabbe and provide optimal care for positive cases. Attendees also reviewed the status of NBS for ALD, CTX, and MLD.

On Day 2, the focus shifted to new treatments, clinical trials, and research advancements. The Leukodystrophy Care Network (LCN) discussed managing care for patients with Vanishing White Matter disease, transitioning care from childhood to adulthood, and educating insurance companies to improve coverage. The day ended with a discussion on LCN's goals for the year ahead.

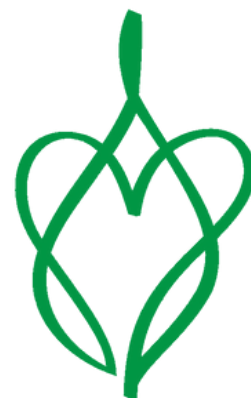
The symposium also featured an inspiring family welcome dinner, where families shared their personal experiences with Leukodystrophy. We celebrated Krabbe disease's inclusion in the RUSP and honored the experts who made it possible: Dr. Dieter Matern, Dr. Joseph Orsini, and Dr. Joanne Kurtzberg.

On Thursday of the Family portion of the symposium, families gained valuable insights from the doctors and scientists about NBS, the LCN, and emerging treatments and trials.

The medical symposium was a resounding success, thanks to all involved.

You can learn more about the 2024 Medical Symposium and view this year's presentations [here](#).

NEWBORN SCREENING



NEWBORN SCREENING

Newborn Screening (NBS) is a state-based public health program that detects rare and potentially fatal diseases prior to the onset of symptoms. For these diseases, early detection and treatment through NBS is essential to avoid irreversible damage and even death.

Each state determines which diseases are included in its NBS program but there is a federal Recommended Uniform Screening Panel (RUSP) that helps set a minimum standard of diseases to screen for. For over two decades, Hunter's Hope has advocated for federal funding to support expanded NBS and has led grassroots efforts across the country for Krabbe NBS. Simultaneously, we have partnered with the leading Krabbe and NBS experts to make continual medical and scientific advancements for Krabbe NBS.

To learn more, click [here](#).

KRABBE NBS COUNCIL

The Krabbe NBS Council is a cohort of clinicians, state newborn screening staff, and experts focused on providing the best possible outcomes for children who screen positive for Krabbe disease through their state's newborn screening (NBS) program. In 2024, the Council met monthly to discuss case studies, improve protocols, and learn from the nation's leading Krabbe NBS and Treatment experts.

To learn more, click [here](#).

FEDERAL ADVISORY COMMITTEE

In 2024, the federal newborn screening advisory committee (ACHDNC) recommended the inclusion of Krabbe Disease on the Recommended Uniform Screening Panel (RUSP) and the U.S. Secretary of Health officially added Krabbe to RUSP on July 1, 2024. This decision is the culmination of over two decades of advocacy and work, and is a huge milestone in our efforts for all children to be screened for Krabbe Disease at birth. Although each state still determines whether to screen for Krabbe, most states choose to be RUSP compliant and we are hopeful for nationwide Krabbe NBS to become a reality in coming years. Learn more about our journey to the RUSP [here](#).

