

*Hunter's Hope Foundation*

*2008 Annual Report*

**Universal Newborn Screening**  
*Every child. Every time. Everywhere.™*



**Krabbe Leukodystrophy**

*Research, Education, Families*



# “MORE”

Dear Friends,

As we go through life, most of us spend the majority of our time trying to keep up with over-loaded schedules, daily demands and routine requirements. All too often we are so caught up with accomplishing our “to do lists” that we fail to take in the blessing of each day. The simplicity of life is so often lost in the shuffle of daily duty. What if we decided to stop... stop for a time to ponder over the blessings right in front of us...the blessings we all too often take for granted.

Our family and the Hunter’s Hope Foundation, in the midst of so many amazing activities and endeavors desire to contemplate and wonder about the unmistakable gift of each new day. Who would have thought ten years ago that today a viable life-giving treatment (cord blood transplantation) would be available for children born with Krabbe Leukodystrophy? Who would have imagined ten years ago that today the Hunter James Kelly Research Institute in partnership with the University at Buffalo would seek to provide premier research into myelin repair? Who would have expected over ten years ago, at the Foundations inception, that today doors would be opened through a Universal Newborn Screening Campaign to provide health and hope to all babies born in the Untied Stated of America? And, who would have possibly imagined that today, a family’s deepest pain and heartbreak would fuel hope and bring joy to the lives of countless children and families today and for generation to come?

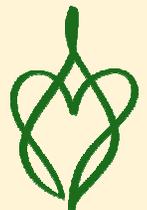
*“...He is able to do immeasurably more than all we ask or imagine...”* (Ephesians 3:20)  
This verse paraphrased from a letter to the Ephesians truly encompasses what we have come to believe... today, God is doing more than we could have ever asked or imagined. We are so grateful to be a part of what we believe God is doing through our sphere of influence and beyond. We are amazed at all that has been accomplished and look forward to each new day of blessing.

Thank you to all our supporters for being an invaluable part of making the gift of today and the promise of tomorrow possible for all children and families. Your generosity is clearly a part of what God is doing to provide “immeasurably more than all we ask or imagine”.

May God bless you.

With Hope,

*Jim & Jill Kelly*



# MISSION

Hunter's Hope Foundation was established in 1997 by Jim Kelly and his wife Jill, after their infant son, Hunter (February 14, 1997 – August 5, 2005) 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. The Foundation's mission and focus is threefold: to fund research necessary to treat and cure Krabbe disease as well as other devastating leukodystrophies, increase newborn screening standards across the United States to obtain early detection and treatment for all treatable diseases, and ultimately Hunter's Hope exists to inspire all parents to thank God for their children.

## 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

*"For I know the plans I have for you," declares the Lord, "plans to prosper you and not to harm you, plans to give you hope and a future." (Jeremiah 29:11)*



# ADVOCACY

## Universal Newborn Screening

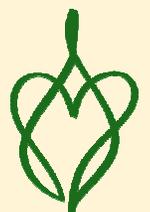
*Every child. Every time. Everywhere.*<sup>TM</sup>

In 2008, the Foundation launched a concerted effort to ensure every child in the United States has a chance for a fair start at life through Universal Newborn Screening (UNBS).

UNBS 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. All babies born in the U.S. receive newborn screening. Most babies appear healthy at birth, yet by screening every baby for every possible disease, serious mental or physical disabilities, even death can be prevented. To ensure no child suffers, the requirement needs to be universal in every state.

Currently, there is an inequity in each states newborn screening program and children are not being diagnosed for these many rare diseases, including Krabbe and other leukodystrophies. The American College of Medical Genetics recommends screening for (54) diseases, yet some states screen for less than (29). With the inequality in the number of diseases screened for state to state, thousands of children are suffering, become permanently disabled, or die needlessly.

Hunter's Hope Foundation has made progress heightening awareness of Universal Newborn Screening. And yet, so much additional work is needed.



