

Hunter's Hope Foundation

2016 Annual Report



Krabbe and Leukodystrophies
Expanded Newborn Screening

Dear Friends,

After Hunter (2/14/97 - 8/05/05) was diagnosed with Krabbe Leukodystrophy, a rare and fatal genetic disorder of the nervous system, we felt hopeless and were provided no insight as to how to combat the disease.

As the dust began to settle, we worked tirelessly to relieve the relentless physical suffering Hunter experienced every day of his life... Pneumonia more times than we can count, feeding issues, pain and complications due to immobility, brittle bones caused by a lack of certain nutrients... The list goes on. Throughout his life, we were forced to navigate his care as we reacted to complication after complication. Yet, the vast majority of issues could have been avoided through proactive and comprehensive care.

In 2016, a longstanding goal of the foundation of medical centers of excellence for Leukodystrophies made astounding progress. The Leukodystrophy Care Network, or LCN, is the culmination of our entire mission and will provide the medical care that every individual with a Leukodystrophy requires to live the best possible life.

We are so grateful for how God continues to use Hunter's life and even Hunter's suffering to bless countless others. We invite you to learn more about the LCN and everything else God has entrusted to us over the past year. As always, we need your continued prayers and support as we work to accomplish all that God has called us to – "immeasurably more than all we ask or imagine," (Ephesians 3:20).

Thank you for your continued partnership as, together, we strive to *make a difference today for someone fighting for their tomorrow...*

With hope,

Jim, Jill, Erin and Camryn Kelly



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 remains unwavering in our mission to increase awareness and understanding of Leukodystrophies and Newborn Screening within the medical community and the general population. This widespread knowledge will enable more timely diagnoses for children affected by Leukodystrophies and result in expanded newborn screening.

The Kelly Family

As co-founders of Hunter's Hope, Jim and Jill, together with their daughters, Erin and Camryn, remain passionate in their commitment to carry out this mission. As public figures in the Western New York community and beyond, they use their platform to share their family's story and the work of Hunter's Hope.

Kelly Family Books and Speaking Engagements

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 all we do at Hunter's Hope. Likewise, each book contains information about Hunter's Hope, Krabbe and other Leukodystrophies, and newborn screening. In addition, a portion of the proceeds benefit Hunter's Hope.



Left: Erin and Jill shared their story on TCT Network. Right: Jim and Jill shared their story at a Mississippi event, which was covered by a local paper.

Expanded Newborn Screening

Virtually every baby born in the U.S. for the last 50 years has undergone newborn screening. A simple heel prick can unlock the door to early discovery and treatment for dozens of potentially deadly diseases that would otherwise go undetected. Yet, each state determines what diseases to screen for at birth.

Newborn Screening for Leukodystrophies

Hunter's Hope continually supports families affected by Krabbe and other Leukodystrophies as they advocate for expanded newborn screening (NBS) in their states. In 2016, legislation for newborn screening for Krabbe was passed in **Louisiana**, and **Kentucky** and **Ohio** launched their Krabbe NBS programs statewide.

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.

In addition to our state advocacy efforts, Hunter's Hope has also advocated federally for increased funding and with the medical and scientific community to create standardized screening and follow-up protocols through the Krabbe NBS Task Force.



Left: Anniston Bazar and family with the Louisiana governor at her bill signing. Right: Anna Taylor (4/28/13 – 4/2/15) at the 2014 Symposium with her parents. The Taylors were instrumental in making Krabbe NBS a reality in KY.

Hunter's Day of Hope and Prayer for Children

Hunter's Day of Hope and Prayer for Children is 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 each year on the Saturday closest to February 14th, Hunter and Jim's birthday. Families enjoy a day filled with kid-friendly entertainment and activities at the free community event hosted by Hunter's Hope. Most importantly, we dedicate time at the event for families to gather and pray for all children.

