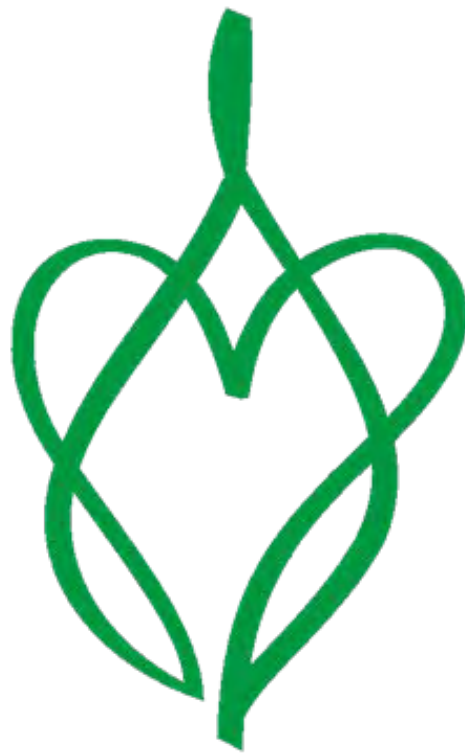


# Hunter's Hope Foundation

*2012 Annual Report*



Krabbe and Leukodystrophies  
Expanded and Universal Newborn Screening

Dear *Friends*,

It's been 15 years since our son Hunter, was diagnosed with Krabbe Leukodystrophy. We vividly remember that day – a day when it seemed like all hope was gone...

Little did we know, that through our son and his suffering, we would come to know and understand what true hope is...



We have witnessed our hopes turn into reality thanks to the many blessings God has bestowed upon our family and the Foundation.

When we established Hunter's Hope in 1997, we were hopeful that one day there would be treatment for children diagnosed with Krabbe Disease. That treatment came in the form of Cord Blood Transplant. Imagine...we now see children with Krabbe walking, talking, running, swimming, and enjoying life! And now, more research is underway to discover even better treatments.

We were hopeful that one day, there would be a way to test every child, so they could be diagnosed in time for life saving treatment – a test that didn't exist when Hunter was born. Through continued research efforts, a Newborn Screen for Krabbe Disease was developed; the screen is now saving lives and further advancing research toward a cure.

Now, we remain hopeful that every state will start screening for this devastating disease – one that can be treated if detected early. We're on the right track, with New York beginning in 2006 and Missouri in 2012. Laws have been passed in New Mexico, Illinois and now New Jersey just this year, and we're hopeful these laws will be implemented soon.

We also set out with the hope of developing a support system for families who were told 'you'll never meet another child with this disease.' This past summer, we hosted our 15<sup>th</sup> Annual Family & Medical Symposium, where families and researchers come together for a week of sharing, learning, and support. What a blessing to provide this and other Family Support Programs so desperately needed!

And throughout the years, we've hoped that we've inspired others through continuing to share what God has done in our lives.

As we enter 2013, we're hopeful that you will continue on this journey with us -- as our hopes and dreams for expanded legislation, research through the Hunter James Kelly Research Institute, and support for families continues to grow.

May God richly bless you and your family!

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 related 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.

## *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 in all matters*



# Education and Awareness



*Dine Out for Hope was held in restaurants around Buffalo on 12/12/12 – Jim Kelly Day. Each customer received information the Foundation and a percentage of all proceeds were donated to Hunter's Hope.*

Hunter's Hope is dedicated to raising awareness about the Foundation, Krabbe and other Leukodystrophies, and educating on the importance of Universal & Expanded Newborn Screening throughout Western New York and the United States. To that end, we pursue numerous programs and activities each year.



*Hunter's Day of Hope for Children is a day of family fun activities, games, food, and prayers for our children.*



*Above Photo: At Hunter's Hope night with the Buffalo Bisons we shared our message with more than 7,000 fans through the video board and an informational table in the gate concourse. The photo is of Jill, Jim and Erin Kelly.*