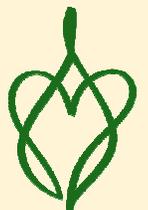
## Federal Government

In 2008, Hunter's Hope worked with several family advocacy groups in crafting legislation, educating legislatures and the general public on the importance of UNBS. In April, Jim Kelly met with legislatures in Washington, D.C. on Capital Hill and participated in a press event with Senators Hilary Rodham Clinton and Christopher Dodd, and Congressman Tom Reynolds in support of the passage of the Newborn Screening Saves Lives Act (S.1858). Because of a collaborative effort, Bill S.1858 was signed into public law by President George W. Bush in April, 2008.



In 2009, Hunter's Hope will continue its advocacy efforts for S.1858 to ensure Bill appropriations in the amount of \$44.5 million dollars be funded and legislation is executed. This important legislation will ensure continuing development and refinement of naming standards, lab improvements, screening tests, and state support.

**Universal Newborn Screening**  
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# Universal Newborn Screening

*Every child. Every time. Everywhere.*™



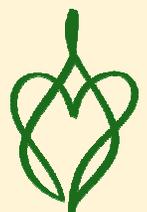
## **State Government**

Newborn Screening (NBS) programs are state-based. Therefore, it is necessary to reach every state, targeting specifically the states that are currently screening for the fewest number of possible diseases.

## ***Kansas***

In April 2008, Jim Kelly met with Kansas Governor Kathleen Sebelius, as well as the Kansas House of Representatives and Senate to encourage expansion of their newborn screening program from (4) diseases to (54). Followed by the passage of legislation, Kansas increased the number of diseases screened to (29) effective July 1, 2008, and plan for expansion to (54) diseases in the near future.

Additionally while in Kansas, Hunter's Hope sponsored a UNBS Education Breakfast that was attended by Kansas family advocates, legislatures, media, and business leaders. To further communicate and stress the importance of a full expansion to (54) diseases, Hunter's Hope developed educational radio Public Service Announcements (PSA), which aired in Kansas from June through September 2008.



## *Pennsylvania*

In June 2008, Jim Kelly met with Pennsylvania Governor Edward G. Rendell, as well as both the House of Representatives and the Senate. In Pennsylvania, newborn screening is offered at most hospitals, but it is not required by law. Therefore, it is not a guarantee and, potentially, screening could be eliminated or reduced. Currently, Pennsylvania screens their newborns for less than (10) diseases. However, as a result of Jim Kelly's meetings and advocacy efforts in June, newborn screening legislation was passed to increase newborn screening to (29) diseases effective July 1, 2009.

Additionally while in Pennsylvania, Hunter's Hope sponsored a UNBS Education Reception that was attended by Pennsylvania family advocates, legislatures, media, and business leaders. To further communicate and stress the importance of newborn screening, Hunter's Hope developed radio Public Service Announcements (PSA) to educate the general public. The PSA's will begin airing in Pennsylvania as funds and/or sponsors become available.

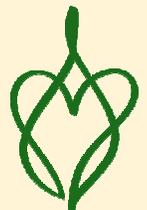


## **Universal Newborn Screening**

*Every child.*

*Every time.*

*Everywhere.<sup>TM</sup>*



## *New York*

### *Krabbe Leukodystrophy*

Hunter Kelly lost his battle to Krabbe Leukodystrophy on August 5, 2005. Since New York began screening for Krabbe disease in August, 2006, over (50) children in the state have screened positive for Krabbe. As a result, one of the first newborns screened with confirmed testing of Krabbe, was treated

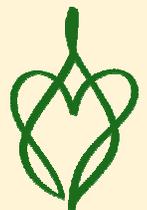


with a Cord Blood Transplant at Duke Medical Hospital, Durham, NC. He is now two years old and expected to live a healthy life. Additionally, as children who screen positive are identified as high risk, they are then followed closely by the New York Krabbe Newborn Screening Consortium.\* They are monitored and treated accordingly to their version of the disease to ensure optimal and timely care.

\*Dr. Patricia Duffner, Director of Clinical Research, Hunter James Kelly Research Institute/ Hunter's Hope, established and manages the New York Krabbe Newborn Screening Consortium. The Consortium consists of Directors (Geneticists) of the Inherited Metabolic Disease Centers of NY, Women and Children's Hospital of Buffalo, Strong Memorial Medical Center, Upstate University Medical Center, Albany Medical Center, Westchester Medical Center, Mt. Sinai Medical Center, Montefiore Medical Center, and Stony Brook Medical Center, designated Child Neurologists at each of the Centers, Transplanters, Neurodevelopmental Pediatricians, Neuroradiologists, Biochemical Geneticists and Newborn Screeners from the Wadsworth Laboratory in Albany, NY.

