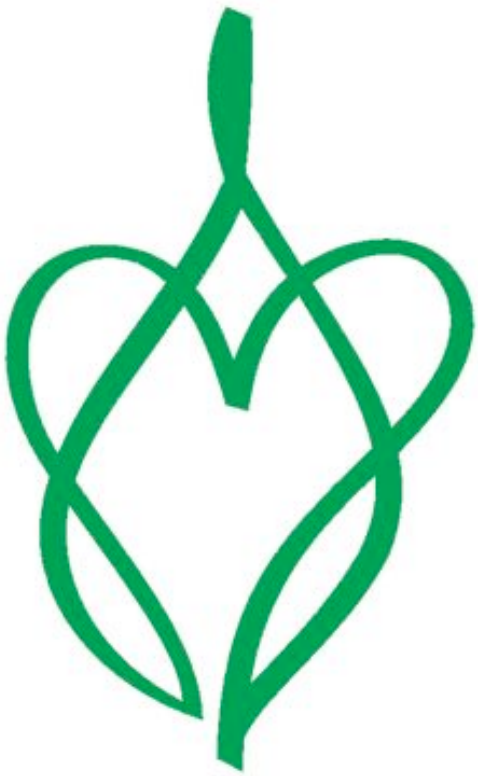
Hunter's Hope Foundation

2017 Annual Report



Leukodystrophy Care Network
Expanded Newborn Screening

Dear Friends,

It has been 20 years since we first heard the word Leukodystrophy. At first, that word meant one thing – a death sentence for our one and only son, Hunter (2/14/97 – 8/5/05).

Over time and by God's grace, the Lord has healed our hearts and helped to change our perspective. He used Hunter's perseverance, bravery, and humility to show us what it truly means to live.

Leukodystrophies are a group of devastating disorders that affect the white matter of the brain, have no cure, and are fatal. But, they are all treatable.

For Hunter, there was no roadmap or guide to tell us what to anticipate or how to maximize his health and comfort. We were lost.

The Kelly Family at the 2017 Hunter's Hope Family & Medical Symposium.

Throughout the last 20 years we've forged a path for research, awareness, and support for children and families affected by Leukodystrophies. Now, we're using this same passion to revolutionize the medical care of children affected by these diseases through the Leukodystrophy Care Network (LCN). Medical providers and affected families are linking arms in order to ensure the best possible level of medical care for the children.

Throughout 2017, monumental progress has been made.

We invite you to join us as we continue to press forward to give our children the dignity, hope, and medical care they deserve.

Together, we will make a difference today for someone fighting for their tomorrow.

With hope,

Jim, Jill, Erin and Camryn Kelly

We rejoice in our sufferings, knowing that suffering produces endurance, and endurance produces character, and character produces hope, and hope does not put us to shame, because God's love has been poured into our hearts through the Holy Spirit who has been given to us.
Romans 5:3-5

Mission

Hunter's Hope was established in 1997 by 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.

While Jim and Jill have been blessed with the opportunity to share Hunter's story and the hope of the Foundation named after their son all over the world, their greatest passion is to bring encouragement and hope to families in the midst of suffering.

Hunter's Hope Foundation was established to address the acute need for information and research with respect to Leukodystrophies. In addition, we 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:

- To broaden public awareness of Krabbe Disease and other Leukodystrophies thus increasing the probability of early detection and treatment.
- To increase newborn screening standards across the United States to obtain early detection for all diseases where early diagnosis can improve the quality of the child's life.
- To gather and provide current, functional information and service linkages to families of children with Leukodystrophies.
- To fund research efforts that will identify new treatments, therapies and ultimately, a cure for 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.

Core Values

We believe...

...that we must remain true to and passionate about our core ideology
...that we must live and preserve our family-oriented and wholesome image
...in respecting and valuing individual contributions
...in truthfulness and honesty in all matters
...in respecting the right of privacy of all individuals

Education and Awareness

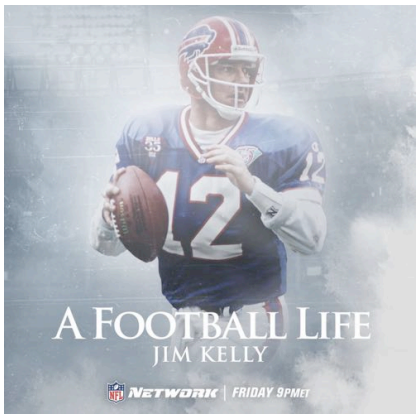
Hunter's Hope's commitment to increase awareness and understanding of Leukodystrophies and Newborn Screening provides important and potentially lifesaving information to the medical community and general population. This widespread knowledge will enable more timely diagnoses for children affected by Leukodystrophies and result in expanded newborn screening.

