

Hunter's Hope Foundation

2011 Annual Report



Krabbe and Leukodystrophies
Expanded and Universal Newborn Screening



Mission

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

- An increase in awareness of Hunter's Hope and our name recognition continued with more exposure of *Without A Word*, *Prayers for Those Who Grieve*, *Prayers of Hope for the Broken Hearted* and the addition of *Hot Chocolate With God*. Awareness increased about Krabbe disease through interviews with Jim & Jill Kelly and their daughters, Erin & Camryn Kelly, on TV, radio, online blogs, print and other media outlets.
- Social Networking was augmented to heighten the awareness of Krabbe, leukodystrophies and Newborn Screening through the use of Facebook and Twitter. Since joining Facebook in 2010, Hunter's Hope has gained over 3,900 followers.
- Hunter's Hope continued to spread awareness through email blasts to constituents in our Convio database, which has grown to over 15,000 active constituents. This is over a 100% increase from the prior year.
- Every Step Walks around the country also helped to educate participants about Krabbe disease and other leukodystrophies, as well as Expanded and Universal Newborn Screening. In December of 2011, we launched our first Convio Advocacy Alert in NJ. Because of the new constituents who signed up for the NJ Walk we had over 100 contacts made to legislators through the Advocacy module from our original listing of 96 people in NJ in just two days.
- Hunter's Hope utilized large scale events such as the Buffalo Bisons' Mystery Ball at Coca-Cola Field to broaden awareness to potentially unexposed groups.
- Hunter's Hope continued to give copies of Jill's books to newly affected families to provide comfort and awareness.
- Hunter's Hope continued to use the annual Radiothon to promote awareness about Krabbe disease and Newborn Screening through first hand interviews with medical professionals and family members of affected children.
- The Foundation continued to share other family stories to increase awareness and educate the public on the importance of Newborn Screening, effects of Krabbe as well as other leukodystrophies and the impact of the Hunter's Hope Foundation on affected families.

Expanded and Universal



Every Child. Every Time.
Everywhere.™

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. Most babies appear healthy at birth, full of life and possibility, yet they could be hiding a rare or potentially devastating disease. By screening every baby at birth, we can prevent serious mental or physical disabilities, even death. Also, by ensuring that every state screens for the same diseases, making NBS universal across the country, no child will suffer unnecessarily because their state was not screening for all possible diseases.

- In 2011 the Center for Disease Control and Prevention (CDC) published “Ten Great Public Health Achievements in the United States from 2001-2010.” In this publication, they cited advancements in Newborn Screening amongst the ten great public health achievements in the United States during the last decade. The CDC stated “improvements in technology and endorsement of a uniform newborn-screening panel of diseases have lead to earlier life-saving treatment and intervention for at least 3,400 additional newborns each year with selected genetic and endocrine disorders.” The Hunter’s Hope Foundation has played an important role in this major achievement. For most of the last decade we have worked closely with Krabbe affected families and have effectively advocated for Expanded and Universal Newborn Screening at the state and federal level.
- We continued to work toward getting Krabbe disease added to the Secretary Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) recommended panel. We formed a team of medical experts in preparation to reapply for the recommendation.
- In parallel with working toward the SACHDNC recommendation, we continued advocating state-by-state for the addition of Krabbe and five other Lysosomal Storage Disorders (LSDs), with a focus on NJ, TN and CA.

Newborn Screening



- Acquired a sponsor and potential co-sponsors of newborn screening legislation in CA, called Jacquelyn's Bill, for the 2012 session as a result of families meeting with their state legislators. Jacquelyn's Bill is named in honor of Krabbe affected Jacquelyn Scott, daughter of Kathleen Scott, a Hunter's Hope employee.
- Announced the availability of Supplemental Newborn Screening (SNBS) for Krabbe and five other LSDs through the PerkinElmer SNBS Packet. Now, no matter where a child is born, parents can ensure that their child is screened for Krabbe and similar diseases.
- Launched the Foundation's first Advocacy Action Alert online module, using the newly implemented advocacy module from Convio. With the first use of the module, over 100 contacts were made to NJ legislators requesting support of Emma's Law.
- New Jersey senate and assembly unanimously passed Emma's Law – to add Krabbe and four LSDs to the NJ newborn screening program. Governor Christie signed Emma's Law into law in early 2012.
- Through the Every Score program, NBS stories and information were highlighted each week for each state of the Buffalo Bills opposing team. This was a fun way to make NFL fans aware of NBS in other NFL states.
- Obtained partnership and grant funds with the federally funded New York and Mid-Atlantic Consortium to create educational materials and resources for parents whose child receives a positive screen for Krabbe disease. The plan and concept documentation were completed as the first phase of the project.
- Dr. Duffner continued to travel to state labs and conferences presenting the NYS NBS Consortium model established for and continuously improving follow-up protocol for positive Krabbe screened children. With the goal of expanding the consortium to include all states screening for Krabbe disease.
- The following states now have a law in place for mandatory screening of Krabbe: New York, New Jersey, Illinois, Missouri and New Mexico.