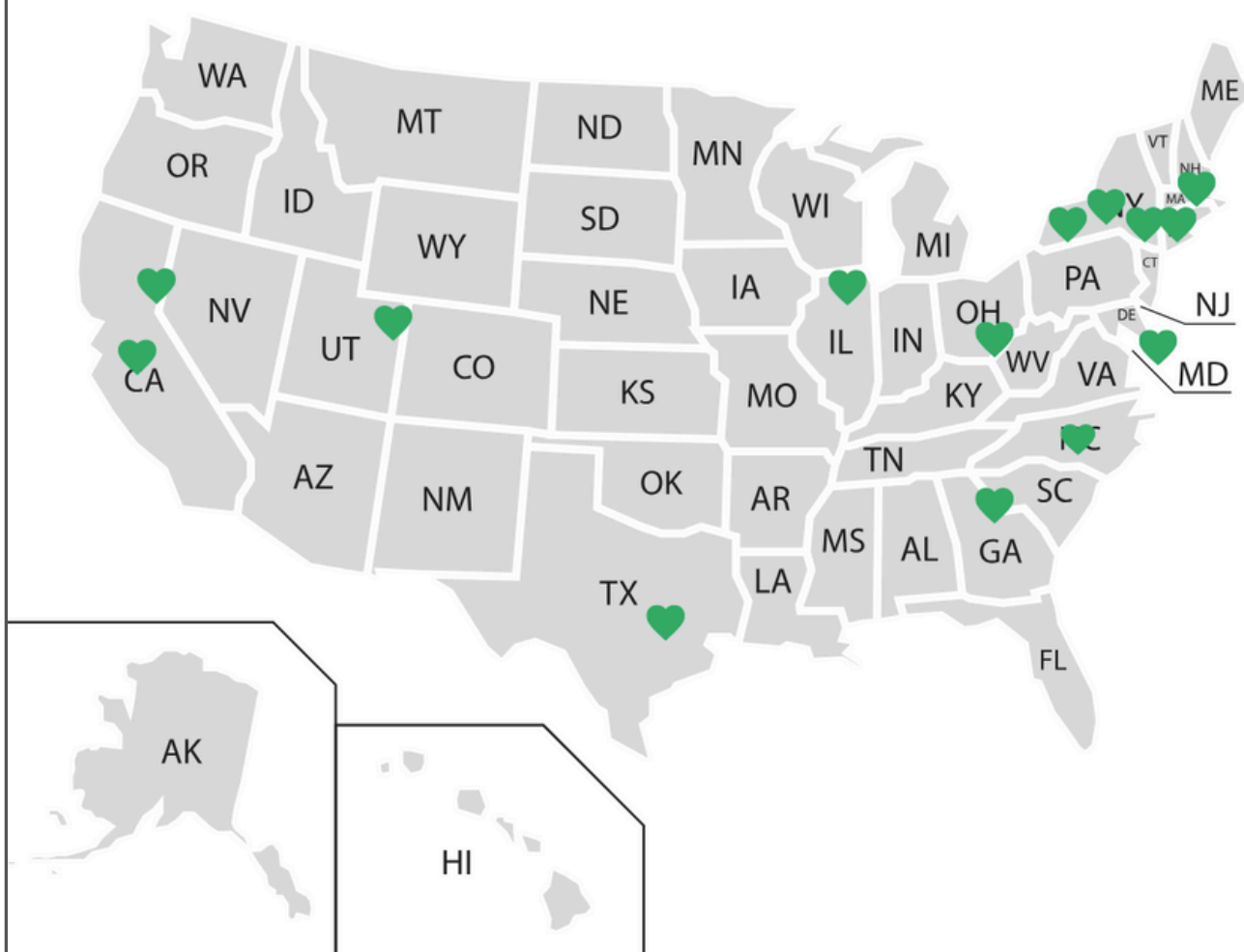
STATE NBS

In 2024, Minnesota became the 12th state to screen for Krabbe disease at birth and we anticipate more states to begin screening for Krabbe Disease in 2025. Find out if your state includes Krabbe on its NBS panel and how to take action on our website. Click [here](#).

Learn more about our Krabbe NBS programs [here](#).

LEUKODYSTROPHY CARE NETWORK

2024 LCN Certified Centers



The Leukodystrophy Care Network (LCN), established in 2015, is a network of medical providers, hospitals, Leukodystrophy organizations, and affected families. The LCN provides innovative therapies, treatment options, expert care, and information to families impacted by Leukodystrophies.

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LCN CERTIFIED CENTERS

The 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, Family Advocates, and Leukodystrophy Experts.

In 2024 we certified three new centers – CHRISTUS Children’s Hospital of San Antonio, Columbia University NYP Morgan Stanley’s Children’s Hospital, and Mount Sinai Hospital.