"We happened to see the Kellys on the Today Show shortly after Bryleigh was diagnosed. We didn't really know about Hunter's Hope, but we got in contact to see how we could make a difference. I knew this was where we were going to make a difference."
Kaprice Shullanberger,
Mom of Bryleigh (MLD)

The Kelly Family
When the news of Hunter Kelly's diagnosis with Krabbe Disease broke, Jim and Jill Kelly received letters from families across the country affected by Leukodystrophies. As a result, Jim and Jill co-founded Hunter's Hope in 1997 and dedicated themselves to helping the countless children and families affected by Leukodystrophy.

As public figures in the Western New York Community and beyond, the Kelly family uses their platform to share their story and the work of Hunter's Hope.

The Kellys share their story of hope through regular speaking engagements and numerous published books. At their speaking engagements, by sharing Hunter's story they bring awareness to Hunter's Hope and its mission. Likewise, each book contains information about Hunter's Hope, Leukodystrophies, and newborn screening. In addition, a portion of the books' proceeds benefit Hunter's Hope.



Left: Erin Kelly, shared her story at the 2017 Kingdom Bound Conference, which welcomed over 32,000 attendees from throughout the United States and Canada. Right: The NFL Network aired "A Football Life: Jim Kelly" on November 2, 2017 exploring the life of Jim Kelly, including the story of his son, Hunter, and Hunter's Hope Foundation.

Special Events and Programs
Throughout 2017, Leukodystrophy families, volunteers, and friends of the Foundation helped to raise awareness and funds for Hunter's Hope. More than 60 events and programs were coordinated throughout Western New York and the entire U.S., raising over $200,000.

Expanded Newborn Screening

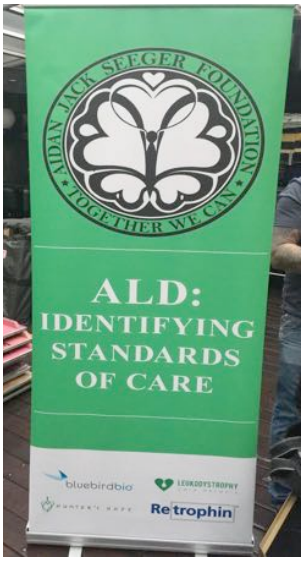
Through Newborn Screening, a simple heel prick after birth can unlock the door to early discovery and treatment for dozens of potentially deadly diseases that would otherwise go undetected.

Nearly four million babies are born in the U.S. each year, yet the diseases a baby is screened for at birth is determined by the state that baby is born in. Since 2005, Hunter's Hope has been partnering with Leukodystrophy families, lawmakers, and key decision makers to expand every state's newborn screening panel to include every disease possible so *Every Child. Every Time. Everywhere.*™ has a fair chance at a healthy start at life.

Newborn Screening for Leukodystrophies
Hunter's Hope works with families affected by Leukodystrophies as they advocate for expanded newborn screening (NBS) in their states.

In 2017, Tennessee and Illinois implemented NBS for Krabbe disease, ensuring that approximately 235,000 more newborns will be screened for Krabbe at birth each year. Additionally, legislation for Krabbe NBS was sponsored in Maine, Massachusetts, and Georgia.

Top: Lennon (Krabbe) with her mom and members of her treatment team. Lennon was diagnosed with Krabbe in 2017 by Ohio's newborn screening program. She was diagnosed early enough to receive treatment to stop the progression of the disease. Bottom: In 2017, Hunter's Hope supported the Aidan Jack Seeger Foundation through a $10,000 grant to host a meeting with Adrenoleukodystrophy (ALD) experts in order to establish standards of care for ALD NBS.



The Foundation collaborated with the medical and scientific community to create standardized screening and follow-up guidelines through the Krabbe NBS Task Force.

Additionally, Hunter's Hope partnered with the Aidan Jack Seeger Foundation and others to advocate for NBS for Adrenoleukodystrophy (ALD) legislatively and in the medical community.

