

# Hunter's Hope Foundation

FOREWORD BY  
FAITH HILL AND TIM MCGRAW

## *Without a Word*

*How a Boy's Unspoken Love  
Changed Everything*



"Jill and I have never shared Hunter's story like this, until now."

JIM KELLY, Hall of Fame Quarterback, Buffalo Bills

JILL KELLY



2010 Annual Report

Dear Family and Friends,

The Kelly Family has been on a very unique journey this year. With the September national book release of our memoir, **Without a Word – How a Boy's Unspoken Love Changed Everything**, our entire family has been on a whirlwind tour of sharing our story across the country. The overwhelming response we have received thus far has exceeded our wildest expectations.

Hunter's legacy lives on, beyond our hopes and dreams and by the grace of God, far beyond our vapor of life here on earth. Sharing Hunter and the incredible ways in which God used his brief yet full life through **Without a Word** has been an immeasurable blessing to our family as well as the Hunter's Hope Foundation.

Children like Hunter need our help. They're the reason we press on and do what we do at Hunter's Hope. And, while most of them will slip in and out of our lives without ever speaking a single word, their lives are filled with a contagious love that speaks clearer and penetrates the soul deeper than words ever could.

We are so thankful for all the support this year from so many wonderful generous people. It's a team effort. It takes people coming together with a common purpose and hope: to save children and bring hope to every child, every time, everywhere. We are so grateful for you.

May the Lord bless and keep you and your family.

With Hope,

A handwritten signature in black ink. It reads "Jill + Jim Kelly". The "Jill" is written in a cursive script. A small plus sign is between "Jill" and "Jim". "Jim" is also in cursive. "Kelly" is written in a more stylized, blocky cursive. The signature is enclosed in a simple rectangular box.



# 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*

# Without A Word

*New York Times Best Seller*

## National Media Highlights

Jim and Jill are blessed to speak and share their story throughout the country. They continue to give hope to others through their family story and *How a Boy's Unspoken Love Changed Everything*, **Without a Word**.

Jim and Jill Kelly kicked off the **Without a Word** National Media Tour with NBC Today Show September 8, 2010 in New York City.



Jim and Jill Kelly continued to share their journey on Fox News on the Sean Hannity Show.

- NBC Today Show • Family Talk with Dr. James Dobson • Hannity •
- Fox & Friends • The Rick & Bubba Show • Pittsburgh Today Live • Fox News Radio •
- International Christian Retail Show • 700 Club • Life Today with James Robison •
- Celebration • The Mike Gallagher Show • Dr. Carol Bernstein •
- KDKA AM Morning News Pittsburgh • Point of View • BlogTalkRadio •
- In the Market with Janet Parshall • The Allen Colmes Show •
- KCBI Radio Texas • DayStar Sports • CBA Retailers + Resources •
- IRN / USA Radio News • Pentecostal Evangel • The Praying Life Podcast •
- Positive Impact Magazine • Significant Living •

# *Without A Word*

*New York Times Best Seller*

## *Speaking & Book Signings*

*Bringing Hunter's Hope to Communities Locally and Around the Nation*

Barnes & Noble, Amherst, NY  
Barnes & Noble, McKinley, Blasdell, NY  
Borders, Rochester, NY  
Bender's Parable Christian, Clarence, NY  
Wegmans, Buffalo, NY  
Alpha & Omega, Rochester, NY  
Joseph - Beth, PA  
Rochester Women's Expo, Rochester, NY  
Summit Educational Resources, NY  
Life Resources Christian Bookstore, Amherst, NY  
Walmart, Batavia, NY  
University at Buffalo, Buffalo, NY  
Whitesville Public Library, Whitesville, PA  
Kingdom Bound, Darien, NY  
Thrive Women's Ministry, Buffalo, NY  
The Chapel at Crosspoint, Gettysville, NY  
Harvest Fellowship Church, Albuquerque, NM  
Bethesda Full Gospel Church, Tonawanda, NY  
Eastern Hills Wesleyan Church, Williamsville, NY  
Wesleyan Church of Hamburg, Hamburg, NY  
Christ Community Church, Brockport, NY  
Southtowns Family YMCA Book Club, Orchard Park, NY  
Christ Community Church, St. Charles, IL  
Fellowship Christian Athletes, Chattanooga, TN  
Alden Community Church, Alden, NY  
MOPS - The Chapel at Crosspoint, Gettysville, NY  
ByGrace Ministries Revive Women's Conference, Lima, NY  
Penn York Camp Spring Banquet, Ulysses, PA  
First Priority of South Mississippi  
CareNet of Scranton, Scranton, PA  
Saddleback Church, Lakeforest, CA  
Lockport Alliance Church, Lockport, NY  
Oakland Church of God, Distant, PA



# Expanded & Universal Newborn Screening

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



Universal 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.