To learn more about LCN Certified Center requirements, please click [here](#).

*Ann & Robert H. Lurie Children’s Hospital of Chicago
Children’s Healthcare of Atlanta
CHRISTUS Children’s Hospital in San Antonio
Columbia University NYP Morgan Stanley Children’s Hospital in NY
Duke Children’s Hospital
Golisano Children’s Hospital, University of Rochester
John R. Oishei Children’s Hospital of Buffalo
Kennedy Krieger Institute
Lucile Packard Children’s Hospital at Stanford
Massachusetts General Hospital
Mount Sinai Hospital of New York, NY
Nationwide Children’s Hospital
Primary Children’s Hospital, Utah
UC Davis Health System*



LCN STEERING COMMITTEE

The LCN is led by our Steering Committee, made up of Leukodystrophy families, to ensure that the patient experience is at the forefront of all we do. The 2024 LCN Steering Committee members are Chris and Kristal Abner, Ron Chapleau, Dianna Greene, Matt and Lauren Hammond, Kristen Malfara, Phil and Amy May, Elisa Seeger, and Christin Webb.

The Steering Committee meets monthly to review the status of the LCN and plan new initiatives.

Part of the LCN Vision is to ensure that the patient voice is central to all we do, that families affected by leukodystrophies always have a seat at the table.



In 2024, the LCN Steering Committee welcomed Chris and Kristal Abner. Their daughter Katelynn was affected by MLD and they are a military family. We're grateful for the insight they bring.

You can learn more about the Abner Family [here](#).

LCN DIRECTORS



2024 LCN Directors

*First Row: Dr. William Benko, Dr. Joanne Kurtzberg, Dr. Jennifer Rubin,
Dr. Ali Fatemi, Dr. Margie Ream*

*Back Row: Dr. Gustavo Maegawa, Dr. Sreenivas Avula, Dr. Hillary Raynes,
Dr. Robert Thompson-Stone*

*Not pictured: Dr. Joshua Bonkowsky, Dr. Florian Eichler, Dr. Bridget Hughes,
Dr. Stephanie Keller, Dr. Keith Van Haren*

In 2024 we launched quarterly meetings with the LCN Directors to increase collaboration and to share expertise. This distinguished group of experts are devoted to providing the best medical care possible and continually make advancements for the leukodystrophy community.

LCN CARE COORDINATORS



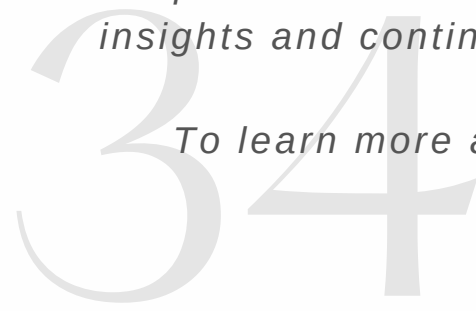
2024 LCN Care Coordinators

*Back Row: Caitlin Griffin, Jennifer MacLean, Kim Hollandsworth, Tovly Orlan
Front Row: Courtney Chambers, Alexandra Vierling, Angela Childers,
Nikki Walsh, Mary Beth Summers, Tara West, Catherine Becker, Emily Stage
Not Pictured: Karen Cleary, Rachel Hickey, Cassandra Ingemansson*

Every Leukodystrophy Care Network (LCN) Center has a dedicated Care Coordinator, typically a Nurse Practitioner or RN, committed to guiding children and adults with Leukodystrophies through their healthcare journey.

Our Care Coordinators are the heart of the LCN and serve as the main point of contact for Leukodystrophy families as they navigate their complex medical needs. They meet as a group every month to share insights and continue to grow in their ability to serve this incredible community.

To learn more about the Care Care Coordinators, click [here](#).