This progress would not be possible without the tireless work of affected families all over the U.S. to ensure that future children born have a chance at a healthy life.

Hunter's Day of Hope and Prayer for Children

New York State Assemblyman Raymond Walter presents members of the Kelly family with legislative resolutions on stage.

Hunter's Hope and the Kelly family believe all children should be celebrated every day. Each year, Hunter's Hope celebrates *Hunter's Day of Hope and Prayer for Children* as a day to remember the *gift* that all children are and to pray for children all over the world.

In Western New York, *HDHPC* is celebrated the Saturday closest to February 14th, Hunter and Jim's birthday. Over 3,000 community members attend this free event and enjoy an afternoon filled with kid-friendly entertainment and activities. Most importantly, times is dedicated at the event for families to gather and pray for all children.

Once again, New York State Assemblyman Raymond Walter and Senator Michael Ranzenhofer sponsored and saw the passage of a resolution recognizing February 14th as Hunter's Day of Hope and Prayer for Children statewide.

"I love when our family gathers with the children on stage and have them join us in prayer. It is amazing to see children come together to pray for other children!"
Jill Kelly, Co-Founder, Hunter's Hope

Children join the Kelly family on stage to join in prayer for all of the world's children at the 2017 HDHPC event.

Research

Since 1997, an overarching goal of the Foundation has been to fund research into the cause, prevention, treatment, and clinical care for children suffering from Leukodystrophies. To that end, Hunter's Hope entered into an agreement in 2008 with the University at Buffalo School of Medicine, to create the Hunter James Kelly Research Institute (HJKRI).

Foundation funded research, including both clinical and basic science, is coordinated through the Institute, which is located in the New York State Center of Excellence in Bioinformatics and Life Sciences (CoE), a prominent part of the Buffalo Niagara Medical Campus.

Ultimately, the mission of the HJKRI is to find better treatments and a cure for those suffering from Krabbe and other Leukodystrophies.

To accelerate advancements and learn more from those affected by the disease today, the HJKRI, led by Lawrence Wrabetz, MD, incorporates both basic science and clinical science programs.

Basic science research focuses on the study of myelin and its diseases by exploring animal and cellular models to understand how myelin is formed, how it is damaged in disease, and how it may be repaired. Myelin is the fatty insulation around axons (the wires of the nervous system) in the brain, spinal cord and nerves. In particular, the HJKRI studies the mechanisms of Krabbe Disease and other Leukodystrophies in order to formulate therapies.

Clinical research analyzes information revealed by newborn screening for Krabbe Disease and other Leukodystrophies. The World Wide Registry for patients with Krabbe Disease aims to improve diagnosis and prognosis and to provide outcome measures for clinical trials.

This integrated approach, together with a critical mass of resources and investigators, will generate information that will promote effective treatment strategies not only for children with Leukodystrophies, but also patients with Multiple Sclerosis, stroke, neuropathies and other diseases in which myelin is damaged.

Hunter's Hope also funds extramural research conducted by leading Leukodystrophy experts.

Medical providers, researchers, and affected families at the 2017 Hunter's Hope Medical Symposium

Leukodystrophy Care Network

When Hunter Kelly (2/14/97 – 8/05/05) was diagnosed with Krabbe Disease, his parents were told there was nothing that could be done, he would not live past his second birthday, and to take him home and make him comfortable until he took his last breath. Hunter lived to be eight and a half years old.

Top: Hunter James Kelly on June 30, 1997, the day he was diagnosed with Krabbe Disease. Bottom: Members of the LCN Steering Committee attend the Child Neurology Society meetings in October 2017 where we had the opportunity to share about the importance of Leukodystrophies and the LCN to over 500 pediatric neurologists.

Hunter's Hope established the ***Leukodystrophy Care Network (LCN)*** in 2015, and continues to make significant strides toward the LCN's mission to revolutionize the health and quality of life for individuals affected by Leukodystrophies with proactive, innovative, and comprehensive medical care standards and specialized centers throughout the U.S., Canada and eventually the world.

Revolutionizing Care for Leukodystrophy Patients

Although, currently there is no cure for Leukodystrophies, they are all treatable. However, with an occurrence rate of 1 in 7,000, Leukodystrophies remain virtually unknown, even in the medical community. This results in families often receiving numerous misdiagnoses, as well as insufficient therapies and treatment options once a correct diagnosis is reached.