Furthermore, once again, New York Governor Andrew Cuomo officially declared February 14, 2016, as Hunter's Day of Hope and Prayer for Children statewide!



Jim, Camryn, Erin and Jill Kelly with Erin Langworthy from Representative Ray Walter's office with the 2016 HDHPC resolution in New York State.

Research

From the inception of Hunter's Hope in 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.

In order to accelerate advancements and also 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 the world's leading Leukodystrophy experts.

Leukodystrophy Care Network



Leukodystrophies are an inherited group of over 50 disorders of the white matter in the brain, affecting 1 in 7,000 individuals. Onset of symptoms can occur in the first months of life through adulthood, inducing a sudden loss of abilities such as voluntary movement and speaking, and result in severe morbidity and death.

Because of the rarity of these devastating diseases, Leukodystrophies remain virtually unknown, even in the medical community, often resulting in misdiagnosis and insufficient therapies and treatment options once a correct diagnosis is reached.

Although currently there is no cure for Leukodystrophies, they are all treatable. And, while most are terminal disorders, individuals affected by Leukodystrophies deserve expert medical care, essential to providing timely treatment and therapies to vastly improve health and overall quality of life.

LCN 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.

The Vision

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 generations to come.

Core Values

The LCN and its Centers Embrace and Promote...

- The Highest Quality of Life
- An attitude that Enhances and Celebrates Life
- The affected individual's Abilities and Potential
- Patient Care as its primary focus
- Long-Term and Comprehensive Care for the prevention of potential complications
- A Multidisciplinary Team approach
- Exceptional Standards of Care
- A commitment to increasing value and Continuously Improving Quality, essential to maintaining excellence.

Strategy

The key elements of the LCN's strategy include the following:

- Guided by Family Advocates to ensure Patient Centered Care
- Learn from existing successful Multidisciplinary Care business models
- Integrate Centers into established, reputable hospital systems
- Utilize Existing Resources where possible
- Established by World Renowned Experts in Leukodystrophies and multidisciplinary care
- Standards of Care are an essential component
- Multidisciplinary Team Model is an essential component
- Ensure data collection and use - Leukodystrophy Patient Registry System, LDC
- Ensure excellence - LCN Advisory Committee
- Involve Government Agencies, Funders and Other Stakeholders throughout the process
- Promote education and growth through Public Awareness Campaigns

Achievements to Date

2015

Planning:

- Conducted research of other disease models
- Identified Cystic Fibrosis and Multiple Sclerosis as good models to learn from
- Documented, shared and launched the LCN Vision
- Held meeting with family advocates and medical experts to review vision, structure, areas of need, and requirements
- Continued enhancing and expanding plan

Organization:

- Determined LCN Organization Structure
- Appointed internal staff leadership and administration to the LCN
- Established Steering Committee Roles and Responsibilities
- Identified and established Steering Committee of family advocates
 - Greg Benton – Myelin Project, World Leukodystrophy Alliance (WLA)
 - Chad & Lisa Borodychuk – Olivia Kay Foundation
 - Patti Chapman - Myelin Project, WLA
 - Matt & Lauren Hammond
 - Jeff Leonard - WLA
 - Robert & Kristen Malfara – The M.O.R.G.A.N. Project
 - Phil & Amy May
 - Bob Rauner – United Leukodystrophy Foundation, WLA
 - Elisa Seeger – Aidan Jack Seeger Foundation, WLA
 - Nathan & Sarai Taylor
 - Mike & Jenna Wallace – The Jackson Project
 - Christin Webb
- Identified and obtained support from medical experts and family advocates
- Developed internal administrative management process and procedures
- Determined Subcommittees purpose, chair and expertise of members

Clinical Practice Guidelines:

- Conducted research on best practices for CPGs
- Collaborated with GLIA on their guidelines
- Developed Clinical Issues Survey

2016

Planning:

- Finalized 2016 LCN Operations Plan
- Developed Multi-Year LCN Plan
- Held first in-person Steering Committee meeting (February)
- Held monthly Steering Committee conference calls

- Improved Subcommittee descriptions and obtained membership support
- Developed short and long term plans for Subcommittee activities including: Data Center, Coordinating Center, and others as listed in this document.