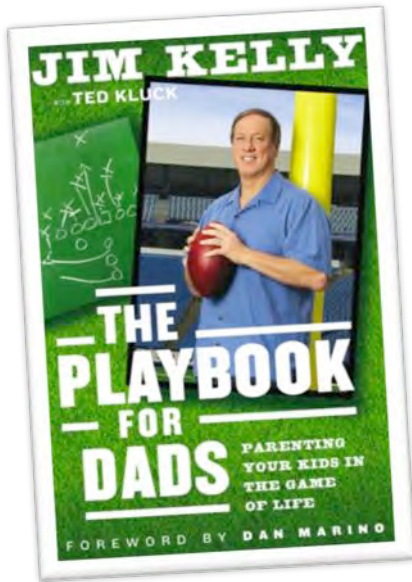
*Above Photo: We enjoyed participated in a Bisons sponsored Home Run Derby with celebrities and over 8,000 fans. The Hunter's Hope Home Run Derby Team: Lindy Ruff (former head coach of the Buffalo Sabres and current head coach of the Dallas Stars), Jim Kelly, Joe DeLamielleure (former Buffalo Bill and Pro Football Hall of Fame Member), Russ Brandon, (CEO of the Buffalo Bills), Fred Jackson (2012 Buffalo Bills Running back).*



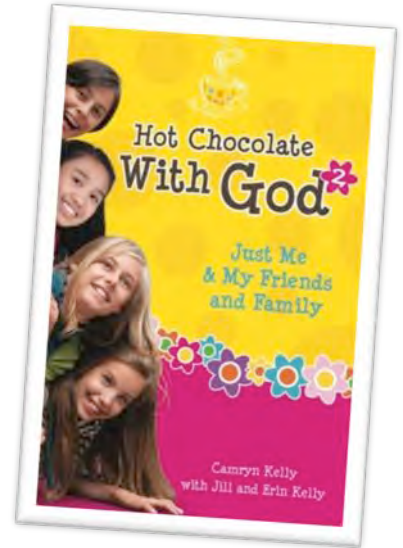
*Left Photo: The 2012 Hunter's Hope Radiothon was broadcasted in Western NY and online August 15<sup>th</sup> - 16<sup>th</sup> on 550AM WGR Sports Radio. Thanks to the celebrity interviews and testimonies from over 15 families affected by Krabbe and similar diseases, \$167,000 was raised to support the Foundation's mission and programs.*



# Education and Awareness



In 2012, *Playbook for Dads* by Jim Kelly and *Hot Chocolate With God 2* by Camryn Kelly were released, along with several DaySpring products by the Kellys. The Kelly Family books have increased awareness of Hunter's Hope, Krabbe Leukodystrophy and Newborn Screening across the country. We continue to receive testimonials from people of all ages as to the life-changing inspiration *Without a Word*, Jill's Prayer Books, and *Hot Chocolate With God* have provided.



As part of Jim Kelly's Every Score fundraising program an iPhone app was developed. It includes a quiz section with football trivia questions and questions about Hunter's Hope, Krabbe disease and other Leukodystrophies and Newborn Screening.



Three-hundred sixty quizzes were taken by 120 different people. This has been a great way to raise funds, spread awareness and have fun at the same time. A continuous improvement plan was implemented to help ensure future success.

To increase awareness of Hunter's Hope, Krabbe disease and newborn screening, in 2012 we worked with a local legislative office staff member to write a legislative resolution in the state of New York to proclaim February 14, 2013 as a Day of Hope and Prayer for Children.

In 2012 we increased our "fans" on Facebook by over 770 people, which averages more than two new "likes" a day during the year. Our Facebook page includes information about our affected families, Krabbe disease and other Leukodystrophies, and newborn screening, and our fundraising programs.

# Education and Awareness



*Above Photo: Erin and Jim Kelly, Christina, Jessie and Drake Levasheff, Jill and Camryn Kelly*

In 2012, Hunter's Hope was blessed by the Levasheff family, who played for and won the Grand Prize on the new game show hosted by Jeff Foxworthy, *The American Bible Challenge*.

Not only did the prize money go toward research at the Hunter James Kelly Research Institute, information about Krabbe and the Foundation was shared on national television.

The Levasheff family supports Hunter's Hope in memory of their son, Judson, who had Krabbe disease.



*Judson Levasheff  
12/24/04 – 11/7/07*

Jim Kelly was the proud recipient of the 2012 Jefferson Award for Public Service. Through this award Jim was able to share about Krabbe disease and Hunter's Hope with a new audience.

The Jefferson Awards annually celebrate America's commitment to public service.