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

### ***Federal***

Hunter's Hope continues to support the Secretary Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) by sitting on the Education and Training Subcommittee. The SACHDNC was formed to advise the 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 sit on the Standing Committee of the American College of Medical Genetics (ACMG) National Newborn Screening Translational Research Network (NNSTRN), a project sponsored by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). The purpose of the NNSTRN 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.

Hunter's Hope also continues as a member of the Genetic Alliance Consumer Task Force on NBS (CTF-NBS). The CTF-NBS works to ensure the integration of consumer perspectives in the planning and implementation of the Genetic Alliance Consumer Focused Newborn Screening projects.

### ***State***

Hunter's Hope supported a New Mexico family in their efforts toward the passing of House Bill 201 into law, which will amend the NM Public Health Act requiring the Department of Health to add five Lysosomal Storage Diseases to the newborn screening panel. The new disorders are: Krabbe, Pompe, Gauchers, Niemann-Pick, and Fabry.

Hunter's Hope launched a national newborn screening education and awareness fundraising campaign, called ***EveryStep***, The Walk for Universal Newborn Screening, *Every child. Every time. Everywhere.*<sup>TM</sup> One of the major goals of ***EveryStep*** is to eventually have an ***EveryStep*** Walk in every state in the country. The Foundation is well on its way to achieving this goal with Walks in NY, NM, CO, AL, RI, FL, NC, MA and CA in just one year.

Hunter's Hope conducted its own research through videotaped interviews with afflicted families at the Hunter's Hope Annual Family and Medical Symposium. The data was collected so that we can further our understanding of the onset of the signs & symptoms of the various forms of Krabbe disease and improve early identification through newborn screening.



# 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 for Excellence in Bioinformatics and Life Sciences at the University at Buffalo.

All Hunter's Hope research is coordinated through the HJKRI. This includes research dedicated toward studying remyelination techniques and studying the biology and pathophysiology of Krabbe disease, leading to the development of effective treatment strategies. This approach will allow both correction of the genetic defect as well as repair of the already damaged brain, providing a total solution for children with Krabbe disease. In addition, research on remyelination techniques will not only help children with Krabbe and other leukodystrophies, but also patients with Multiple Sclerosis, stroke, and other diseases in which there is white matter destruction of the brain.



## HJKRI Leadership

Dr. Larry Wrabetz,  
Dr. Laura Feltri,  
Jill and Jim Kelly,  
Dr. Patricia Duffner,  
Dr. Michael Cain,  
University at Buffalo  
Dean of Medical School

On August 13, 2010, Dr. Lawrence Wrabetz, a neuroscientist from Milan, Italy, was named the inaugural director of the Institute, while his wife, Dr. Laura Feltri, a noted cell biologist and neurologist, joins the team to establish the Institute's first basic science laboratory.

Drs. Wrabetz and Feltri join Dr. Patricia Duffner, the HJKRI Clinical Director, in leading efforts to find a cure for Krabbe disease and other leukodystrophies.





# Hunter James Kelly Research Institute

## *Clinical Research Projects Published*

### **Krabbe World Wide Registry**

The Krabbe World Wide Registry (WWR) is an international registry of patients with Krabbe Disease. Under the leadership of Dr. Patricia Duffner, the WWR has grown to include extensive parent provided information and medical records of more than 140 Krabbe patients.

The WWR is essential for newborn screening (NBS). The NBS test alone does not provide sufficient information to predict which positive screens are the rapidly progressive Early Onset Infantile form of the disease which require emergency consideration for cord blood transplantation. Therefore, it is important to understand early signs of the disease, enzyme activity, genetic mutations and outcomes of diagnostic studies, such as MRI, spinal tap, nerve conduction velocities, etc. Researchers revere the Hunter's Hope Krabbe WWR as the most comprehensive and useful collection of natural history data of any rare disease.

Two research studies stemming from the WWR are the ***Early Infantile Krabbe Disease (EIKD): Results from the Krabbe World Wide Registry*** and ***The Effect of Galactocerebrosidase (GALC) Activity on Age of Symptom Onset in Krabbe Disease (KD)***. The EIKD study was developed to better understand the EIKD phenotype. Through analysis of the WWR data of 67 children, invaluable natural history data is now available for future therapeutic trials. *The Effect of GALC Activity on Age of Symptom Onset in KD* study used the WWR data to determine if GALC activity predicts phenotype and survival. While low GALC activity does not predict phenotype, it was determined that higher activity in the abnormal range was not identified in the early infantile variant, and therefore, it can be concluded that consideration of emergent cord blood transplant can likely be avoided in those with higher (albeit abnormal) GALC activity.