A substantial inequality exists in the care of individuals affected by Leukodystrophies. Twenty years after Hunter's diagnosis, families are still told to take their child home and make them comfortable until they take their last breath. Through collaboration and multidisciplinary care, the LCN is transforming the approach and outcomes of medical care for individuals affected by Leukodystrophies.

"I used to look at a child and say 'Boy, we should just try to figure out how to make them comfortable and let that be that.' Hunter's Hope and their families have taught me a lot. I admire the Foundation's vision, and its ability to keep focused on that and move things forward in Krabbe and Leukodystrophy Care."
Jennifer Kwon, MD, MPH,
University of Rochester Medical Center

Establishing Standards of Care

In 2017, six workgroups, comprised of LCN clinicians and family advocates, began to create Leukodystrophy Clinical Practice Guidelines (CPGs) in the areas of Krabbe Newborn Screening, Treatment, Neurology, Diagnosis, Respiratory, and Musculoskeletal. These guidelines will establish a peer-

reviewed standard of care based on the latest research, medical evidence and consultation with experts on best practices, to ensure that individuals with Leukodystrophy have the best possible medical care, improving length and quality of life.

The CPG focus areas were determined through a Clinical Issues Survey distributed by the LCN in 2016. The survey received over 300 responses from individuals affected by Leukodystrophies.

Ensuring Excellence Through Collaboration
Leukodystrophy individuals and their families are at the core of the LCN and remain a key component in every aspect of the Network. The LCN is led by a Steering Committee consisting of more than 19 Leukodystrophy family members, representing 10 different Leukodystrophies. In addition, the LCN works collaboratively with Leukodystrophy family advocates, medical providers, and organizations to ensure patient care remains the LCN's primary focus.

Partner organizations include:
Aidan Jack Seeger Foundation
ALDConnect
Believing for Bryleigh
Bethanys Hope Foundation
Global Leukodystrophy Initiative
Olivia Kay Foundation
PMD Foundation
The Jackson Project
The M.O.R.G.A.N Project
United Leukodystrophy Foundation
World Leukodystrophy Alliance

"We were asked to be a part of the LCN, and that has given us a lot of opportunity to plug in and be a part of making a difference for other children. It helps me, as the father of a child who had a Leukodystrophy and passed away, it helps me to feel like I am making a difference for her. She is the motivation of us wanting to do good things for other children. Hunter's Hope has opened up the door for us to do that across the nation."
Chad Borodychuk, Dad of Olivia (Alexander Disease, 10/10/08 – 4/28/17) LCN Steering Committee Member

Members of the LCN Steering Committee at the 2017 Hunter's Hope Family and Medical Symposium

Family & Medical Symposium

Each year, Hunter's Hope gathers the world's leading medical and scientific Leukodystrophy experts together with families affected by these diseases for a week of learning, sharing and relationship building. Families from all over the world gather to learn from medical experts about the disease that affects their children.

The 2017 Hunter's Hope Family and Medical Symposium was held at Holiday Valley Resort in Ellicottville, New York, July 16-21, 2017; and welcomed 47 Leukodystrophy families with over 70 researchers and medical experts.

Medical Symposium
The experts in attendance worked together on six Clinical Practice Guidelines (CPGs) for Leukodystrophies, discussed advancements and care protocols for Krabbe NBS, received updates from states with mandates for Krabbe NBS, and learned about scientific advancements regarding treatments and a cure for Leukodystrophies.

The most impactful component of the Medical Symposium is the opportunity to introduce researchers to families affected by Leukodystrophies at our Family Welcome Dinner.

Dr. Joseph Orsini of the NYS Newborn Screening lab with Elmer (Krabbe) and his mom at the Symposium Family Welcome dinner. Elmer was the first child to screen positive for Krabbe after New York added the disease to its newborn screening panel in 2006.

Family Symposium

Families attended educational sessions led by the world's leading experts to learn the most current information about the diseases affecting their children. In addition, families formed lifelong friendships with one another, gaining the support needed as they cope with these devastating disorders. The magnitude of the love and hope felt throughout the week is difficult to put into words – it is truly profound.

The Families at the 2017 Hunter's Hope Family and Medical Symposium

Hunter's Hope made it possible for families to attend the Symposium, regardless of their financial ability by covering all meal and lodging expenses for the week. Additionally, the Foundation awarded over $17,000 in travel assistance to families unable to afford the cost of travel, who may not otherwise have been able to attend.