Recognizing both the famous and the unknown, individuals and organizations, the awards reflect that of contributing toward the larger good.

Honorees are chosen on the basis of two main criteria: the outstanding nature of the acts of service and the impact on the community of those acts.



# Education and Awareness



One of the primary ways the Foundation shares its mission across the country is through ***Every Step***, “*The Walk for Every Child. Every Time. Everywhere.™*” to benefit Hunter’s Hope.

***Every Step*** is our national walk that raises awareness about newborn screening, Krabbe and other Leukodystrophies, and raises funds to continue in our mission. ***Every Step*** is also a practical way for a community to rally support of families affected by these devastating diseases.

Hunter’s Hope staff members assist walk coordinators by providing a website for each walk, media and marketing elements, and the support needed for planning and execution of an event of this magnitude.

In 2012, there were nine ***Every Step Walks*** across the U.S. –in Alabama, California, Colorado, Oregon, Massachusetts, Illinois and three walks in New York State. Each walk honored at least one family who has been affected by Krabbe or another Leukodystrophy. Walkers enjoyed a day of family fun while learning about the importance of newborn screening for diseases like Krabbe and how they can advocate for newborn screening expansion and improvement in their state.



# Expanded & Universal Newborn Screening

## *Every Child. Every Time. Everywhere.™*

**Newborn Screening** looks for serious developmental, genetic, and metabolic disorders that would not otherwise be detected. For these diseases early detection and treatment is *essential* to preventing irreversible mental or physical disabilities, even death.

***Unfortunately, the number of diseases a child is screened for depends on which state they are born in.*** Due to an inequity in each state's newborn screening program, children are not being diagnosed for many of these diseases in time for treatment. For children with these disorders, the earlier the child is diagnosed, the better chance the child has to survive.

The Hunter's Hope Foundation continued its newborn screening education and awareness, and advocacy efforts to ensure that every child born in the United States is screened for all possible diseases to provide an equal opportunity for a healthy start at life.

### ***Federal Newborn Screening***

Hunter's Hope continues to support the Secretary Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) by serving on the Education and Training Subcommittee. The SACHDNC was formed to advise the U.S. Secretary of Health regarding the most appropriate application of universal newborn screening tests, technologies, policies, guidelines and standards for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders.

Hunter's Hope also continues to serve on the Standing and Bioethics Committees of the National Newborn Screening Translational Research Network (NBSTRN), a project sponsored by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). The purpose of the NBSTRN is to develop a National Coordinating Center that will help to improve the health outcomes of newborns with genetic or congenital disorders by means of an infrastructure that allows investigators access to robust resources for newborn screening research. Furthermore, Hunter's Hope has actively participated in the planning stages of the Newborn Screening Saves Lives Reauthorization Act, which was introduced to the U.S. Congress in early 2013 in efforts to provide much needed funding for NBS programs and research throughout the U.S.

Educational resources were created for Krabbe NBS positive screen families through a partnership with NYMAC.

Website and brochures were made available to all New York and Missouri Metabolic Centers to help parents understand newborn screening, Krabbe and how to ensure the best care for their child.





# Expanded & Universal Newborn Screening *Every Child. Every Time. Everywhere.*<sup>TM</sup>

## ***State Newborn Screening***

This year, a high priority was given to state level advocacy efforts. Hunter's Hope staff encouraged families throughout the country to request legislation mandating the addition of Krabbe and five other Lysosomal Storage Disorders (LSDs) to their state's newborn screening panels. The collaborative efforts of the Foundation and our families resulted in:

**Missouri** became 2<sup>nd</sup> state to officially implement Krabbe Newborn Screening for all MO infants.



**New Jersey** Governor, Chris Christy, signed Emma's Bill into law, mandating the addition of Krabbe and four other LSDs to New Jersey's Newborn Screening Panel.

Emma Daniel's family was heartbroken to learn that had Emma only been born one state over, in New York, she could have been screened for Krabbe at birth and in time for life saving treatment.

*Left Photo: New Jersey Governor, Chris*

Legislation introduced in **California and Tennessee** to add Krabbe and five other Lysosomal Storage Disorders to their Newborn Screening Panels. Although neither bill passed into law in 2012, a strong foundation was laid, greatly increasing our chances for success in 2013.