The purpose of the Consortium is to establish and continually improve the NY State Krabbe Newborn Screening follow-up program. The program includes: criteria for referrals, evaluation protocol, transplantation criteria, group-wide studies, database/registry and developmental/functional outcomes study.

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## Universal Newborn Screening

*Every child.*

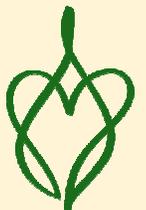
*Every time.*

*Everywhere.* <sup>TM</sup>



Additionally, in 2008 Hunter's Hope spread awareness about the importance of Universal Newborn Screening to thousands of people through many programs and events. Hunter's Hope sponsored education receptions, managed exhibits, and/or attended medical and life science conferences. The following is a list of the major events/conferences where Hunter's Hope participated in 2008:

- American College of Medical Genetics (ACMG)
- Society for Inherited Metabolic Diseases (SIMD)
- American Academy of Pediatrics (AAP)
- American Society of Human Genetics (ASHG)
- Lysosomal Disease Network (LDN)
- Mother's of Preschoolers (MOPS)
- Babies R Us Education Programs
- Federal Advisory Committee on Newborn Screening

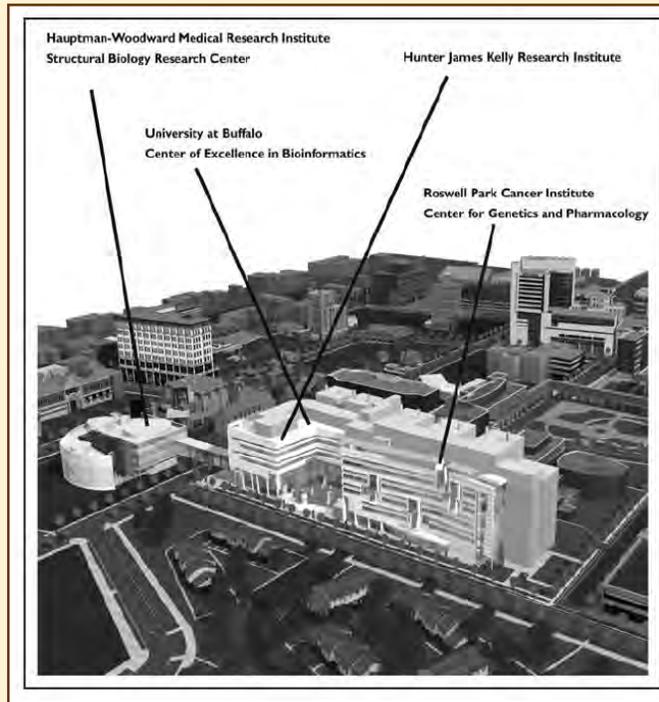


## HUNTER JAMES KELLY RESEARCH INSTITUTE

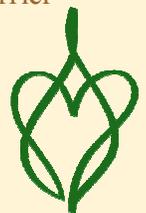
In 2008, Hunter's Hope Foundation entered into a partnership with the University at Buffalo regarding the establishment of the Hunter James Kelly Research Institute (HJKRI).

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. The NYS Center of Excellence is part of the Buffalo Life Science Complex.

The Buffalo Life Science Complex is a collaborative effort of Roswell Park Cancer Institute, the University at Buffalo, and the Hauptman-Woodward Medical Research Institute. The new complex builds on long-standing academic and research collaborations among the partners by physically linking the facilities and allowing for shared core research laboratories. While each of these structures will house distinctly different research functions, the work is synergistic and represents a continuum in the developments of new therapeutics and diagnostics for a wide range of diseases. Together the science and resources contained in the BLSC represent an enviable collection of intellectual and technical capacity that has the potential to propel Buffalo Niagara to the forefront of the country's burgeoning life science industry.



