Dear Friends,

For our family, 2014 was an extremely challenging year as Jim battled cancer for the second time. Throughout such a difficult circumstance, the outpouring of love and support was truly overwhelming. The same was true when Hunter was first diagnosed with Krabbe…

Since founding the Foundation in 1997, our mission to serve children affected by Leukodystrophies and their families, raise awareness about these diseases to promote early detection, and fund research into better treatments and a cure has been realized beyond what we could have ever imagined.

Our Family Care Programs continue to grow as we confront the practical needs so many of our families face, while also providing the hope and understanding desperately needed to navigate through such devastating circumstances.

Through our Education and Awareness efforts, Krabbe and Leukodystrophies are more commonly understood in the general population. Furthermore, several states are making progress toward Newborn Screening for Krabbe to ensure all children are given the chance for the healthy life they deserve.

The Hunter James Kelly Research Institute continues to expand while making advancements toward better treatments and a cure for Krabbe and other Leukodystrophies.

To all who’ve supported the work of Hunter’s Hope, together, we are making a difference.

The progress made in 2014 outlined in this document would not have been possible without your support.

Thank you…

For joining our team…

For understanding the extreme and urgent need…

For believing in us…

We are hopeful for the future and hope you’ll join us in our mission.

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 Krabbe Disease and other 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 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.

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 steadfast in our mission to increase understanding of Krabbe, Leukodystrophies and Newborn Screening within the medical community and the general population. It is our conviction that this widespread knowledge will enable more timely diagnoses for children affected by these diseases and eventually, nationwide newborn screening for all possible Leukodystrophies to ensure the chance for lifesaving treatment these children deserve. Additionally, by expanding awareness of the needs confronted by Hunter’s Hope, support is garnered to further our mission in support of the Leukodystrophy community we so diligently serve.

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 carrying out the Foundation’s mission. Every interview, speaking engagement – whatever the occasion is used to raise awareness about newborn screening and Leukodystrophies.

Kelly Family Books
The Kellys share their story of hope through numerous published books. 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.

Kelly Tough
In 2014, Jim was diagnosed with his second bout with cancer. The outpouring of love and support was overwhelming. In the midst of this difficult time, the family’s mantra, “Kelly Tough” went viral, resulting in the sale of several pieces of merchandise with proceeds benefitting Hunter’s Hope. This is yet another example of the natural connection between the Kelly Family and Hunter’s Hope. Through this trying time, Erin Kelly began speaking at various events and in 2015 will release her first book, Kelly Tough.
**MyFanClip**
Jim’s MyFanClip, a custom designed multi-purpose clip, was launched in 2013 and is now available for a variety of collegiate and NFL teams in stores across the U.S. The back of every package provides information about Hunter’s Hope and a link to our website. A portion of the proceeds benefit Foundation named for his son.

**Jim Kelly’s Every Score**
Every Score enables football fans to cheer on their team, while also supporting Hunter’s Hope. Through Every Score, Buffalo Bills fans make pledges to Hunter’s Hope for every point scored by the Bills. Once pledges are fulfilled, participants are entered to win autographed Bills memorabilia in weekly drawings. Corporate partners also support the program through various packages. In 2014, the total number of pledges increased by 40% and the total amount donated almost doubled.

Most importantly, participants were educated about Hunter’s Hope, Leukodystrophies and Newborn Screening each week and on the Jim Kelly’s Every Score iPhone App.

Each week, affected children and newborn screening facts were featured through Every Score

**Social Media**
In 2014, the Hunter’s Hope Social Media pages had a combined increase of 63% in following. These platforms enable us to raise awareness about the Foundation and our mission to the general population on a daily basis.
Expanded and Universal Newborn Screening

For the past 50 years, virtually all of the more than 4 million babies born in the U.S. annually have undergone newborn screening. Newborn Screening is a state-based public health system that is essential for preventing the devastating consequences of a number of medical conditions not clinically recognizable at birth.

Progression of Krabbe Disease can be halted if the treatment is administered before irreversible damage occurs. Therefore, it is important that all children are screened for Krabbe and similar diseases at birth through newborn screening. Hunter’s Hope advocates for all children to be screened for all possible diseases where early diagnosis can make a positive impact on the life of the child.