*Above Photo: Phil May and Scarlett Measles at the Tennessee state capitol. Scarlett was diagnosed with rare, adult onset Krabbe as a teenager and received a bone marrow transplant to halt the progression of the disease. Phil joined her efforts in honor of his son, Dylan, who was not diagnosed in time for treatment.*



*Left Photo: (Center) California Senator Tony Strickland with (Left) Rod, Kathleen, Brooke and Bella Scott and (Right) Steve, Nicole, and Trevor Aldrian, just before testifying to the Senate Health Committee. These families shared with lawmakers how early detection through Krabbe newborn screening could have saved Trevor, Jacquelyn, and countless others from this devastating disease.*



# Expanded & Universal Newborn Screening *Every Child. Every Time. Everywhere.*<sup>TM</sup>



Hunter's Hope families worked in many other states across the country to begin advocating for Krabbe newborn screening.

After Reesa Stutzman was diagnosed with Krabbe Disease, her family shared her story and the difference Krabbe NBS would have made for her in their home state of **Arizona** and in **Missouri**. Although the fight is just beginning in Arizona, Missouri officially began screening all newborns for Krabbe in August 2012.

*Left Photo: Sean, Jamie, Reesa and Mike Stutzman shared their story with Arizona policymakers.*

The Wilson family showed **Oregon** legislators the difference early detection and treatment for Krabbe makes by introducing them to their two sons: Marshall, who went undiagnosed until the disease was too far progressed for treatment and Michael, who was diagnosed and treated before symptomatic and is now a thriving toddler.

The Wilsons are committed to advocating for Krabbe newborn screening in Oregon until all children have the same chance at a healthy life as Michael did.

*Photo: The Wilson Family  
(Left to Right, Top Row) Tammy, **Michael**, David,  
(Middle) Bryce, **Marshall**, Melaney,  
(Front) Mason*



# Hunter James Kelly Research Institute

The Hunter James Kelly Research Institute (HJKRI) is a partnership between The University at Buffalo and the Hunter's Hope Foundation. The HJKRI is located in downtown Buffalo, New York, in the New York State Center of Excellence in Bioinformatics and Life Sciences at the University at Buffalo.

All Hunter's Hope research is coordinated through the HJKRI, including the study of remyelination techniques as well as the biology and pathophysiology of Krabbe disease, in order to develop effective treatment strategies. This approach will allow the correction of the genetic defect together with the repair of damaged myelin, to provide a **total solution** for children with Krabbe disease. In addition, research on remyelination techniques not only benefits children with Krabbe and other leukodystrophies, but also patients affected by Multiple Sclerosis, stroke, and other diseases in which there is white matter destruction to the brain.

## *Neuroscientists at UB's HJKRI Show How Turning Down Synthesis of a Protein Improves Nerve, Muscle Function in Common Neurophathy*

A potential new treatment strategy for patients with Charcot-Marie-Tooth disease is on the horizon, thanks to research by neuroscientist, Dr. Laura Feltri, now at the University at Buffalo's Hunter James Kelly Research Institute and their colleagues in Italy and England. And while CMT is the focus of this particular research, the work is helping scientists at the HJKRI enrich their understanding of myelin disorders in general. "What we learn in one disease, such as CMT, may inform how we think about toxins for others, such as Krabbe's," said Dr. Larry Wrabetz, Director of the Hunter James Kelly Research Institute.

*Right Photo:* Dr. Larry Wrabetz, Dr. Laura Feltri



## *Families Visit the Institute*

Jackson White and his father, Marshall visited the HJKRI last summer when visiting the area for the annual symposium. Jackson was diagnosed with a later onset of Krabbe as a toddler and received a transplant to halt the disease's progression.

Jackson and other families in attendance were encouraged by the Institute's research for Krabbe and feel more hopeful than ever that improved treatments and a cure are in our future.



# Hunter James Kelly Research Institute

## ***Clinical Arm***

The Institute welcomed Dr. Tom Langan as Clinical Director, to replace Dr. Patti Duffner who retired from the position.

### **The HJKRI Clinical Research Center has four major goals:**

1. To improve outcomes of children identified for Krabbe Disease through newborn screening
2. To improve understanding of the natural history of Krabbe disease
3. To increase awareness of Krabbe disease through education
4. To provide clinical care

To achieve the first goal, the NYS Krabbe Consortium, a multidisciplinary group of child neurologists, geneticists, newborn screeners, neuroradiologists, transplanters and developmental pediatricians, was established in 2006 in response to the advent of newborn screening for Krabbe disease in NYS.