The Kellys with some of the special children at the 2017 Hunter's Hope Family and Medical Symposium

Family Programs

Hunter's Hope was created, in part, to confront the overwhelming needs families face as they care for children affected by Leukodystrophies. Through its Family Programs, Hunter's Hope serves hundreds of families affected by Leukodystrophies.

Hunter's Hope strives to give every family suffering from a Leukodystrophy love and support throughout the most trying time of their lives. In 2017, over 660 notecards and 40 care packages were sent to affected children and their families throughout the year – to celebrate a birthday, in remembrance of a child's heaven date, to welcome a new family to Hunter's Hope, or just to let someone know we were praying for them as they walked through a particularly challenging time.

The following programs have been established to support and encourage those afflicted, and their families, as they struggle to endure, adjust, and cope with the demands of these fatal illnesses.

Wall of Fame
of more than 400 children affected by Leukodystrophies are displayed on this inspiring page of the Hunter's Hope website. The Wall of Fame gives families an opportunity to honor their loved ones. Their faces serve as a constant reminder why Hunter's Hope exists – for the strong, courageous children and adults affected by these devastating diseases.

The Wall of Fame is a tribute to all Leukodystrophy children, and everyone affected by these devastating diseases.

Ralph C. Wilson Jr. Wish Gift
Leukodystrophy families are faced with tremendous stress, emotional pain, and financial hardship as they care for a child with a debilitating and fatal disease. Affected children require round the clock medical attention, which often requires one or both parents to give up their job for an extended period of time. Hunter's Hope provides assistance in unique or extreme circumstances to allow Leukodystrophy families to give the best possible care to their child.

It is difficult for families to travel, even to daily activities with their child, especially as their child grows, getting bigger and heavier, and needing more equipment to remain comfortable. In 2017, Hunter's Hope assisted in providing the families of Gemma (Krabbe), and Victoria (Krabbe) wheelchair accessible vans.

Left: Victoria shows off her new ride. Right: Gemma and her mom explored their new van for the first time! For Victoria and Gemma's families these vans will allow them to travel safely with their girls to and from doctor appointments, therapy sessions, and to provide them with a better quality of life.

After extreme flooding occurred in Houston, TX, the de la Cruz family was displaced from their home and relying on friends and family for a place to stay. The Foundation was able to assist the family in by providing funds for the family to put down a security deposit for a new home.

Additionally, children affected by Leukodystrophy require tens of thousands of dollars in equipment and supplies just to live each day. Unfortunately, many insurance companies often do not cover these necessary pieces of equipment, and most families cannot afford to purchase them on their own. Through its *Equipment and Supply Exchange* program, the Foundation facilitates donations from families who offer their no longer needed equipment to bless other families in need. Hunter's Hope pays for one family's equipment to be shipped to another and in 2017, provided $24,585 worth of equipment and supplies to affected children.

Left: The de la Cruz family at the Hunter's Hope Family & Medical Symposium is able to provide a safe home to Abel (Vanishing White Matter Disease) after the Houston floods due to the Foundation's assistance
Right: Grayson has Krabbe Disease. Through the Equipment and Supply Exchange his family received thousands of dollars' worth of equipment to needed to provide Grayson with the best possible care.

Financial Position

Total Income – $768,505
Total Expenses – $860,850

Net Assets, beginning of 2017 – $949,532
Net Assets, end of 2017 - $857,189

2017 Board of Directors and Officers

Jim Kelly
President
Co-Founder, Hunter's Hope

Jill Kelly
Chairwoman
Co-Founder, Hunter's Hope

Erin Kelly
Secretary
Hunter's Sister

Camryn Kelly
Board Member
Hunter's Sister

Paul Boser
Board Member
Pyramid Brokerage Company
Cushman & Wakefield Alliance

Greg Connors
Board Member
Esq. of Connors & Ferris, LLP

Phil May
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VP & General Manager of Warner/
Chappell Music Publishing in Nashville

Annie McCune
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Vogt Family Foundation Board Member

Brad Rye
Board Member
Senior Vice President, Mower

Steven Schmitt
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Sherex Fastening Solutions

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Jacque Waggoner
Chief Executive Officer
Hunter's Hope Foundation