**Leukodystrophy Death Rates In The United States** - This study estimated mortality rates according to age ( $<5$  and  $\geq 5$  years) and disease type in patients with leukodystrophies (ICD-10 code E75.2). The National Center for Health Statistics Micro Mortality File was used to identify records listing leukodystrophy as the cause of death. This is the first study to report diagnosis and age specific death rates in patients with leukodystrophies in the U.S. Findings showed that Krabbe disease is the dominant cause of leukodystrophy deaths among children under 5 years of age and Metachromatic Leukodystrophy is the dominant cause of death in individuals 5 years of age or older.

More information about these and other HJKRI Clinical Research Projects can be found on the Hunter's Hope website.

# Family & Medical Symposium



## 2010 Symposium Families

The Hunter's Hope Annual Family and Medical Symposium was held at Beaver Hollow Conference Center in Java, New York, from July 19<sup>th</sup> through July 25<sup>th</sup>. More than 120 family members, including 16 children affected by Krabbe or another leukodystrophies, and 45 researchers attended the 2010 Symposium.

During the family program, there were seven medical and scientific focused educational seminars lead by experts in research, developmental and treatment fields. In addition, the symposium provided four breakout sessions focused on family dynamics to help facilitate support systems amongst those in attendance as they deal with the devastating effects of these diseases. We also provided childcare services for over 30 children, including those affected by Krabbe and other leukodystrophies.

Because of the financial strain many affected families face, we strive to make the symposium affordable for all who desire to attend. To accomplish this, Hunter's Hope continued to cover 75% of the cost of attendance (including lodging, meals and other accommodations) for all attending adults. We also covered 100% of the cost for affected children, siblings under the age of 16, as well as for adults unable to financially contribute to the cost of their stay. For families who would have otherwise been unable to afford the cost of travel, we awarded over \$8,000 in travel scholarships through the Hunter's Hope Helping Hand Grant program. Without the generous contribution of the Wal-Mart State of Giving Grant and the Buffalo Bills Youth Foundation Grant, this would not have been possible.



# Family & Medical Symposium



2010 Symposium Siblings



The family portion of the Symposium accomplished two main objectives. First, families received current medical information pertinent to treatments and a cure from the researchers and clinicians who attended the medical program. Second, a nurturing environment was provided for the 100+ 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. Many tears were shed, but the love and joy was immeasurable.

***Jim Kelly and Jeremy Thoms having fun at the Symposium***

Jeremy's older brother Alexander, died from Krabbe disease. Jeremy also has Krabbe disease, but Jeremy was diagnosed early enough to have a life saving cord blood transplant.

# Family & Medical Symposium



## Some of Our 2010 Symposium Researchers

Each year, the Symposium brings together families affected by leukodystrophies as well as leading researchers and clinicians with the goal of continuing educating and enhancement of current treatments to halt disease progression and alleviate symptoms of Krabbe and related leukodystrophies.

This year's medical portion of the symposium assembled 45 medical experts who specialize in rare metabolic diseases to discuss clinical outcomes, recent research and discoveries pertinent to treatment of Krabbe Disease and other leukodystrophies as well as advancements in newborn screening. Discussion topics focused on comparisons of newborn screening experiences in select state and university laboratories, and the clinical follow up of children identified through positive screens. The two-day roundtable discussions compared practices in an effort to standardize and improve diagnosis, follow up and treatment of children with Krabbe disease on a state and national level.

Their findings also reinforced the value of newborn screening, which is not only instrumental for successful treatment of Krabbe through Cord Blood Transplantation, but also advances research and understanding of this rare disease in hopes of finding a cure.





# Hunter's Homes



Since 2005, Hunter's Hope has been providing support to families when their sick child needs hospitalized care at Duke Hospital in Durham, North Carolina. A critical need for families when traveling to Durham from another city is being able to afford lodging accommodations for an undetermined length of time.

To lighten the financial burden, Hunter's Hope offers four completely furnished apartments called "Hunter's Homes," located in Durham approximately 4.7 miles from Duke Hospital. Our Hunter's Homes are available to our leukodystrophy families while their child receives treatment (cord blood transplant or pre/post transplant check ups) at the hospital. Since acquiring the apartments, each unit has been occupied on a continual basis, with families staying from two weeks, up to one year. There is no charge for a family to stay. It is our goal to provide families with a "home away from home" atmosphere during a very difficult time.



The apartments range from 2-bedroom/ 2-bath accommodations to 2-bedroom/1-bath. Thanks to our strategic partner, Aaron Rents, each apartment is fully furnished with all necessary furniture including the luxury of a desktop computer. With the help of Bed, Bath & Beyond, Wal-Mart, Liam Hammonds Memorial Foundation and private family donations, the apartments are completely equipped with all other household necessities.

