Hunter’s Hope Foundation

2018 Annual Report

Leukodystrophy Care Network
Expanded Newborn Screening
Dear Friends,

In 2018, we were blessed to celebrate the 20\textsuperscript{th} Anniversary of the Hunter’s Hope Foundation and Jim’s third time beating cancer.

Throughout his life Jim has been known for his toughness as an athlete and an individual. Athletes are a special breed. They push themselves to keep going, even when their body aches, and their brain tells them to stop, they push themselves past their limits.

For Leukodystrophy children, like our son Hunter (2/14/97 – 8/05/05) fighting against these “limits” is part of their daily routine.

\begin{quote}
\textit{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.} \textit{~ Romans 5:3-5}
\end{quote}

Leukodystrophy children are fighters, they are miracles, and they have so much to teach us. They teach us to love courageously, that we are stronger than we could ever imagine, to celebrate life and to have hope and faith that through God’s grace we are making a difference.

Words cannot express the joy that our family has experienced, because of our precious son Hunter and the many beautiful Leukodystrophy children and families we have been fortunate to meet over the last 20 years.

In 2018, we announced the first eight Certified Leukodystrophy Care Network Centers at leading hospitals throughout the country. These Centers are collaborating together with families, researchers, and medical experts to revolutionize the medical care available to our “Leukodystrophy Fighters,” so one day, we can win our Superbowl, Stanley Cup, World Series, Masters, etc., of finding a cure for all Leukodystrophies.

Through God we have accomplished so much, BUT we have so much more to do.

Thank you for helping us provide 20 years of HOPE to countless families. Please continue this journey with us as we, as my husband Jim says, “make a difference today for someone fighting for their tomorrow.”

With hope,

Jill Kelly
Hunter’s Mom
Chairwoman, Hunter’s Hope

Camryn, Parker and Erin Kelly-Bean, Jim and Jill Kelly at the 2018 Hunter’s Hope Family and Medical Symposium.
Our 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 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, as well as better treatments and therapies for children affected by Leukodystrophies and result in expanded newborn screening.

The Kelly Family

When news of Hunter Kelly’s diagnosis broke, Jim and Jill Kelly received an outpouring of support from people all over the world, including families affected by Leukodystrophies. They knew they needed to make a difference for future children born with Leukodystrophies. As a result, Jim and Jill co-founded Hunter’s Hope 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.

In 2018, in front of over 3.9 million television viewers, Jim Kelly was honored with the Jimmy V Award for Perseverance during the ESPYS. During his acceptance speech, Jim made it a point to mention his son, Hunter, and recognize Leukodystrophy families throughout the world.

Additionally, throughout 2018, Jim and Jill Kelly visited children’s hospitals, schools, and churches to deliver special h.b. bears to hundreds of children. The teddy bear was created specifically to celebrate Hunter’s Hope’s 20th Anniversary, and named h.b., after Hunter Kelly’s nicknames, Hunter Boy, and Hunter Buddy.
Community and Family Partners

Throughout 2018, Leukodystrophy families, volunteers, and friends of the Foundation raised awareness and funds for Hunter’s Hope by hosting events and campaigns throughout Western New York and the entire U.S.

Wendy’s of Buffalo
Wendy’s of Buffalo raised funds for Hunter’s Hope for the tenth year in a row, through its Give a $1, Get a $1 campaign. The promotion, which ran from early January to Mid-February, was executed at Wendy’s restaurants throughout Buffalo and Rochester, NY, as well as Erie, PA. As a result of the campaign, Wendy’s of Buffalo presented Hunter’s Hope with a check for $63,750, making their ten-year total funds raised nearly $600,000!

Members of the Wendy’s of Buffalo staff also donated their time and product to serve complimentary food and drink at 2018’s Hunter’s Day of Hope & Prayer for Children.

RetroBuffalo
With news of Co-Founder Jim Kelly’s third diagnosis of cancer announced in 2018, many fans and supporters desired to show their support for him and the entire Kelly Family. RetroBuffalo made this possible with the release and sale of its Kelly Tough t-shirts and sweatshirts, donating proceeds to Hunter’s Hope. In 2018, RetroBuffalo raised over $9,800 for the Foundation through its Kelly Tough sales.