In 2012 the Consortium became the Multi-State Krabbe Consortium to include Missouri, the newest state screening for Krabbe disease, and in preparation for additional states as they begin screening for Krabbe. The group continued to provide a consistent statewide approach to the process, identifying risk groups of babies with positive newborn screens. Standardized baseline and long term neurodiagnostic protocols continued to be refined as new information indicated the need. The consortium continued to expand and improve the clinical/database registry of children with positive newborn screens/confirmatory testing.

The second goal of the Clinical Center is to improve understanding of the natural history of Krabbe disease including whether clinical, biochemical, genetic and/or neurodiagnostic parameters might predict phenotype. To accomplish this goal, an international registry of patients with Krabbe disease was established in 2008 (the World Wide Registry). Parent questionnaires and medical records are accessed and reviewed with a focus on clinical signs and symptoms, disease course, family history and results of biochemical, genetic and neurodiagnostic studies. In order to increase the number of patients with a known genotype, mutation analysis was performed on saliva and newborn blood spots. Results were then compared with clinical course to provide genotype/phenotype correlations. In addition, MRIs from affected children were reviewed in an effort to correlate neuroradiologic findings with phenotype and disease course.

The third goal of the Clinical Center is to increase awareness of Krabbe disease through education. To this end, Dr. Duffner, Clinical Director Emeritus was a visiting professor throughout the US as well as at national and international genetic, pediatric and neurology meetings discussing newborn screening for Krabbe disease and the clinical manifestations of this disorder. Dr. Duffner also addressed state newborn screening advisory panels.

The fourth goal of the Clinical Center is to provide clinical care for children with Krabbe disease as well as those with positive newborn screens for the disease. A clinic was established by Dr. Patricia Duffner at the Women and Children's Hospital of Buffalo. In the future, as new therapies come on line, we anticipate having an active translational research component to the Clinical Center.



# Hunter James Kelly Research Institute

## ***Basic Science Arm***

The mission of the HJKRI Basic Science Arm is to develop a multi-disciplinary approach to understand how myelin is formed, how axons and myelin are damaged in disease, and how they may be repaired.

### **The HJKRI Basic Science Arm has five major goals:**

1. To study myelin formation as a source for strategies of myelin repair
2. To study consequences of myelin damage such as neurodegeneration
3. To provide better cellular and animal models for identifying mechanisms of disease
4. To exploit models to perform preclinical studies of therapies
5. To translate the research of HJKRI into prognostic, diagnostic and treatment application

1. Dr. Pablo Paez is studying the role of channels that allow calcium (that acts as a signal) to enter the cells that make myelin in the brain. He has previously shown that these channels are regulated by electrical activity and when activated, they promote the number, migration and maturation of the cells that make myelin. He is now studying whether the same channel could also be important for repairing myelin damage. This is important because there are already drugs available that regulate these channels and could be useful for promoting myelin repair in leukodystrophies.

2. HJKRI has several candidates and hopes to hire a new faculty member to work on neurodegeneration as a consequence of myelin disease.

3. Drs. Daesung Shin, Laura Feltri and Lawrence Wrabetz have engineered new transgenes that will allow GalC, the Krabbe disease gene, to be removed from specific cell types in the brain or peripheral nerves of mice. As a result, they can ask in which cell is loss of GalC activity and resulting psychosine accumulation most important for disease. This information will specify cellular targets for treatment, and provide new models for preclinical trials of therapy.

4. Drs. Shin and Feltri are employing the twitcher, and eventually new mouse models of Krabbe disease (Aim 3) to correlate psychosine toxicity with disease. They will also perform comprehensive analysis of metabolites from the brains of these animals to identify additional, new toxins. This may explain previous observations that psychosine levels do not always correlate with disease.

5. Neither the DNA mutation in a GalC disease gene, nor the enzyme activity of the diseased GalC protein predict with certainty when disease will appear or how severe it will become. This prevents families and their doctors from making informed decisions about treatment. Drs. Shin and Feltri are studying how cultured cells handle diseased GalC protein and its enzyme activity in order to explain why they are not predictive of disease.