The Hunter James Kelly Research Institute is the only one of its kind in the world. The Institute's focus is on cures for Krabbe disease and other leukodystrophies, as well as myelin\* repair for other destruction disorders, such as multiple sclerosis and stroke. There are two arms of the Institute: basic research and clinical research. The basic research arm will research myelin diseases and myelin repair, with a focus on aspects that are likely to affect therapeutic strategies in the near future. Its research program will emphasize fundamental questions such as how neurons and glia die during neurodegenerative diseases and trauma, how such sequelae might be prevented, how affected cells might be replenished, as well as studies of the blood brain barrier and the inflammatory processes that exacerbate many myelin-related diseases.

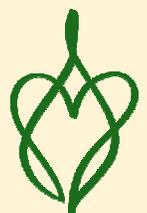




The clinical arm of the Institute will develop and implement a consistent statewide approach to the initial neurodiagnostic and long-term evaluation of infants with Krabbe disease and other leukodystrophies identified by New York State's program of Universal Newborn Screening. Results of these evaluations will be transmitted to the Center's registry of data management and analysis. It is anticipated that this approach will become the national model for Universal Newborn Screening for neurologic diseases. Another goal of the Center is to bring scientific breakthroughs from the laboratory to the clinical arena by organizing and conducting clinical treatment trials for children with Krabbe disease and other myelin disorders. Finally, we anticipate the Center will become a valuable national resource for clinical researchers studying Krabbe disease as well as for physicians and families.



*\*Myelin is the white matter of the brain and nervous system*

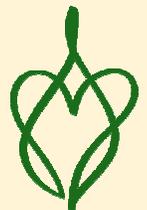


# FAMILY & MEDICAL SYMPOSIUM



In 2008 the Hunter's Hope Annual Family and Medical Symposium was held in Ellicottville, NY at the beautiful Holiday Valley Resort and Conference Center. Forty families along with several prominent doctors, scientists and researchers attended the conference hosted by the Hunter's Hope Foundation.

The Hunter's Hope Family and Medical Symposium provides an opportunity to bring together scientists, doctors, families, Strategic Partners, staff, volunteers, Board of Directors and Scientific Advisory Board for four days filled with sharing information, learning and supporting one another. Funded by the Foundation with assistance from family donations, the Symposium is an opportunity to gain in-depth information about leukodystrophies, to learn about the latest developments in scientific research and medical care, to identify available resources and supports, and to develop personal and family support systems.



# HUNTER'S HOMES

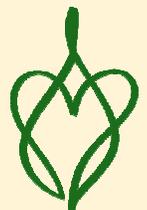


Hunter's Hope has three apartment homes located in Durham, North Carolina just 5 miles away from Duke University Hospital. Hunter's Homes are available to any of our leukodystrophy families that come to Duke Hospital for pre-transplant testing, transplant treatment or post-transplant follow-up at no charge to the families. The apartments come fully furnished with all the living room and bedroom furniture graciously donated from

Aaron Rents. All kitchen, bathroom and other furnished items have been donated by individuals. Included are the electric, water, trash, sewer, cable and internet services. The homes are available on a first come first serve basis and there is no minimum or maximum length of stay. In 2008 the apartments were fully occupied serving 18 families.

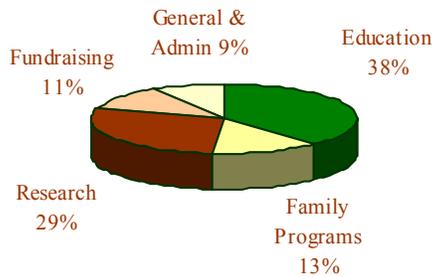


*"We are so incredibly blessed to keep being able to stay at the apartments and it sure makes being away from home more tolerable. This is absolutely incredible and no words will ever be good enough to describe our sincere gratitude to Hunter's Hope, and all the support we have received." ~Zoe Moore's Family*



# FINANCIAL POSITION

## 2008 Programs & Support Expenses



Total Expenses - \$1,556,320

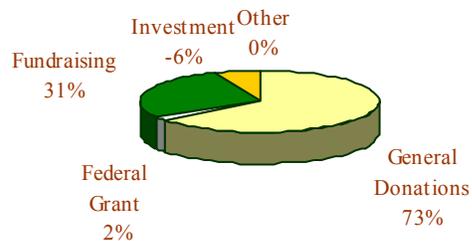
As a small non-profit organization, Hunter's Hope Foundation relies on philanthropic support to advance our mission. We continue to be blessed by the generosity of committed volunteers, donors, and strategic partners, which was once again proven in 2008.