Education & Awareness:

- Published LCN brochure and website
- Had Informational Booth at Child Neurology Society Conference

Centers & Certification:

- Determined and documented criteria for LCN Center Certification
- Developed RFI for candidate centers
- Identified potential candidate centers
- Sent RFI
- Invited top RFI responses (potential candidate centers) to participate in the LCN Meeting at the 2016 Symposium
- Planned goals and objectives of candidate centers' participation at Symposium LCN Meeting
- Determined process for evaluating candidate centers
- Evaluated candidate centers, established partnership and developed plan for each to move toward certification

Clinical Practice Guidelines:

- Conducted Clinical Issues Survey (CIS)
- Published CIS link on HH website and other websites
- Identified top areas from CIS for clinical care guidelines
- Identified CPG development team members for top areas
- Created CPG development plan for top five issues
- Established RFP process for CPG development
- Announced RFP process
- Awarded five grants in 2016 to be fulfilled in 2017 (\$10K each)



2016 LCN Steering Committee Meeting

Top Row: Lisa & Chad Borodychuk, Elisa Seeger, Phil May, Kathleen Scott, Nathan Taylor, Mike Wallace, Matt Hammond, Greg Benton, Bob Rauner, Kristen & Robert Malfara Bottom Row: Jenna Wallace, Amy May, Sarai Taylor, Jacque Waggoner

Family & Medical Symposium

The 2016 Hunter's Hope Annual Family and Medical Symposium was held at Holiday Valley Resort in Ellicottville, New York, from July 25th through the 31st. At the 2016 Symposium, we hosted 53 families affected by Leukodystrophies, together with over 70 researchers and medical experts.

Medical Symposium

The experts in attendance worked together on Clinical Practice Guidelines 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 was the opportunity to introduce researchers to families affected by Leukodystrophies at our Family Welcome Dinner.



2016 Hunter's Hope Medical Symposium Attendees

Left: Medical Symposium Session; Center: Dr. Joanne Kurtzberg (Duke Children's Hospital), Jill Kelly & Jacque Waggoner (Hunter's Hope), Dr. Amy Waldman (Children's Hospital of Philadelphia) Right: Dr. David Wenger (Thomas Jefferson University), Dr. Larry Wrabetz (Hunter James Kelly Research Institute)

Family Symposium

In 2016, the Foundation welcomed 53 families affected by Leukodystrophies, for a week of learning, sharing, and fun. 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.

Hunter's Hope made it possible for families to attend the Symposium, regardless of their financial ability. The Foundation covered all meal and lodging expenses for the week. For families unable to afford the cost of travel, the Foundation awarded over \$25,000 in travel assistance to families who would not otherwise be able to attend.



Top Left: The Kelly Family at the 2016 Symposium Balloon Release; Top Right: Elmer, his mom and friends cross the 2016 Symposium Walk finish line; Bottom Left: The kids had fun in Kid Kamp while the parents were learning; Bottom Right: The Garcia Family traveled all the way from California to spend time with other families affected by Leukodystrophies

Family Programs

Hunter's Hope was created, in part, to confront the overwhelming needs families face as they care for a children affected by Leukodystrophies. Hunter's Hope serves hundreds of families affected by Leukodystrophies that have registered with the Foundation through our Family Programs, designed to address these critical issues and meet their needs.

Hunter's Hope strives to give every family suffering from a Leukodystrophy love and support throughout the most trying time of their lives. In 2016, over 560 cards and/or 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



The names and photos of hundreds of 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. These beautiful faces are a constant reminder of why Hunter's Hope exists – for the strong, courageous children affected by Leukodystrophies.

Photo: Emma Daniels (7/20/09 – 3/24/12) from New Jersey, one of the many beautiful faces on the Wall of Fame.

