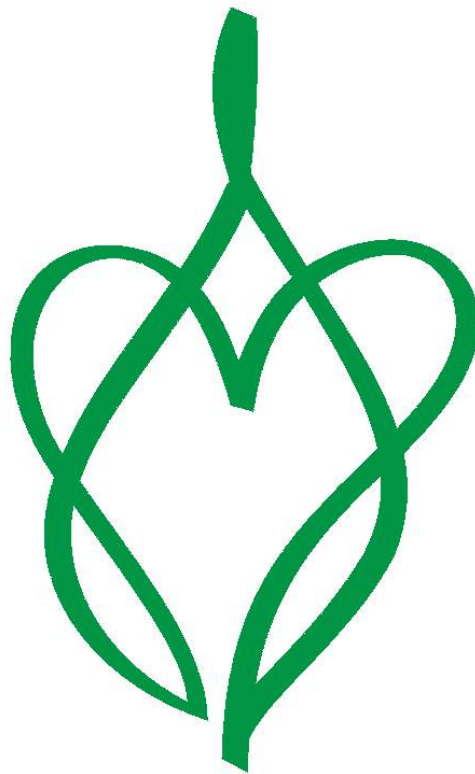


Hunter's Hope Foundation

2015 Annual Report



Krabbe and Leukodystrophies
Expanded Newborn Screening

Dear Friends,

As we reflect over 2015, we are once again filled with gratitude... To God, to our families and to all of our supporters for making another year of service to such a deserving community possible.

It's hard to believe that this was our 18th year as a Foundation... In that time, we've been blessed to serve hundreds of leukodystrophy families and countless more through our efforts to expand newborn screening. Monumental progress has been made but there is still more work to be accomplished. This year, we have continued in our efforts for improved newborn screening standards throughout the U.S. Our Family Programs provided unique but very necessary services to hundreds of families facing immense devastation and loss. Research advancements bringing us closer to better treatments and a cure for Leukodystrophies were underway.

In addition to all of our other programs and initiatives in 2015, we launched the Leukodystrophy Care Network (LCN). The LCN exists to provide proactive and innovative care to individuals affected by Leukodystrophies. Our goal is for LCN Centers to exist throughout the U.S., Canada, and eventually the world. We believe the LCN is key to revolutionizing the medical care and long-term health outcomes for those affected by these devastating diseases.

We are excited for what the coming year will bring as we remain dedicated to our mission of making a difference for these incredible children and their families. We cannot do it alone. Thank you for being a part of our team. You are a blessing!

With Hope,
Jim, Jill, Erin and Camryn Kelly



Jim, Jill, Erin and Camryn Kelly on the set of The Today Show to promote Erin and Jill's book, *Kelly Tough*.

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 unwavering in our mission to promote increased 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 the Foundation's mission. Every interview, speaking engagement, every *opportunity* is used to raise awareness about Hunter's Hope, newborn screening and Leukodystrophies.

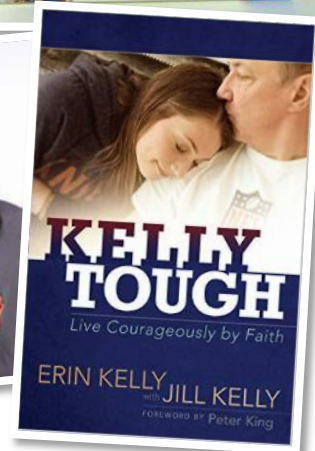
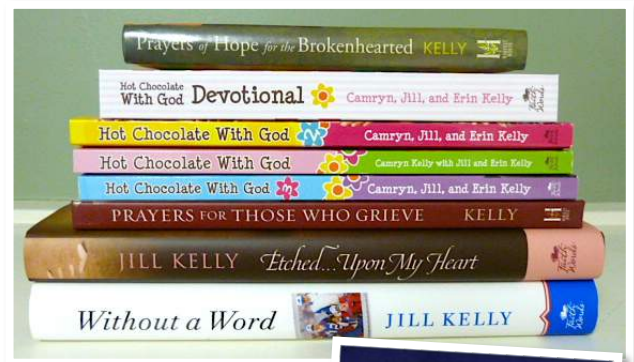
Kelly Family Books

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 2015, *Kelly Tough: Live Courageously by Faith* by Erin Kelly with Jill Kelly was released and became a NY Times Best Selling book! The book was widely publicized with a book tour and multiple national media interviews, bringing awareness to Hunter's Hope and our mission.