Hunter James Kelly Research Institute



The mission of the Hunter James Kelly Research Institute (HJKRI) is to study myelin and its diseases. The HJKRI incorporates both basic and clinical science programs.

Basic research is based on a multi-disciplinary approach to understand how myelin is formed, how it is damaged in disease and how it may be repaired. In particular, HJKRI will study disease mechanisms of Krabbe disease in order to formulate therapies.

Clinical research analyzes information revealed by newborn screening for Krabbe disease and other leukodystrophies. The World Wide Registry for patients with Krabbe disease aims to improve diagnosis and prognosis, and to provide outcome measures for clinical trials.



***Dr. Larry Wrabetz, Dr. Laura Feltri
Leaders of the Basic Science Arm of Institute***

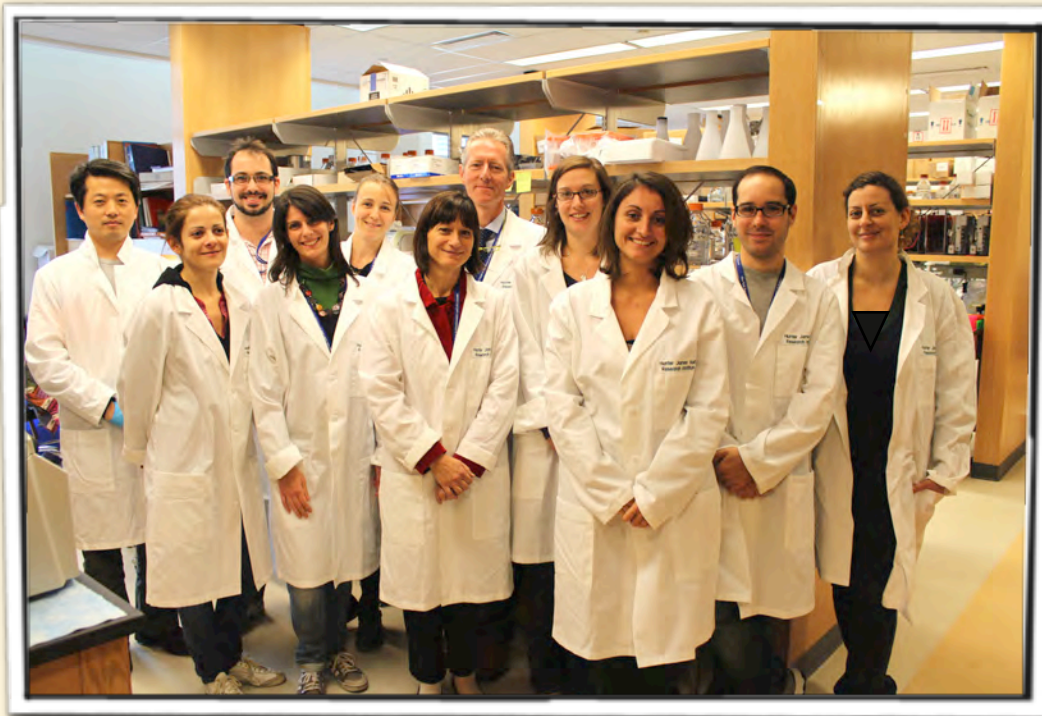
This integrated approach, together with a critical mass of resources and investigators, will generate information that will promote effective treatment strategies not only for children with leukodystrophies, but also patients with Multiple Sclerosis, stroke, neuropathies and other diseases in which myelin is damaged.



***Dr. Larry Wrabetz, Dr. Laura Feltri
Jill Kelly, Jim Kelly,
Dr. Patricia Duffner, Clinical Director
Dr. Michael Cain, Dean UB Medical School***



Hunter James Kelly Research Institute



Dr. Larry Wrabetz and Dr. Laura Feltri and Some Members of Their Research Team

With the 2011 arrival of highly regarded neuroscientists Lawrence Wrabetz and Laura Feltri, the mission of the Hunter James Kelly Research Institute (HJKRI) is moving forward with great fervor. Drs. Wrabetz and Feltri were dubbed “physician-scientist superstars” by Michael Cain, dean of the School of Medicine and Biomedical Sciences. Dr. Larry Wrabetz holds a primary appointment in the Department of Neurology, with a secondary appointment in the Department of Biochemistry; Feltri has a primary appointment in Biochemistry. The husband-wife research team arrived in Buffalo in late spring from Milan, Italy, with family and laboratories, including 10 research associates—eight of Italian and two of French descents—and 56 lines of transgenic mice.