Newborn Screening for Krabbe and Similar Disorders

Hunter’s Hope continually supports families affected by Krabbe and similar disorders as they advocate for expanded newborn screening in their states. In 2014, legislation for newborn screening for Krabbe and similar disorders was introduced in Arizona, California, Connecticut, Maryland, Michigan, Pennsylvania and Tennessee with families in several other states continue to work to that end.

Hannah’s Law

In late 2014, Pennsylvania governor signed Hannah’s Law, mandating the addition of Krabbe and similar diseases to the state’s newborn screening panel. The bill is named in honor of Hannah Ginion (1/15/13 – 12/28/14), whose courageous battle with Krabbe inspired the law.
Take Action
Hunter’s Hope assists families in advocating for expanded newborn screening in their state. We provide informational resources, contact other affected families in state to join their efforts, and refer to experts to provide the most current medical and scientific information. We also create an “Action Alert” through the Hunter’s Hope website so constituents can email their legislators in support of a bill within one minute. In 2014, more than 50,000 emails were sent through our website in support of expanded newborn screening throughout the U.S.

NBS Community
Hunter’s Hope is involved with various organizations, committees and meetings within the newborn screening community throughout each year. In 2014, Hunter’s Hope served on committees with the Newborn Screening Translational Research Network and New York Mid Atlantic Consortium for Genetic and Newborn Screening. We were also invited to present in D.C. at the Rare Disease Legislative Advocates meeting and attended several other key meetings throughout the year, all to ensure a voice is given on behalf of those affected by Krabbe and similar disorders.

Supplemental Newborn Screening
Throughout 2014, parents from around the world continued to purchase Supplemental Newborn Screening Packets from the Hunter’s Hope website, enabling them to make sure their child is screened for Krabbe and 60 other disorders, no matter where they live.
Hunter’s Day of Hope and Prayer for Children

Hunter’s Day of Hope and Prayer for Children helps us fulfill our mission to inspire gratitude to God for the gift of children.

Our ultimate goal is to have a global Day of Hope & Prayer for Children each year, making this an international day for people throughout the world to pray for children.

In Western New York, HDHPC is celebrated each year on the Saturday closest to February 14th, as it is both Hunter and Jim’s birthday. Families spend time having fun together at this free community event hosted by Hunter’s Hope. Most importantly, we dedicate time at the event for families to pray for all children. At the 17th Annual HDHPC we were honored to host over 4,000 members of the community for this special day at the Buffalo Bills Fieldhouse.

Those outside of Western New York have the opportunity to participate through a virtual celebration, via social media and the Hunter’s Hope website.

Once again, New York Governor Andrew Cuomo officially declared February 14, 2014, as Hunter’s Day of Hope and Prayer for Children statewide!

On the main stage, hundreds of children join Jim and Jill Kelly in prayer and Jim gets to spend time with some of his cutest fans during the Annual Hunter’s Day of Hope & Prayer for Children event.
Special Events

In 2014, over $310,500 was raised through various special events held throughout the year.

Dine Out for Hope
For one day in November, several restaurants in Western New York gave a portion of their proceeds to Hunter’s Hope. Customers enjoyed great food, while learning more about Leukodystrophies and newborn screening.

Rosicki Gala
Hunter’s Hope partnered with Rosicki, Rosicki and Associates, LLP to execute the 10th Annual Rosicki Gala, raising over $45,000. We are so grateful for their continued generosity.

550 Auction
In 2014, Hunter’s Hope partnered with Entercom Buffalo/WGR 550 Sports Radio to raise over $71,000! Throughout the day, listeners gained a deeper understanding of Krabbe and other Leukodystrophies as well as the importance of newborn screening through interviews with affected families, the Kellys, and many of their celebrity friends. Various companies and individuals donated items for the auction to benefit Hunter’s Hope.

Wendy’s Frosty’s & Fries
For the past several years, local Wendy’s raised awareness and funds for Hunter’s Hope through Frosty’s & Fries coupon sheets. In 2014, over $50,000 was raised through this special program.

Another great year at the Rosicki Gala!

Our friends at a local Wendy’s helping us celebrate another successful year!
Every Step Walk

Every Step is our national walk to raise awareness and funds to support our mission. The Hunter’s Hope staff works with volunteers throughout the country to coordinate and host an Every Step Walk in their local community. The walk is an effort to engage individuals, families, and organizations across the country to support families affected by Krabbe and Leukodystrophies, fund research and advocate for expanded newborn screening.