The Brackbill Family
Leukodystrophy families, such as the Brackbill family of Hershey, PA also aimed to spread awareness and raise funds. The Brackbills partnered with their local athletic club to hold a special workout event, raising over $6,000 for Hunter’s Hope and its mission.

Top: A Wendy’s of Buffalo employee serves chili to guests during Hunter’s Day of Hope and Prayer for Children.

Top: The RetroBuffalo team show off their Kelly Tough shirts with Jim and Jill Kelly. Bottom: The Brackbill family with a photo of daughter Tori (Krabbe, 7/30/14 – 3/27/16).
Expanded Newborn Screening

Newborn Screening (NBS) is a state-based program. With a simple heel prick after birth, early discovery and treatment is possible for numerous deadly diseases that may 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, and varies greatly by state. Since 2005, Hunter’s Hope has partnered with Leukodystrophy families, lawmakers, and key decision makers in an effort 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

In 2018, ten states included Krabbe in their newborn screening panel. As a result, at least six children were diagnosed and treated early because of the screening.

A major milestone was achieved in 2018, when the FDA approved the Krabbe Newborn Screen, which will help to further expand Krabbe Disease newborn screening throughout the country, beyond the current states that have passed legislation to add the test to their newborn screening panel.

The Foundation also led collaboration efforts among Leukodystrophy medical experts and affected family members to established standards of care for infants diagnosed with Krabbe through newborn screening. As a result, in February 2018 the Consensus guidelines for newborn screening, diagnosis and treatment of infantile Krabbe disease were published in the Orphanet Journal of Rare Diseases.

Top: Owen (Krabbe Transplant) crosses the finish line at the 2018 Family Symposium Walk. His family knew to test him after his sister Mabry Kate (3/13/14 – 2/7/15) was diagnosed with Krabbe Leukodystrophy. Bottom: A snippet from the February 2018 edition of the Orphanet Journal of Rare Diseases.

Ezra (Krabbe Transplant) crosses the finish line at the 2018 Family Symposium Walk. Due to his state including Krabbe in its newborn screening panel, Ezra was diagnosed early enough to receive a cord blood transplant.
Hunter’s Day of Hope and Prayer for Children

Hunter’s Hope and the Kelly family believe all children should be celebrated every day. Each year, the Foundation celebrates Hunter’s Day of Hope and Prayer for Children (HDHPC) 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. In 2018, over 1,500 community members attended this free event and enjoyed an afternoon filled with kid-friendly entertainment and activities. More than 25 organizations donated their time and services to host children activity booths, ten businesses donated food and drink for guests, and over 80 individuals volunteered their time to make the annual event a great success.

Most importantly, time was dedicated during the event for families to gather and pray for all children.

Top Left: A little boy plays in a go kart provided by the Bills Fan Thunder Organization. Middle Left: A boy climbs through an inflatable obstacle course donated by Bounce Nation, Inc. Bottom Left: NYS Assemblyman, Ray Walter, presents Hunter’s Hope Co-Founder, Jim Kelly, with declarations from the NYS Senate and Assembly pronouncing February 12, 2018, as Hunter’s Day of Hope & Prayer for Children in New York. Right: Children play football games with a Hunter’s Hope volunteer.
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. 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.

Hunter’s Hope established the Leukodystrophy Care Network (LCN) in 2015 and continues to make significant strides toward its 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 Medical Care
Although, currently there is no cure for Leukodystrophies, they are all treatable. However, with an occurrence rate of 1 in 7,000, Leukodystrophies still remain virtually unknown, even in the medical community. As a result, families often receive 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-one 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 Leukodystrophy patients.

Establishing Standards of Care
In 2018, six workgroups, comprised of LCN clinicians and family advocates, continued work on Leukodystrophy Clinical Practice Guidelines (CPGs) in the areas of Krabbe Newborn Screening, Treatment, Neurology, Diagnosis, Respiratory, and Musculoskeletal. These guidelines 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.