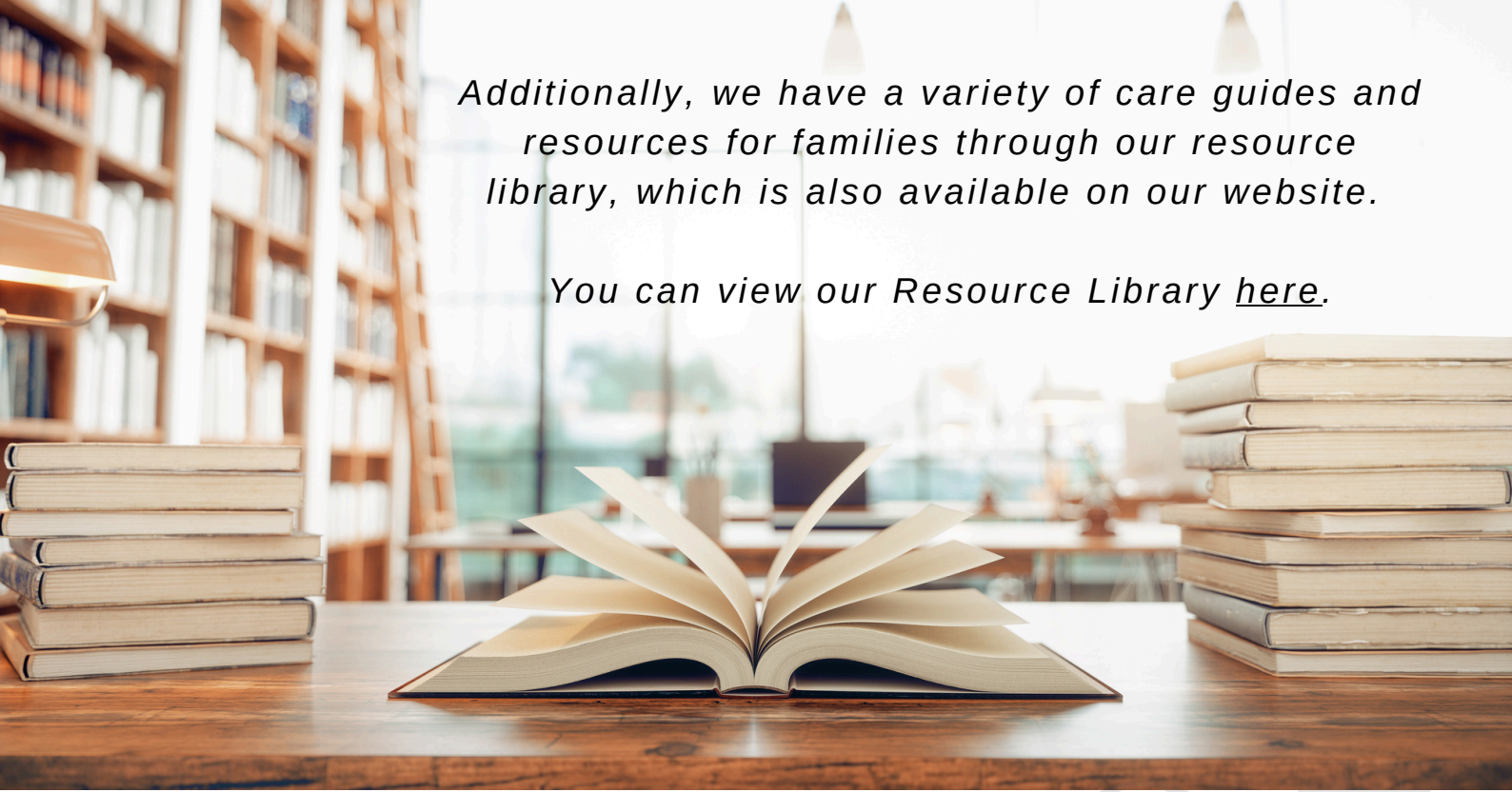


LCN CLINICAL PRACTICE GUIDELINES

Through the LCN Clinical Practice Guidelines (CPGs), leukodystrophy standards of care are established, published, and continually improved as needed. These publications not only provide guidance for our LCN Centers but are published in medical journals and are available to all medical providers. This year we launched several more CPG workgroups focused on Krabbe Newborn Screening to help providers as their states begin screening for the disease.