# Family & Medical Symposium

The Hunter's Hope Annual Family and Medical Symposium was held at Holiday Valley Resort in Ellicottville, New York, from July 31<sup>st</sup> through August 5<sup>th</sup>. Nearly 40 families affected by Krabbe or other leukodystrophies together with over 60 researchers attended the 2012 Symposium.

Discussion topics from the 2012 Medical Symposium included treatments of animal Krabbe models such as gene therapy and Cord Blood Transplant, MRI findings and neuropathology of children transplanted for treatment of Krabbe disease, newborn screening techniques and updates from states screening for (or planning to screen for) Krabbe, genotype/phenotype correlations, remyelination of the central nervous system and more.

The Foundation's staff worked closely with the scientific and clinical directors of the Hunter James Kelly Research Institute (HJKRI) to create the Medical Symposium's invitation list and to coordinate travel arrangements and lodging accommodations. The team at the HJKRI determined the presenters and topics to be discussed at this two-day roundtable workshop, ensuring that the maximum amount of progress was made toward our overall goal of improved detection, treatment and ultimately a cure of Krabbe and diseases like it.

Perhaps the greatest accomplishment of the symposium is the opportunity for families affected by Krabbe or another leukodystrophy to build relationships with one another. The complexities that affected families face are extremely unique and overwhelming – they can only be truly understood by others in similar circumstances. The hope and strength families in attendance receive from one another is indescribable.

All of this was made possible through generous support of the Wal-Mart State of Giving Foundation. We also received support from the Buffalo Bills Youth Foundation and the Peace, Love and Trevor Foundation.



*Stephen and Amanda with their daughter, Lauren Loughheed, who has Krabbe disease.*



*Terri and Scott Hammonds who lost their son, Liam to Krabbe disease, holding Sandrine Dion who has Krabbe disease and has had a transplant.*

# Family & Medical Symposium



*2012 Hunter's Hope Family and Medical Symposium Families*

During the family portion of the symposium, seven educational seminars were given by the world's leading Krabbe and leukodystrophy experts. Families also participated in four breakout sessions focused on family dynamics, designed to help those in attendance form support systems with other families who know firsthand the devastation caused by these diseases. Childcare was provided for over 30 children, including those affected by Krabbe and other leukodystrophies, so that parents could devote their full attention to the information presented.

Due to the financial strain many affected families experience, we strive to make the symposium affordable for all who desire to attend. This year, Hunter's Hope continued to cover at least 75% of the cost of lodging, meals and other accommodations for all attending adults and paid all expenses for affected children, siblings under the age of 16, and adults unable to financially contribute to the cost of their stay. Additionally, we awarded over \$17,000 through the *Hunter's Hope Helping Hand Grant Travel Assistance* program to families who could not afford their travel expenses.

# Family Support Programs

Hunter's Hope Foundation is fully committed to providing encouragement, education and support to our families. Our hope and prayer is that you feel connected to our family and join us in this fight against these devastating diseases. To achieve our mission, our Family Programs encompass key areas designed to meet the needs of our families.

## ***Hope for Life***

Everyday, children affected by Krabbe and other leukodystrophies are defying the expectations placed on them. ***Hope for Life*** shares stories of hope and find helpful resources as parents care for and enjoy time with their affected child.

*"Those of us who knew Hunter will tell you that he changed us in profound ways. The grass somehow appeared greener, and the array of beauty that colors our world and the intricate details of creation became more vibrant. Simple things we were usually too busy to appreciate filled us with gratitude because, incredibly, God used the simplicity of the common to show us how uncommon simple things really are.*

*Hunter loved life...all of it. His suffering didn't take away from his ability to enjoy life; it only made him enjoy what he could that much more."* ~ Excerpt from 'Without a Word', Chapter 8, 'Hunter at One and Two.'

## ***Family Care***

The Hunter's Hope ***Family Care*** program aims to help our families by providing special care through personal outreach to establish positive communication and a meaningful relationship. In 2012 Hunter's Hope reached out to 60 new families and 545 registered families, to provide information regarding our family programs, World Wide Registry, Wall of Fame, Education and Awareness, and Advocacy opportunities. Additionally, we sent numerous Welcome Packages, Birthday and Heaven Day Cards, Grief Packages and 'Thinking of You' Packages.