Hunter's Hope remains solid, and with success from our special events including the annual Candlelight Balls, Radiothon, and Every Step Walk, we are hopeful in what the future holds to ensure the life of every child, every time, everywhere is saved!

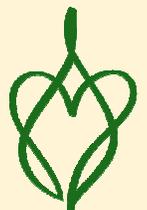
Net Assets, beginning of 2008 - \$1,295,055

Net Assets, end of 2008 - \$656,289

## 2008 Revenues & Other Support



Total Income - \$917,554



# 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, Fessenden, Laumer & DeAngelo

**David Janca**

Board Member

Founder, Value Centric

**Frank Kopfer**

Board Member

Retired C.F.O., Gaymar Industries

**Jack Martin**

Board Member

President/Founder, J. Fitzgerald Group, Inc.

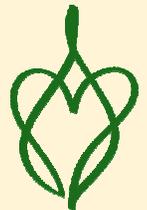
**David G. Young**

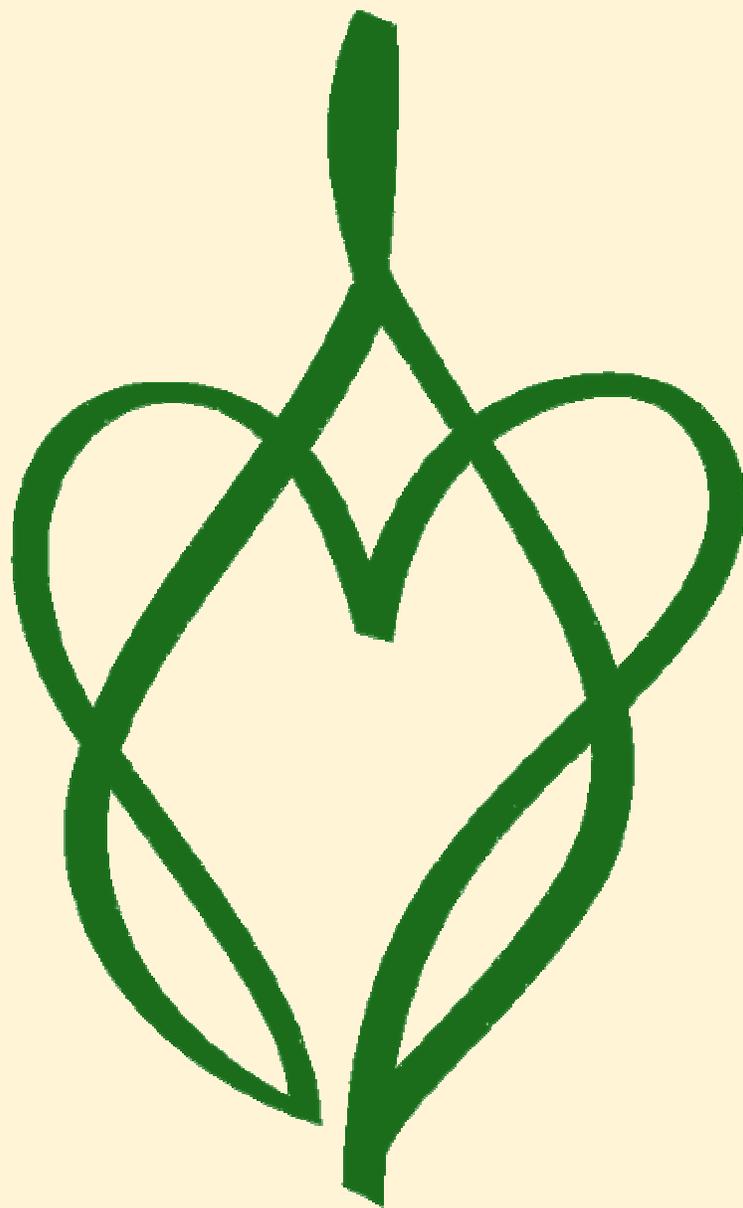
Board Member

Founder, GENESIS PPG

**Jacque L. Waggoner**

Chief Executive Officer





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