View our CPGs [here](#).

LCN RESOURCE LIBRARY



Additionally, we have a variety of care guides and resources for families through our resource library, which is also available on our website.

You can view our Resource Library [here](#).

Learn more about the LCN [here](#)

OUR PARTNERS

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KRISTEN AND MORGAN MALFARA

We are honored and most grateful for our partnership with Kristen Malfara and the establishment of Morgan's Legacy Gift.

In 2024 Morgan's Legacy Gift supported 37 Gifts, a Sensory Room Experience at this year's Symposium, and more, totaling more than \$27,000.

You can learn more [here](#).

With much gratitude and honor, Hunter's Hope Foundation and the Abner Family established Katelynn's Butterfly Kisses.

The Katelynn's Butterfly Kisses Endowment Fund of \$1,000,000 established in August 2023 produced spending funds of \$50,000 this year, where half went towards Metachromatic Leukodystrophy (MLD) Newborn Screening, the Leukodystrophy Care Network (LCN), MLD Families, and Sibling Support, with priority given to military families affected by Leukodystrophy.



CHRIS, KRISTAL, WYATT, AVALYNN, AND KATELYNN ABNER

You can learn more [here](#).

SHOP



Legacy Collection

Throughout its history, Hunter's Hope has crafted a unique theme annually, reflecting the spiritual journey of our lives at the time. These themes are deeply rooted in the scriptures, drawing inspiration from what God is orchestrating in our lives. The Legacy Collection gathers together these themes from various years, encapsulating the spiritual essence of our journey over time. We pray you will be blessed by them.

To learn more about the Legacy Collection, click [here](#).



SHOP



The **HH x MH collection** is a collaboration between the Hunter's Hope Foundation and mental health community. Inspired by Erin Kelly and her desire to help people and end the mental health stigma, HH x MH seeks to address and support the needs of individuals and families facing various mental health battles. This collaboration forms a support system through awareness and advocacy that emphasizes the interconnectedness of physical, emotional, spiritual, and mental health. Ultimately, through the podcast, apparel, booklets and more, the HH x MH collection was created to inspire hope, perseverance, and faith while providing compassionate support for individuals suffering with depression, anxiety, grief, and other mental health struggles.

To learn more about the Keep Going line, click [here](#).



Hunter's HERO

MONTHLY DONORS

MAKING A DIFFERENCE

feeling

Have a wonderful feeling of knowing you are a Hero to those children and their families suffering from Leukodystrophy.

every tomorrow

Make a difference today and every tomorrow in the lives of children and their families who so desperately need your help.



sustain

Sustain programs that improve quality of life. Family Care, Wish Gift, Equipment Exchange, Family and Medical Symposium, Leukodystrophy Care Network, Newborn Screening, and others.

exclusive

Become a member of our exclusive Hunter's Hero Community where you will be invited to special meetings with opportunities to learn the impact of your generosity and to provide your input.

We are so thankful for our Hunter's Heroes!

Their monthly gifts make a sustainable impact for families affected by Leukodystrophy.

Join our Hunter's Hero Community [here](#).



2023 AUDITED FINANCIALS

REVENUES

| | |
|-------------------|--------------|
| GENERAL DONATIONS | \$ 588,325 |
| GRANTS | \$ 167,932 |
| ENDOWMENTS | \$ 1,224,000 |
| TOTAL | \$ 1,980,257 |

EXPENSES

| | |
|----------------------|-------------|
| G & A | \$ 80,271 |
| FUNDRAISING | \$ 66,612 |
| EDUCATION NBS | \$ 233,928 |
| FAMILY ASSISTANCE | \$ 285,208 |
| LCN NBS RESEARCH | \$ 380,273 |
| TOTAL | \$1,046,292 |

| | |
|------------|-------------|
| NET ASSETS | \$2,225,696 |
|------------|-------------|