One family shared -

"The day we received our welcome package Peyton had only been home post transplant for MLD for two days. The smile on his face said it all. The bear goes everywhere with us. Peyton simply named him...Hunter! The book Without a Word was amazing - every emotion is in this book. I can't believe on top of everything that Hunter's Hope does, they also make it a point of making sure you feel welcome and part of something great." ~ Jessica White, mom to Peyton

## ***Wall Of Fame***

The Wall of Fame was established March of 2012. This section of the Hunter's Hope website provides families a location to honor their affected children by displaying each child's photo, name, and a link to their website or Caring Bridge site. To date, the site features 258 affected children.





# Family Support Programs

## *Hunter's Homes*

The doctors at Duke are leaders in providing treatment for leukodystrophies through Cord Blood Transplantation. Children receiving transplants must stay near Duke from six months to a year for post-transplant follow up visits. Since 2005, Hunter's Hope has provided a 'home away from home' for families receiving treatment at Duke and continue to do so through the Ronald McDonald House of Durham. Five families lived in our Hunter's Homes throughout their long-term stay in 2012.

To continue to provide help for families at Duke, Hunter's Hope and the Ronald McDonald House of Durham established a partnership to provide Leukodystrophy families receiving treatment at Duke University Hospital the comforts of home at no cost to the families.

Located on the Duke University Campus and just minutes from Duke University Hospital, our Hunter's Home provides families receiving treatment at Duke a fully furnished 'home away from home.' Comforts of the home include: private bedrooms, inviting community spaces, daily home-cooked meals and a stocked kitchen, a playroom, computer room and laundry facilities, as well as a network of support through interactions with other families, staff and volunteers.



## *Equipment & Supply Exchange Program*

The Equipment & Supply Exchange Program fulfills the equipment and supply needs of Krabbe and Leukodystrophy children by assisting families place pieces of equipment and supplies they no longer need. Sixteen exchanges were completed in 2012, providing our families with more than \$33,928 in equipment and supplies.

*Left Photo:* Kenan Witezak, one of many recipients of the Exchange Program, received this car seat, designed especially for children with special needs.

# Hunter's Wish Gift & Kaden's Kisses

## *Hunter's Wish Gift*

Hunter's Wish Gift aims to provide for unique or extreme circumstances of families struggling to meet the needs of their affected child.

The most notable gift in 2012 was Hunter's Hope's partnership with the Peace Love and Trevor Foundation and Liam Hammonds Foundation, to award the D'Amicos, a family affected by Krabbe, \$22,000.00 towards the purchase of a wheelchair accessible van for their son John.



*Top Left Photo: John D'Amico, Michael & Michele D'Amico  
Top Right Photo: John D'Amico*



## *Kaden's Kisses*

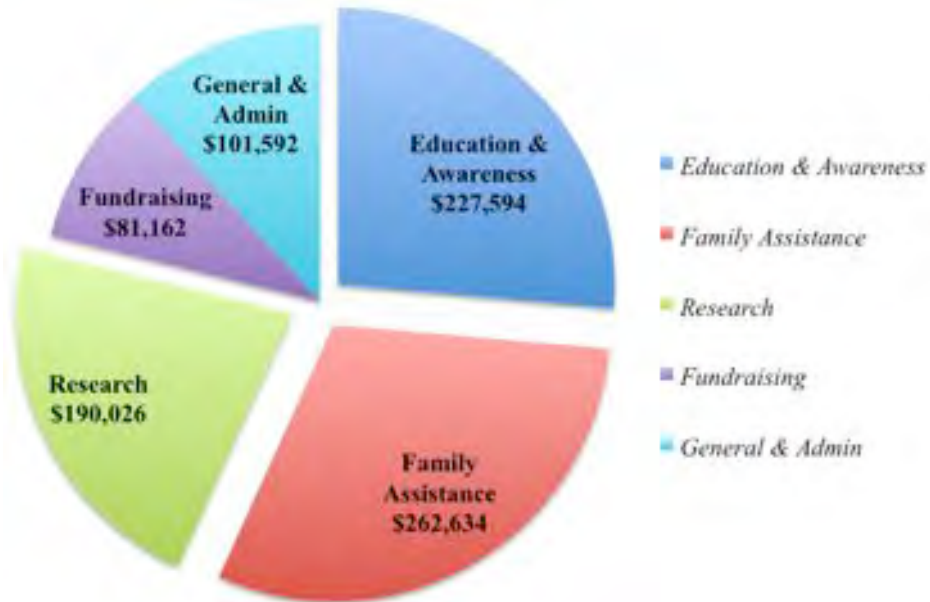
Kaden's Kisses was added to the Hunter's Hope Family Programs in 2009. This special Family Program Fund was established by the Brunner Family after their 2 ½ year old son, Kaden W. Brunner, died from a tragic automobile accident. Their hope is to share Kaden's love with other hurting families who have lost a child.