Throughout the summer of 2015, Jill and Erin had several speaking events at venues throughout the U.S. providing unique opportunities to share Hunter's story and Hunter's Hope with previously unreached audiences.



Top: Kelly Family Books;
Bottom Left: Jill & Erin Kelly;
Bottom Right: Kelly Tough by Erin and Jill Kelly

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 Krabbe

Hunter's Hope continually supports families affected by Krabbe and other Leukodystrophies as they advocate for expanded newborn screening in their states. In 2015, legislation for newborn screening for Krabbe was introduced in Kentucky, Massachusetts, Maine, Minnesota, Mississippi, New Hampshire, Ohio, Tennessee and Wisconsin, and families in several other states continued to work to that end.

In 2015, Krabbe Newborn Screening was mandated in **Kentucky, Ohio** and **Tennessee**. By December of 2015, nine states had mandates for the inclusion of Krabbe in their newborn screening program, with New York and Missouri screening for Krabbe. NM, IL, NJ, PA, KY, OH and TN all have varying implementation dates.

This progress would not be possible without the tireless work of our families throughout the U.S. Although it is too late for these laws to benefit their own children, they are dedicated to ensuring that future children born in their states have the fair chance at life they deserve.



Left: Anna Taylor (4/28/13 – 4/2/15) and her parents at the Kentucky capitol; Center: Tennessee families at the signing of the Mabry Kate Webb Act Right: Ohio Families with Representative Jim Buchy and Senator Keith Faber (not pictured) successfully advocated for expanded newborn screening for Krabbe.

One State at a Time

Advocating for expanded newborn screening is a grassroots effort at Hunter's Hope. Once a family begins the process in their state, we provide informational resources, contact other affected families in state to join their efforts, and refer 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 2015, more than 50,000 emails were sent through our website in support of expanded newborn screening throughout the U.S.



Each of these children inspired legislation for Krabbe NBS in 2015.

Top row:
Anna Taylor (KY),
Addilyn Davis (ME),
Ryan Nocera (MA),
Gemma Ward (MS),
Mabry Kate Webb, (TN),
Collin Cushman (WI)

Krabbe NBS Task Force

In October 2015, Hunter's Hope launched the Krabbe Newborn Screening Task Force. This group is comprised of parent advocates, clinicians, researchers, and newborn screening staff from states screening for Krabbe. The Task Force was created to address various opportunities to continuously improve Krabbe NBS and make it increasingly more accessible nationwide. Currently, the Task Force is focused on creating Clinical Practice Guidelines for Krabbe Newborn Screening and Follow Up to ensure children with a positive screen have the best possible outcomes.



The first Krabbe NBS Task Force Meeting in Buffalo, NY, October 2015

Supplemental Newborn Screening

Throughout 2015, parents from around the world purchased 225 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



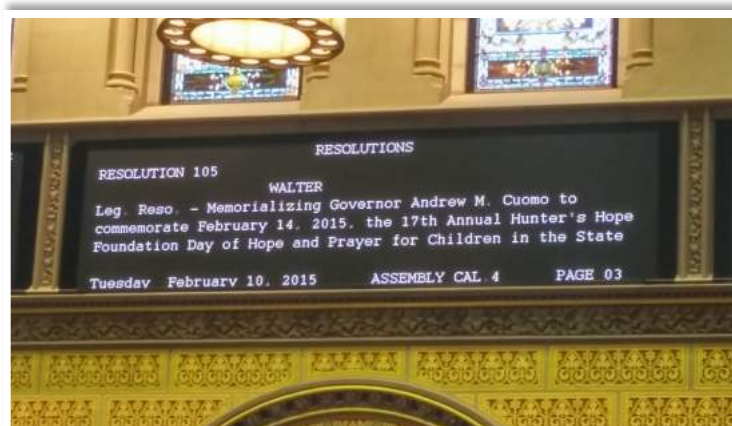
Camryn, Jim, Jill and Erin Kelly were so disappointed that the 2015 HDHPC had to be cancelled due to inclement weather.

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. Unfortunately, the 2015 HDHPC had to be cancelled due to inclement weather.

Those outside of Western New York still had 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, 2015, as Hunter's Day of Hope and Prayer for Children statewide!



2015 Hunter's Day of Hope and Prayer Resolution in the state of New York!

Research

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 Leukodystrophy 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, Leukodystrophies 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.