The Krabbe World Wide Registry increased the number of registered patients by 30% in 2011. Over 70 MRIs have been acquired and analyzed in an effort to better predict outcome based on these results.

Hunter’s Hope received \$10,000 from the Buffalo Sabres Foundation to begin a project to analyze the newborn screening blood spots stored over time by states of Krabbe affected children in our registry. Twelve families were identified in California of which four specimens were secured in 2011. More are expected to be secured in California and in other states. This study will help to better predict phenotype from genotype and other factors that are looked at through newborn screening.

Family and Medical Symposium



Each year, the Hunter's Hope Family & Medical Symposium brings together families affected by leukodystrophies as well as leading researchers and doctors with the goal of sharing clinical and research findings to accelerate the discovery of treatments, to halt disease progression and alleviate symptoms of Krabbe and related leukodystrophies. The 2011 Symposium was held at the beautiful Beaver Hollow Inn and Conference Center in Java, NY.

The family portion of the Symposium accomplished two main objectives. First, families received current medical information pertinent to treatments from the doctors and researchers who attended the medical program. Second, we provided a nurturing environment for the 120+ family members to share in each other's experiences by giving them the opportunity to build a strong support system with other families whose situation is similar to their own. This is an invaluable opportunity unique to this program. Additionally, all arrangements are made at the conference center for each family's individual needs. These special accommodations are imperative for children with such extreme medical needs and their families to travel to and attend the conference.



Scientific and Clinical Research Agenda

- Determination of psychosine in dried blood spots of Krabbe diseased patients (Joseph Orsini)
- A facile method for the analysis of psychosine in pathological tissue samples (Yu-The Li)
- Psychosine induced abnormalities in peroxisome and myelination and related therapeutics (Avtar Singh)
- The psychosine conundrum (Ernesto Bongarzone)
- Psychosine Toxicity: New targets, new mechanisms, new concerns (Mark Noble)
- Psychosine Toxicity: Membrane Perturbation or Protein Interactions? (Mark Sands)
- Combination therapy in twitcher (Mark Sands)
- CNS-directed gene/neural stem cell approaches for leukodystrophies (Angela Gritti)
- Gene therapy for leukodystrophies: Can it be delivered to the human brain? (Patricia Musolino)
- Gene and cell therapies using the mouse model of Krabbe disease (Mohammed Rafi)
- Mesenchymal lineage stem cells have pronounced anti-inflammatory effects in the twitcher mouse model of KD (Bruce Bunnell)
- Roles of macrophages in myelin repair: Studies of twitcher mice (Yoichi Kondo)
- The Hopkins experience with intrauterine transplants (Barbara Bambach)
- The Lysosomal Disease Network: Pilot study on neurodegenerative disease (Chester Whitley/ Jeanine Utz)
- Gestational factors that may influence the severity of Krabbe disease progression and onset (Margot Mayer-Proschel)
- Later onset Krabbe disease: results of the world wide Krabbe registry (Patti Duffner /Ahmed Abdelhalim)
- Later onset Krabbe disease in Catania, Sicily (Agata Fiumare)
- Familial heterogeneity in late onset GLD (Edwin Kolodny)
- Results of HCT in later onset KD: the Minnesota experience (Elsa Shapiro)

Hunter's Homes



"Thank you so much
Hunter's Hope!"

This apartment has
made a hard time so
much easier. This is
truly a home away
from home."

- Miles Family

Since 2005 Hunter's Hope has been providing special fully furnished apartments for our families receiving cord blood transplant treatment at Duke Medical Center. These four apartments are called Hunter's Homes. They have been continually occupied over the years, giving our families a "home away from home" as long as needed at no cost to them.

The Homes are located just minutes from the Medical Center for convenience. Each Home is fully furnished thanks to our strategic partner, Aaron's, who provides each apartment with all necessary furnishings, including a desktop computer. With the help of Bed, Bath & Beyond, Walmart, Liam Hammonds Memorial Foundation, and private family donations, the apartments are completely equipped with other household necessities such as kitchen appliances, dishes, bedding, towels, and more.

The apartment complex has many amenities including a swimming pool and playground.

Equipment & Supply Exchange

Hunter's Hope Equipment and Supply Exchange program has been designed to help fulfill the equipment or supply needs of Krabbe and leukodystrophy children as well as help families place equipment and supplies that they are no longer using.

Over \$25,210 worth of equipment was exchanged in 2011 serving 14 families.



"I can hardly type through the flood of joyful tears seeing Anaya Cassin sitting in my Jacque's wheelchair. I am so thankful that this sweet girl could benefit from Jacque's equipment! I pray this piece of equipment helps to bring them many beautiful memories just as it brought to us.

It's a huge blessing for us to know that Jacque is continuing to serve other's even though she's been gone now for 4 years. Thank you Hunter's Hope for this resource of giving and blessings."