In 2014, over 650 walkers participated in six walks!

Thank you to all participants who made the 2014 walks so special – Meridian, MS (left), Buffalo, NY (center) and Syracuse, NY (right).
Hunter James Kelly Research Institute

When co-founders Jim and Jill Kelly began Hunter’s Hope in 1997, one of their primary goals was funding research to find treatments and ultimately a cure for Krabbe and other Leukodystrophies. As time progressed it became clear that a central location exclusively devoted to Krabbe and similar diseases was the best way to advance research efforts.

In 2008, Hunter’s Hope joined the University at Buffalo to create the Hunter James Kelly Research Institute (HJKRI). To maximize its effectiveness, the HJKRI approaches research from two primary perspectives — Basic Science, which involves laboratory based research exploring the animal and cellular models of the disease, and Clinical Research, which studies the disease in affected patients. This comprehensive method facilitates new insight into Krabbe and other Leukodystrophies, paving the way to improved treatments and a cure in the most efficient manner possible.

Basic Science - HJKRI

The Basic Science Research at the HJKRI, led by Lawrence Wrabetz, MD, is comprised of six state-of-the-art laboratories devoted to studying the cause, effects, and potential therapies of Krabbe Disease and other myelin disorders. The researchers at the HJKRI create cellular and animal models to analyze the complex details of the disease, to progress research from the animal model to clinical trials, to better understand the pathology of the disease, improve diagnosis and predict onset, and ultimately, better treatments and a cure.

Clinical Research - HJKRI

The Clinical Research Center, led by Thomas J. Langan, MD, works to improve understanding of the natural history of Krabbe disease, what factors and tests best predict its onset and severity, and which treatment options are most effective. At the center of this research is the World Wide Registry for Krabbe disease (WWR).

World Wide Registry for Krabbe Disease

Shortly after Hunter’s Hope was founded in 1997, the Foundation began gathering medical information from affected families. In 2008, this registry officially became the Krabbe World Wide Registry and is now the center of all clinical research at the HJKRI. The information catalogued in the WWR provides vital insight into diagnosis, outcomes, symptom management, and treatment. The WWR and its research are completely dependent upon family participation.
In 2014, Hunter’s Hope and the HJKRI partnered with the Newborn Screening Translational Research Network, which is funded by the National Institutes of Health, to begin utilizing their Longitudinal Pediatric Data Resource. This database provides a secure and protected infrastructure for data collection, analysis, and sharing with other researchers, and is the optimal platform for storing data gathered through the WWR. We are excited to utilize this resource to further advance Krabbe and Leukodystrophy research.

**Extramural Research**

**Role of Psychosine in Krabbe Disease**
Through a collaborative effort with Dr. Langan at the HJKRI, Joseph Orsini, PhD, from New York State’s Newborn Screening laboratory, and Dieter Matern, MD, PhD, from the Mayo Clinic, are investigating the role of psychosine in Krabbe disease to determine if increased levels are associated with the onset of disease in patients identified through newborn screening (NBS). Preliminary results suggest that measuring psychosine in newborn dried blood spots could serve as a second tier test in NBS for early infantile Krabbe disease. Great progress was made in 2014 leading to future studies to prove this theory.

**Long-Term Follow Up for Krabbe**
Hunter’s Hope and the HJKRI joined forces with Chet Whitley, MD, and the Lysosomal Disease Network. Through a collaborative application to the Rare Disease Clinical Research Network (NIH Funded), the HJKRI proposes to follow the developmental and functional outcomes of children identified through Krabbe newborn screening.

**Gene Therapy**
Steven Gray, PhD, at the University of North Carolina’s Gene Therapy Center, is another researcher whose work is supported by Hunter’s Hope. Dr. Gray is investigating the means to globally deliver a gene to the nervous system, bridging the gap between earlier encouraging laboratory studies in animal models and a possible human treatment. This approach uses a modified virus called AAV, which has been designed to carry a therapeutic gene, essentially serving as a molecular delivery truck or “vector” that is injected into the spinal fluid. This is a routine outpatient procedure with minimal risk.