**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

*Top:* Kaprice Shullanberger, Family Advocate (Believing for Bryleigh), Dr. Joanne Kurtzberg, Leukodystrophy Network Center Director and Tara West, Clinical Care Coordinator (Duke University School of Medicine) at the 2018 Hunter’s Hope Family and Medical Symposium. *Bottom:* Members of the LCN Steering Committee at the 2018 Hunter’s Hope Family and Medical Symposium.
Family and 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 2018 Hunter’s Hope Family and Medical Symposium was held at Holiday Valley Resort in Ellicottville, NY, July 16th-21st. Supported by nine organizations, including the NFL Foundation, Thomas & Jeanne Elmezzi Foundation, The Jackson Project, and Ralph C. Wilson Jr. Foundation.

Medical Symposium

More than 60 Leukodystrophy researchers and medical experts from throughout the U.S. attended the 2018 Hunter’s Hope Family and Medical Symposium.

Newborn screening staffers and NBS follow-up physicians from seven different states participated in a Leukodystrophy NBS meeting where they discussed advancements and care protocols and began work on a new set of CPGs for Late-Onset Krabbe Disease.

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

Family Symposium

Nine Leukodystrophy families experienced their first Hunter’s Hope Family and Medical Symposium with 46 additional affected families in 2018.

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.

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 $21,000 in travel assistance to families unable to afford the cost of travel, who may not otherwise have been able to attend.
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 services hundreds of families affected by Leukodystrophies.

Hunter’s Hope strives to give every family affected by Leukodystrophy love and support during the most trying time of their lives.

Honoring Leukodystrophy Children

In 2018, over 600 notecards and 90 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 names and photos of more than 460 children affected by Leukodystrophies are displayed on the Wall of Fame 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 of why Hunter’s Hope exists – for the strong, courageous children and adults affected by these diseases.

The Hunter’s Hope Wall of Fame, serves as a tribute to all Leukodystrophy children, sharing images and details of hundreds of Leukodystrophy children from throughout the world.
Ralph C. Wilson, Jr. Wish Gift
Leukodystrophy families face 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 assists Leukodystrophy families during unique or extreme circumstances so they may provide the best possible care to their child.

Austin Owen, is 12 years old and has Adrenoleukodystrophy (ALD). Austin was diagnosed with ALD when he was 8 years old. Although he received a bone marrow transplant to stop the progression of the disease, he still experiences severe impairments since he was not diagnosed and treated prior to the onset of symptoms.

As Austin has grown it has become increasingly more imperative for him to have a wheelchair accessible van to be able to travel safely and comfortably. For children with Leukodystrophies, their wheelchairs provide them the support needed to prevent alignment issues in their spines, so traveling in a wheelchair accessible van becomes even more important as they outgrow the ability to use a properly fitted car seat.

Austin’s father is a single parent. He saved over $3,000 dollars to contribute toward the van and received additional donations from four other smaller leukodystrophy organizations to help fund the total amount of a van. Hunter’s Hope granted him a Wish Gift in the amount of $6,800 to cover the remainder of the van.

Throughout 2018, Hunter’s Hope fulfilled nine family “wishes” totaling over $25,000.

Equipment and Supply Exchange
Children affected by Leukodystrophy require tens of thousands of dollars in equipment and supplies just to live each day. Unfortunately, many insurance companies do not cover these necessary pieces of equipment and most families cannot afford to purchase them on their own. Through the Equipment and Supply Exchange, 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 2018, provided $18,745 worth of equipment and supplies to affected children and their families.
Financials

2018 Revenues and Other Support

- General Donations: $603,734
- Grants: $125,000

Total Income: $766,781
Net Assets, beginning of 2018: $857,189

2018 Program and Support Expenses

- Family Assistance: $420,405
- Education and Awareness: $210,773
- Research: $38,861
- Fundraising: $89,766
- General & Admin: $64,308

Total Expenses: $824,113
Net Assets, end of 2018: $957,230
2018 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
Board Member
VP & General Manager of Warner/Chappell Music Publishing in Nashville

Brad Rye
Board Member
Senior Vice President, Mower

Steven Schmitt
Board Member
Marketing Manager, Sherex Fastening Solutions

Robert Sawicki
Board Member
Managing Director & CEO, Frontcourt

Jacque Waggoner
Chief Executive Officer
Hunter’s Hope Foundation