- Kathleen Scott
Jacquelyn's Mom

"Eden and I are so thankful for the bath chair! It's so nice to be able to bathe her in the tub again, and she loves taking a bath! Lots of smiles and giggles at bath time, instead of tears! Thank you!!"

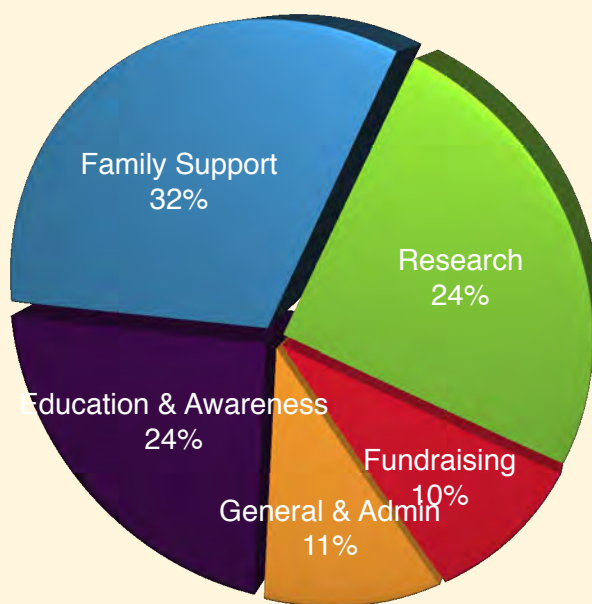
-Beth Brooks
Eden's Mom





Financial Position

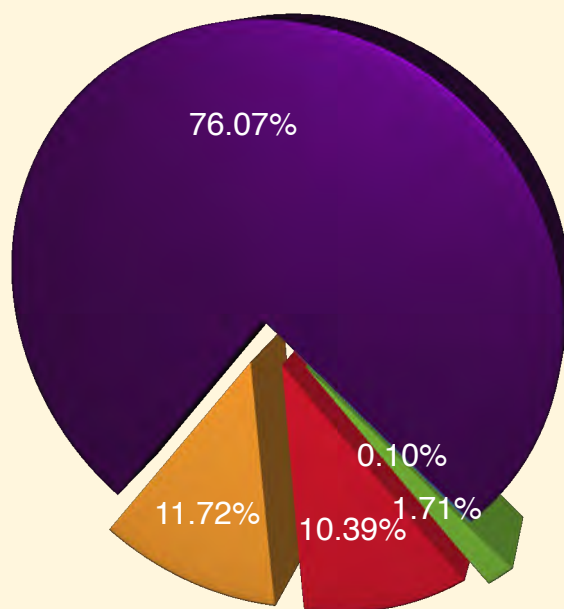
2011 Program & Support Expenses



- Education & Awareness
- Family Support
- Research
- Fundraising
- General & Admin

Education/Awareness	\$232,015
Family Assistance	\$308,182
Research	\$229,701
Fundraising	\$ 91,991
General & Admin	\$106,031
<i>Total</i>	<i>\$981,261</i>

2011 Revenue & Other Support



- General Donations
- Investment Income
- Federal Grants
- Fundraising
- Other

General Donations	\$687,979
Investment Income	\$ -938
Federal Grants	\$ 15,499
Fundraising	\$ 93,948
Other	\$ 0
<i>Total</i>	<i>\$796,488</i>

Net Assets, beginning of 2011 - \$831,942

Net Assets, end of 2011 - \$872,419

Board of Directors & Officers

Jim Kelly - President & Co-Founder, Hunter's Hope Foundation

Jill Kelly - Chairwoman & Co-Founder, Hunter's Hope Foundation

Roger Palczewski - Secretary/Treasurer, C.O.O., Rosina Food Products, Inc.

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

Charles DeAngelo - Board Member, Partner of Fessenden, Laumer & DeAngelo

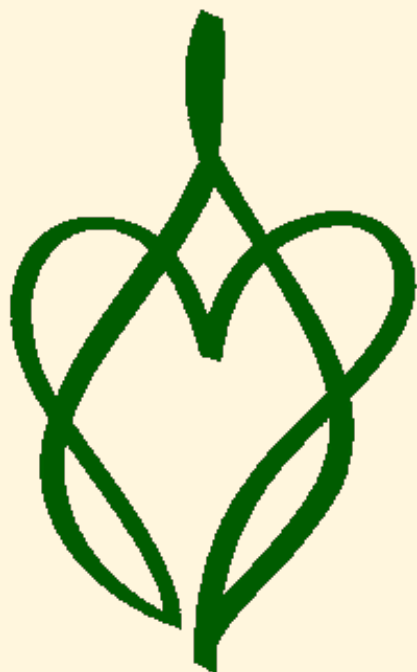
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