**Enzyme Replacement Therapy for Krabbe Disease**
Hunter’s Hope supports the research of Steven LeVine, PhD, from the University of Kansas Medical Center. Dr. LeVine is examining the potential of enzyme replacement therapy (ERT) as treatment for Krabbe disease. His innovative approach delivers the therapeutic enzyme (GALC) to the central nervous system through a non-invasive procedure. This work in the mouse model may lay the foundation for clinical trials and pave the way for new treatments for Krabbe and similar diseases.
Leukodystrophy Care Network

Leukodystrophies are a group of more than 40 genetic, neurological disorders that are defined by a progressive degeneration of the white matter in the brain. Nearly 51,000 people in the United States and Canada have some form of leukodystrophy. Nearly all patients are very young children, who will live with the disease for between 3 and 20 years.

Over the last 18 years, Hunter’s Hope has taken a leadership role in advocating for research, screening, and understanding of how preventative and symptomatic treatments can improve children with leukodystrophy’s quality of life and health. Today, significant achievements have been made in both lab science and patient data evaluation that is moving science towards a cure for leukodystrophy.

But while we wait for a cure, thousands of children with leukodystrophy suffer every day. Treatments are available to halt the progress of the disease and treat symptoms such as broken bones, frequent pneumonia, kidney stones, corneal abrasions, and system failures that affect the child’s ability to sleep, eat, speak, and move. While children today with leukodystrophy will not be cured, they can live meaningful, pain free lives, with the appropriate medical protocols and support.

Children suffer because medical professionals don’t have the information or resources available to help the children in their care.

In Western New York, across the country, and in Canada, university and hospital leadership have recognized a gap in workforce knowledge and quality of care and have embraced the vision of a network of medical providers who can educate and support one another, providing patients with a better standard of care.

Hunter’s Hope is working toward the recruitment of experts, and planning, to join forces with at least 40 medical experts, 20 family members, several leukodystrophy-focused foundations, and 20 children’s hospitals across the United States and Canada to design and implement a system of care that supports shared resources and improved quality of life for patients with leukodystrophy.

The Leukodystrophy care Network (LCN) will be made up of a Coordination Center located in Western New York and Care Centers across the United States and Canada. The Coordination Center will serve as the Network’s governance, protocol, and research hub while providing direct service for children across Western New York with leukodystrophies.
At each Care Center, a multidisciplinary team will evaluate all medical information and develop a long-term comprehensive care plan for each child they treat. Each expert will have a role in developing the care plan and providing care and support. Care Centers across the US and Canada will be networked together in order to leverage the best service match for each child, to provide resources, and to share data collection that supports implementation goals and long-term research into leukodystrophies. The team will address the identified service gaps in four key areas—Early Diagnosis, Treatment, Preventative Medicine, and Symptom Management—within their region while working with the larger network to address them more globally.

Together the LCN Care Centers will work as a collaborative learning community vetting and integrating best practices, leveraging funding and expertise, sharing protocols, standards, and data in order to best serve individuals and creating a shift in the medical culture, by providing the medical community with the tools and support they need to change their approach to care.

The treatment standard established through the LCN will work to halt the progress of the disorders when possible, prevent complications, and supports children affected by leukodystrophies as they battle the disorders’ disabling and painful symptoms.

Given the scope of the project, it has been essential that significant effort be invested in the project’s design, planning, and strategy. The first year of the project has been dedicated to planning, which began at the beginning of the 2014 calendar year through recruitment of medical experts and hospitals, attendance by Hunter’s Hope leadership at two strategic conferences, and the development of materials to guide the experts’ implementation strategy.

In the coming years, the Coordination Center will be established in Buffalo and 4-7 Care Centers will also be established across the US and Canada. In year three, our goal is for the number of Care Centers to continue to grow in order to create a network of care with a global reach. The advisory committee and governance will continue to provide support for the Care Centers and will expand in order to meet the needs of the Care Centers and to systematize the care that is provided through them in order to assure the highest quality.
The 2014 Hunter’s Hope Annual Family and Medical Symposium was held at Holiday Valley Resort in Ellicottville, New York, from July 23rd through the 30th. At the 2014 Symposium, we hosted 43 families affected by Krabbe or other Leukodystrophies, together with over 60 researchers and medical experts.

**Medical Symposium**

At the 2014 Medical Symposium an array of issues were covered throughout the two-day round table discussion. Newborn screening leaders from New York, New Jersey, Missouri, Illinois, Arizona and Tennessee attended, providing an update on current or proposed Krabbe newborn screening programs in their states. Discussions were centered upon improving newborn screening for Krabbe, as well as clinical and basic science research to gain a better understand of and find better treatments and ultimately a cure for Leukodystrophies.