In 2010, as in prior years, all Hunter's Homes were fully occupied.





# Hunter's Wish Gift & Kaden's Kisses

A very special part of the Family Programs is our Hunter's Wish Gift. Gifts are granted to a family when there is an apparent need. In 2010 Hunter's Hope helped several families with various gifts. One of the major gifts was for Dalton's family where we help the family acquire a customized vehicle for Dalton. Dalton requires special transportation on a daily basis. He has Krabbe disease, but is surviving due to a bone marrow transplant from his twin sister, Dakota. Through the continuous giving of our supporters, Hunter's Hope is honored to have helped Dalton's family with a gift that appeared to be unattainable to them.

*"Thank you for your kind gift. The van has already been a blessing to our family. Words cannot express how it feels to have the van and to know that we have not had to make any financial changes.*

*Thank you! Thank you!!! We will always be grateful!"*

*- by Dianna, Dalton's very proud Mother.*



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 will help alleviate some of the financial burden faced by families who have lost a child.

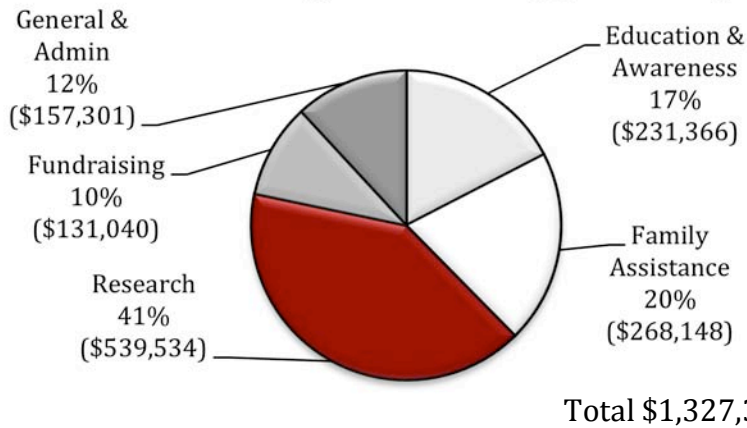
In 2010 Kaden's Kisses provided support to six families, totaling more than \$17,200.



# Financial Position



## 2010 Program & Support Expenses



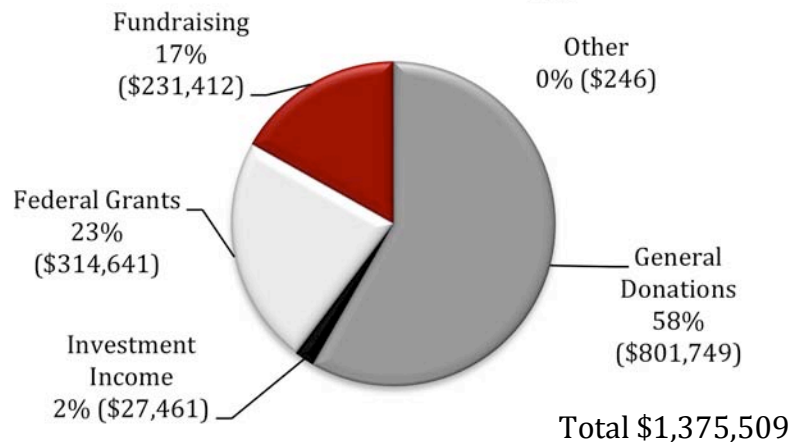
Hunter's Hope continues to rely on philanthropic support to advance our mission.

Once again, we have been blessed by the generosity of committed volunteers, donors and strategic partners.

The federal research grant contributed a large amount of funds with its closure in 2010.

Our Candlelight Balls continued to generate high income. But, given the limited capacity for the galas to expand, the Foundation began to apply more focus and resources on our Every Step Walk nationally.

## 2010 Revenue & Other Support



Our Walks are designed to offer exponential growth opportunities as well as increase our ability to educate people nationally. We hope the Walks will become one of our primary income sources in the future positioning us for significant growth.

Net Assets, beginning of 2010 - \$783,822

Net Assets, end of 2010 - \$1,068,724



# Board of Directors and Officers

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President Co-Founder, Hunter's Hope Foundation

Jill Kelly

Chairwoman Co-Founder, Hunter's Hope Foundation

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Secretary/Treasurer C.O.O., Rosina Food Products, Inc.

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Chief Executive Officer

# Hunter's Hope Foundation



Hunter's Hope Foundation  
P.O. Box 643  
Orchard Park, NY 14127  
(716) 667-1200  
[www.huntershope.org](http://www.huntershope.org)