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 often do not cover these necessary pieces of equipment and most families cannot afford to purchase them on their own. We facilitate 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 2016, provided \$94,785 worth of equipment and supplies to affected children.

Ralph C. Wilson Jr. Wish Gift

Through *Hunter's Wish Gift*, we help provide for unique or extreme circumstances so that our families can provide the best possible care for their child. Our most requested Wish Gift is for assistance in purchasing a wheelchair accessible van so families are able to travel safely with their growing child, which we were able to grant to Laura (MLD) and the Glaudemans Family in

2016. We also provided a wheelchair lift to Salvatore (MLD) and the Sereno Family so that Sal can safely get in and out of his home and more easily participate in his family's daily activities.



Wish Gift - Top Left: Salvatore Sereno (MLD) in his new wheelchair lift; Top Right: Laura Glaudemans with the keys to her wheelchair accessible van; Equipment & Supply Exchange - Bottom Left: Tenley Thompson (Krabbe) can now sit at the table with her family; Bottom Right: MJ Hadnot (Krabbe) can be more mobile in his new chair.

Raising Awareness and Support

Throughout 2016, numerous events were held in Western New York and in other locations throughout the U.S. to help support the Hunter's Hope mission. We are grateful for your support in carrying out our mission!



Every Score is a fun way for Bills fans to support Hunter's Hope while cheering on their team and winning great prizes.



The 2016 Kelly Tough 12K in Buffalo was a great day for all involved! We also had walks and runs throughout the country.