The most impactful component of the Medical Symposium is the opportunity to introduce researchers to families affected by Krabbe and newborn screening. Meeting families and children affected by these disorders is extremely inspiring for those in attendance to advance their research and confront the urgent need for change.
Family Symposium

In 2014, the Foundation welcomed 43 families affected by Leukodystrophies, 12 for the first time, 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 these diseases so parents can provide their children with the best possible care. In addition, families form 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 palpable.

Hunter’s Hope strives to make it possible for families to attend the Symposium, regardless of their financial capabilities. The Foundation covered all meal and lodging expenses for the week. For families unable to afford the cost of travel, the Foundation awarded over $18,000 to families who would not otherwise be able to attend.

In 2014, NBC Sports filmed footage at the Symposium to feature in the Hall of Fame Halftime show and on NBC Nightly News, resulting in widespread national exposure of Hunter’s Hope, newborn screening and Leukodystrophies.
Family Care Programs

Since our inception, our priority has been to confront the overwhelming needs families face as they care for a children affected by Leukodystrophies. Hunter’s Hope serves the over 700 families affected by Krabbe and other Leukodystrophies that have registered with the Foundation through our Family Care Programs, designed to address these crucial issues to meet the needs of our families.

When an affected family registers with Hunter’s Hope, our Director of Family Programs, who knows firsthand the extreme needs of families coping with Krabbe and other Leukodystrophies, contacts them. Each family is informed of the programs available through Hunter’s Hope. This relationship and personal contact is maintained throughout each year.

Hunter’s Hope strives to give every family suffering from a Leukodystrophy love and support throughout the most trying time of their lives. In 2014, over 500 cards and 32 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.

**Hope For Life**
When a child is diagnosed with Krabbe or another Leukodystrophy, the prognosis is grim. Many families are told to make their child comfortable and prepare for them to die. Through Hope for Life, Hunter’s Hope encourages families to never underestimate the potential of a child affected by a Leukodystrophy and inspires families to live life to the fullest, making the most of every moment. We want every family to know that they are not alone in this journey and that there is hope… Hope for LIFE.

**Wall of Fame**
The names and photos of over 370 children affected by Krabbe and other 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 Krabbe and Leukodystrophies.
Hunter’s Homes

In coordination with the Ronald McDonald House in Durham, NC, the Foundation provides our Hunter’s Home to Leukodystrophy families whose child is being treated or evaluated at Duke University Medical Center. For children fortunate enough to be diagnosed in time for lifesaving treatment, the process can take 6 months to a year. Hunter’s Hope is able to help remove some of the financial burden by providing a home-away-from-home for families who need it most so parents can focus on their child’s health.

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 2014, provided $56,770 worth of equipment and supplies to affected children.

Hunter’s 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 Elias and his family in 2014.

Kaden’s Kisses

The Kaden’s Kisses Fund is a special family program established in 2009 through Hunter’s Hope by the Brunner family in honor of their son Kaden, after he died in a tragic automobile accident. The hope of this program is to share Kaden’s love with families dealing with the loss of a child. In 2014, over $40,000 was provided to families grieving the loss of a child, to help alleviate some of the burden associated with end of life expenses.
Financial Position

2014 Program and Support Expenses

- General & Admin: $92,781 (8%)
- Fundraising: $96,901 (9%)
- Education & Awareness: $357,405 (31%)
- Research: $311,590 (27%)
- Family Assistance: $280,936 (25%)

2014 Revenues and Other Support

- Investment Income: $39,031.00
- Grants: $246,088.00
- General Donations: $605,204.00

Total Income – $1,591,889
Net Assets, beginning of 2014 – $654,460
Total Expenses – $1,144,296
Net Assets, end of 2014 – $1,102,053

Net Assets, beginning of 2014 – $654,460
Net Assets, end of 2014 – $1,102,053
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

David Janca
Board Member
Founder, Value Centric

Anne McCune
Board Member
Vogt Family Foundation Board Member

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

Lauren Gidley
Secretary/Board Member
President, Prosperity Wealth Management

Steven Schmitt
Board Member
Marketing Manager, Sherex Fastening Solutions

Connie Scherrer
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VP & General Manager of Warner/Chappell Music Publishing in Nashville