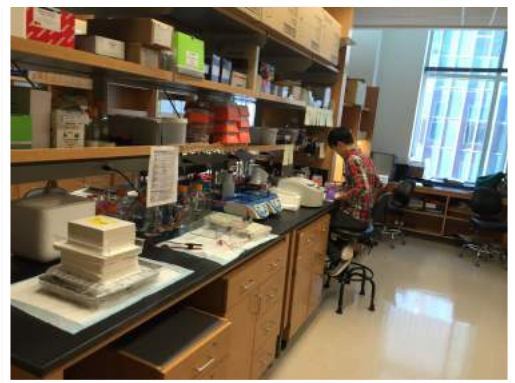
Clinical Research - HJKRI

The Clinical Research Center 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.



One of the many labs within the HJKRI

Extramural Research

Role of Psychosine in Krabbe Disease

Through a collaborative effort with Drs. 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 2015 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.

Death Certificate and Disease Registry Data for Epidemiological Description of Leukodystrophy Diseases

Dr. Randy Carter at the HJKRI is working to provide an epidemiological description of each Leukodystrophy that is observed in infants and is in the Global Leukodystrophy Initiative (GLIA) registry. The concentration on infantile forms of Krabbe stems from the need to provide information useful to states that are planning or considering NBS programs with screening for Leukodystrophies and to treatment centers that provide care to infants that are diagnosed with Leukodystrophies.

Leukodystrophy Care Network



Hunter Kelly
(2/14/97 – 8/05/05)

Leukodystrophies are an inherited group of over 40 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 of them 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.

In 2014 Hunter's Hope began defining a vision and strategy for helping a desperate community, those affected by Leukodystrophies. Several months of research and input from numerous experts were gathered and documented—we are grateful for the willingness of so many that freely provided their expertise, and for their desire to work together with us to realize this vision.

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 will 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**



Olivia (Alexander Disease) and her parents were greeted by other families who were also attending the LCN meeting.

- **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**.

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 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 continuous excellence - **LCN Advisory Committee**
- Involve **Government Agencies, Funders and Other Stakeholders** throughout the process
- Promote education and growth through **Public Awareness Campaigns**

Throughout 2015, extensive progress was made in realizing this vision. In May 2015, we hosted the first LCN meeting, gathering over 50 affected families, clinicians and other Leukodystrophy advocacy groups to establish the framework of the structure and functionality of the Network. In July of 2015, an additional day was added to the Medical Symposium to allot time for presentations from 9 prospective LCN Centers. Additionally, the LCN Steering Committee was formed, comprised of affected family members and representing 9 other Leukodystrophy organizations. The Steering Committee provides oversight and leadership for all LCN activities, ensuring that the LCN always remains true to patient-centered care.

This year, we also published the LCN website, LCN brochure, hosted a booth at the Child Neurology Society meeting, and continued to grow and develop working relationships with potential centers, laying the groundwork for even more growth in 2016.



2015 LCN Meeting

Left: Clinicians and families worked together to build the framework for the LCN.
Center: We were blessed to have so many affected parents attend this important meeting.

Family & Medical Symposium



2015 Hunter's Hope Family & Medical Symposium - Left: Hailey (Unspecified Leukodystrophy) with MJ (Krabbe) and his mom, Audrianna Burks. Center: Drake, Christina and Jessie Levasheff holding a picture of Judson (12/24/04 – 11/7/07). Right: Jim Kelly and Tori Brackbill (7/30/14 – 3/27/16).

The 2015 Hunter's Hope Annual Family and Medical Symposium was held at Holiday Valley Resort in Ellicottville, New York, from July 6th through the 12th. At the 2015 Symposium, we hosted 48 families affected by Leukodystrophies, together with over 64 researchers and medical experts.

Medical Symposium

At the 2015 Medical Symposium an array of issues were covered throughout the workshop. Newborn screening leaders from New York, New Jersey, Missouri, Illinois, Minnesota and Michigan 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 understanding of and find better treatments and ultimately a cure for Leukodystrophies. Also, an additional day was added to discuss Clinical Care through the Leukodystrophy Care Network.

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



2015 Hunter's Hope Medical Symposium Attendees



2015 Hunter's Hope Family Symposium

Family Symposium

In 2015, the Foundation welcomed 48 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 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 profound.

Hunter's Hope makes 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 to families who would not otherwise be able to attend.



Left: Jill with Dalton (Krabbe) and Sandrine (Krabbe).
Right: Our families make lasting friendships during this special week

Family Care 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 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.



We send Heaven Date cards in memory of our children in heaven. This card was sent to a family in Spain.

Hunter's Hope strives to give every family suffering from a Leukodystrophy love and support throughout the most trying time of their lives. In 2015, over 529 cards and 20 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 a 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 for life.