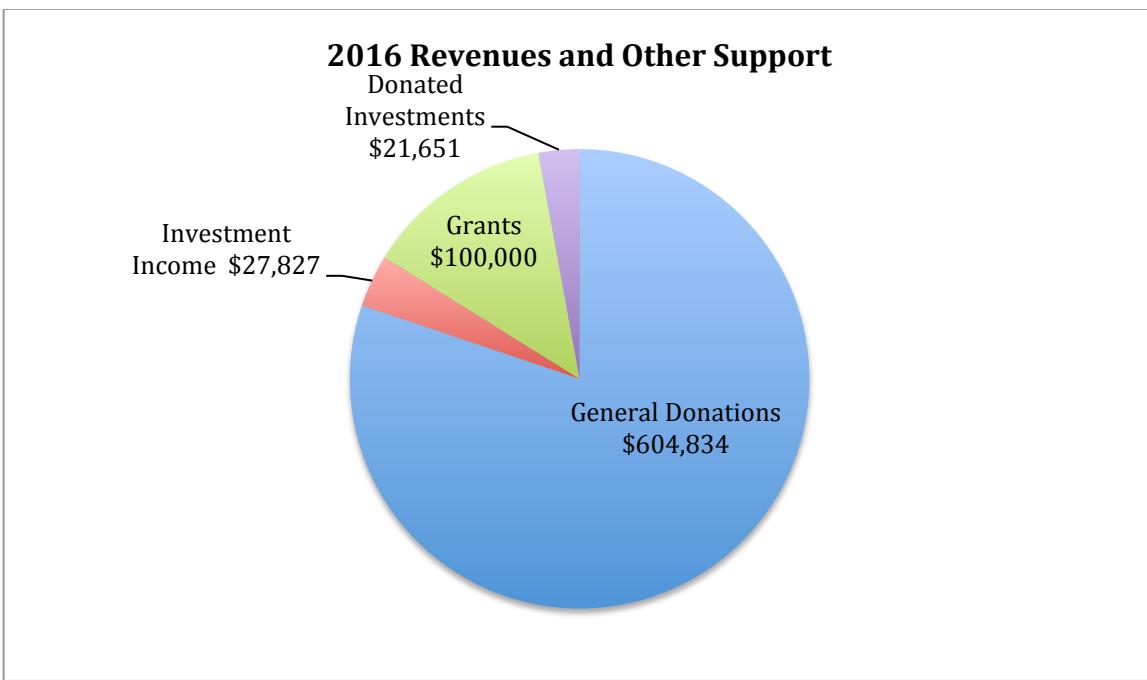
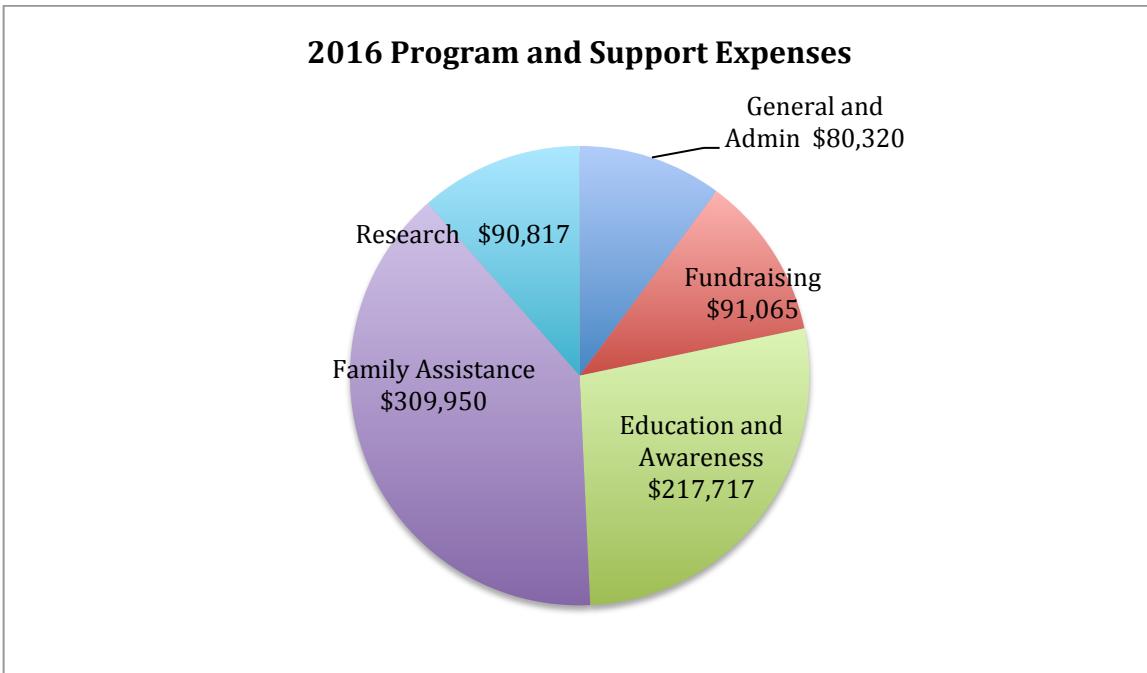


Frosty's & Fries is a WNY tradition – proceeds are donated to Hunter's Hope.



Reeds Jenns Jewelers created a beautiful Hunter's Hope Jewelry line to raise funds and share our message of hope.

Financial Position



Total Income – \$737,938
Total Expenses – \$789,869

Net Assets, beginning of 2016 – \$1,001,465
Net Assets, end of 2016 - \$949,534

2016 Board of Directors and Officers

Jim Kelly
President
Co-Founder, Hunter's Hope

Jill Kelly
Chairwoman
Co-Founder, Hunter's Hope

Erin Kelly
Board Member
Hunter's Sister

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

Brad Rye
Board Member
Senior Partner, Eric Mower + Associates

Anne McCune
Board Member
Vogt Family Foundation Board Member

Kevin Gavagan
Board Member
Owner, QCI Asset Management

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

Michelle Tharnish
Treasurer/Board Member
Partner with Sixt, Wengewicz & Tharnish,
CPAs

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Robert Sawicki
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Jacque Waggoner
Chief Executive Officer
Hunter's Hope Foundation