Kaden's Kisses aims to help alleviate some of the financial burden faced by families who have lost a child.

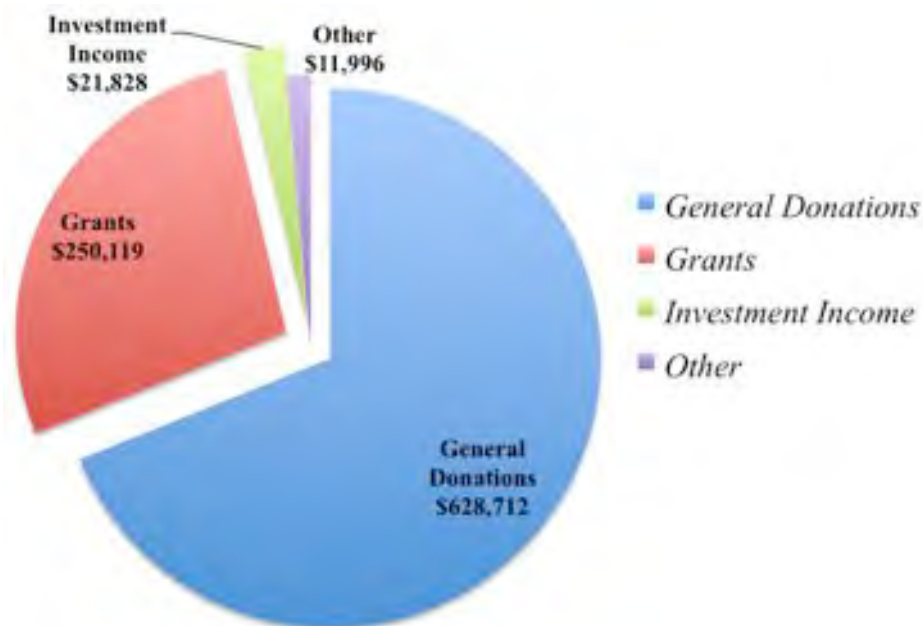
This special program awarded **29 families** in 2012 assistance for the funeral and/or headstone costs resulting from the loss of a child. These awards totaled \$25,975.

# Financial Position

## 2012 Program and Support Expenses



## 2012 Revenue and Other Support



Total Income – \$912,655  
Total Expenses – \$863,008

Net Assets, beginning 2012 – \$647,169  
Net Assets, end of 2012 – \$753,375



# Board of Directors and Officers

Jim Kelly

President, Co-Founder, Hunter's Hope Foundation

Jill Kelly

Chairwoman, Co-Founder, Hunter's Hope Foundation

Roger Palczewski

Secretary/Treasurer, Hunter's Hope Foundation  
C.O.O., Rosina Food Products, Inc.

Greg Connors

Board Member, Hunter's Hope Foundation  
Director, Esq. of Connors & Ferris, LLP

Charles DeAngelo

Board Member, Hunter's Hope Foundation  
Director, Fessenden, Laumer & DeAngelo

David Janca

Board Member, Hunter's Hope Foundation  
Director, Founder, Value Centric

Lauren Gidley

Board Member, Hunter's Hope Foundation  
President, Prosperity Wealth Management

Phil May

Board Member, Hunter's Hope Foundation  
Manager of Warner/Music Publishing in Nashville

Jack Martin

Board Member, Hunter's Hope Foundation  
President/Founder, J. Fitzgerald Group, Inc.

Michelle Tharnish

Board Member, Hunter's Hope Foundation  
Partner with Sixt, Wengewicz & Tharnish, CPAs

Jacque L. Waggoner

Chief Executive Officer, Hunter's Hope Foundation