Hunter Kelly, the day he was diagnosed with Krabbe

Wall of Fame

The names and photos of hundreds of 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 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. Housing is often needed for six months to a year as children undergo treatment for Krabbe or another Leukodystrophy. 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, enabling parents to 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 2015, provided \$57,675 worth of equipment and supplies to affected children.



Tenley (Krabbe) loves the Tomato Chair she received through the Equipment & Supply Exchange. It enables her to comfortably be involved with her family's daily activities.



Marshall on his first ride in his new van!

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 Marshall and the Wilson family in 2015.



Kaden kissing his little sister Kylie

Kaden's Kisses

The *Kaden's Kisses* Fund is a special family program that was 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 2015, over \$39,290 was provided to 24 families grieving the loss of a child, to help alleviate some of the burden associated with end of life expenses.

Raising Awareness and Support

Throughout 2015, numerous events were held in Western New York and in other locations throughout the U.S. to help support the Hunter's Hope 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 2015 Kelly Tough 12K in Buffalo was a great day for all involved! We also had walks and runs throughout the country.



Above: My Fan Clips have information on each package about Hunter's Hope and a portion of the proceeds is donated to the Foundation.

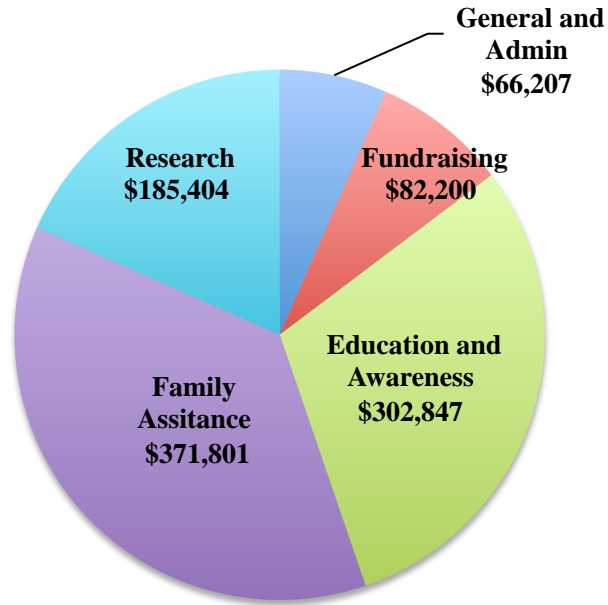
Top Right: 2015 marked the 11th annual Rosicki Gala, which raised \$30,000. Their generosity is a blessing!

Bottom Right: Thank you to our friends at Wendy's for another successful Frosty's and Fries fundraiser!

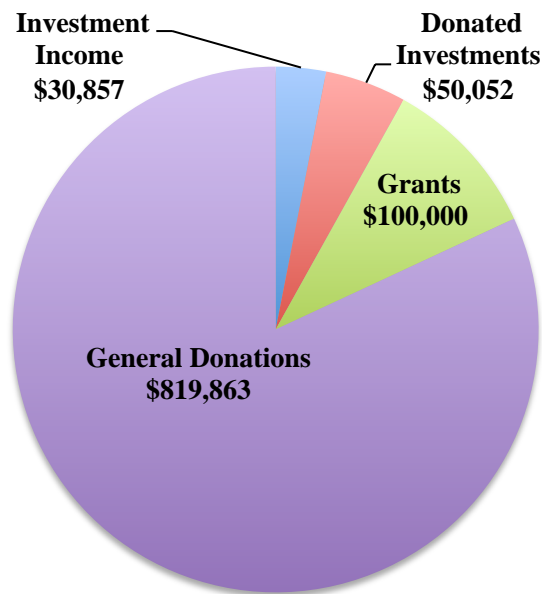


Financial Position

2015 Program and Support Expenses



2015 Revenues and Other Support



Total Income – \$908,871
Total Expenses – \$1,008,459

Net Assets, beginning of 2015 – \$1,001,465
Net Assets, end of 2015 – \$1,102,053

2015 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

Lauren Gidley
Secretary/Board Member
President, Prosperity Wealth Management

Steven Schmitt
Board Member
Marketing Manager, Sherex Fastening
Solutions

Russ Russell
Board Member
Chief Advancement Officer, Detroit PAL

Robert Sawicki
Board Member
Managing Director and CEO, Frontcourt

Jacque Waggoner
Chief Executive Officer
Hunter's Hope Foundation