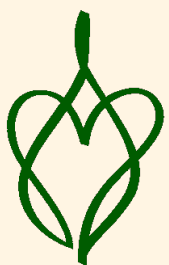


Hunter's Hope Foundation



Krabbe, Leukodystrophy,
Universal Newborn Screening

2009 Annual Report

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



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.



Universal Newborn Screening

Every Child. Every Time. Everywhere.TM

ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ
ΥΠΟΥΡΓΕΙΟ ΥΓΕΙΑΣ
ΓΕΝΙΚΗ ΔΙΕΥΘΥΝΣΗ ΥΠΗΡΕΣΙΩΝ
ΕΠΙΧΕΙΡΗΣΙΑΚΟ ΠΡΟΓΡΑΜΜΑ
ΥΓΕΙΑΣ ΚΑΙ ΑΣΦΑΛΕΙΑΣ ΤΗΣ
ΒΙΟΪΚΗΣ ΠΑΡΑΓΩΓΗΣ

Since the inception of the campaign in 2005, Hunter's Hope has worked with great determination to increase NBS standards nation-wide through their Universal NBS Campaign. In efforts to expand NBS programs, the Foundation has launched a legislative campaign, traveling state-to-state to urge congressional leaders to approve and fund expanded NBS legislation. Thus far, Hunter's Hope has participated in advancements in the number of diseases tested in New York, Kansas, Pennsylvania, Arizona, Missouri, and Illinois. Hunter's Hope seeks to continue the newborn screening campaign until all 50 states are screening for all possible diseases.

In 2009, under the provisions of the Newborn Screening Saves Lives Act, Congress established The Hunter Kelly Newborn Screening Research Program within the NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). The program is authorized to carry out, coordinate, and expand research in newborn screening. The goal is to increase the number of conditions that can be diagnosed at birth, to understand the long-term effects of living with these conditions, and to foster the development of new treatments.



National Institute of Health Newborn Screening Research Named in Memory of Hunter Kelly

ESTABLISHED IN MEMORY OF HUNTER KELLY

"It is fitting that the NICHD's research program in newborn screening bears Hunter Kelly's name," said Susan Shurin, M.D., Acting Director of the NICHD. "Through the foundation established in his memory, Hunter's family has increased awareness of the need for research to expand newborn screening, and worked tirelessly to ensure that routine newborn screening and treatment can be expanded to cover a far greater number of disorders than is possible today."

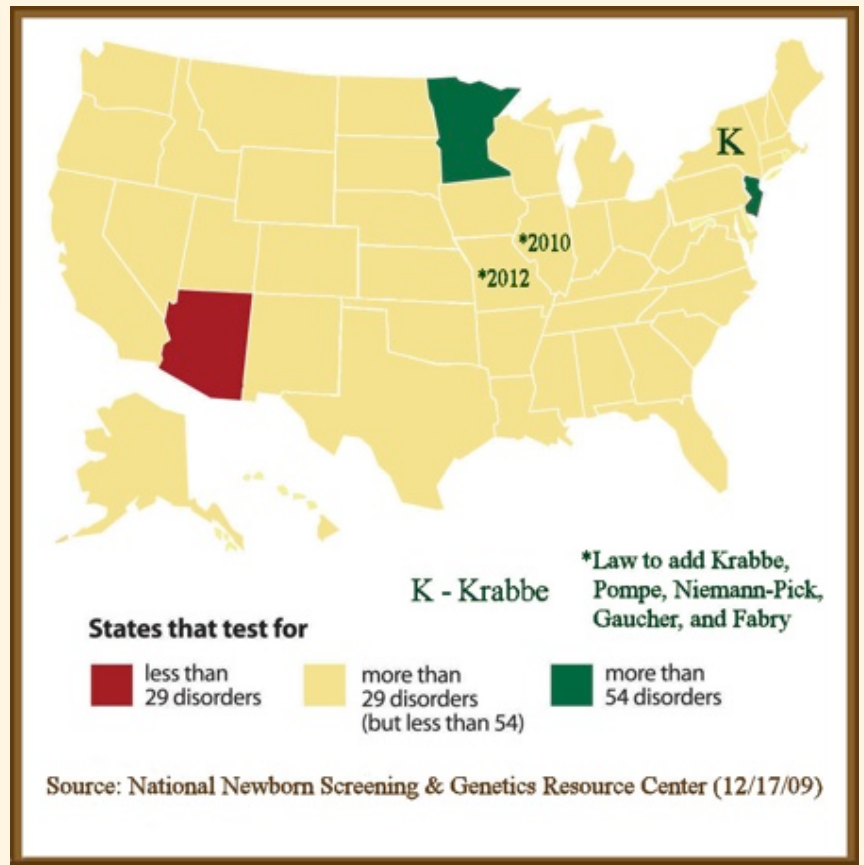
"The implementation of the Newborn Screening Saves Lives Act is an acknowledgement that newborn screening plays an important role in the prevention of disease and disability, and recognizes the need for continuing research to improve newborn screening methods," explained Duane F. Alexander, M.D., Senior Scientific Advisor on Global Maternal and Child Health, at NIH's Fogarty International Center. "Through their advocacy, the Kelly family has played a leading role in promoting this research, not just for the condition that affected their son, but for the full range of these often rare disorders," Dr. Alexander said.

Dr. R. Rodney Howell, M.D., Special Assistant to the Acting Director of the NICHD, and chair of the Advisory Committee on Heritable Disorders in Newborns and Children, Office of the Secretary of the U.S. Department of Health and Human Services added that research conducted under the authority of the Hunter Kelly Newborn Screening Program will include efforts to identify new screening technologies, as well as research on managing conditions that can be detected through screening. Under the program, the Newborn Screening Translational Research Network Coordinating Center will provide the infrastructure support needed to accomplish these goals.



Universal Newborn Screening

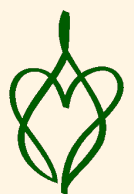
Hunter's Hope has continued its advocacy efforts for the NBS Saves Lives Act (S.1858) to ensure Bill appropriations in the amount of \$44.5 million dollars be funded and legislation is executed. This important legislation will ensure continuing development and refinement of naming standards, lab improvements,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



The Secretary Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) was formed to advise the Secretary 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 has the honor of sitting on the SACHDNC's Subcommittee on Education and Training.

In 2009, Hunter's Hope was invited to join 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 continued 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.



Missouri Adds Krabbe Disease



Bill HB716 was named after Brady Cunningham, a southeast Missouri boy who succumbed to Krabbe disease before his first birthday. His parents, Jessy and Dustin Cunningham, brought Brady to the Capitol shortly before he died to urge lawmakers to approve the bill. They believe Brady's visit encouraged the passage of the legislation. Brady's Bill mandates that by the year 2012, all newborns born in the state of Missouri will be tested for Krabbe, Pompe, Gaucher, Fabry and Neiman-

Pick diseases. Brady's legacy will live on through Bill HB716, Brady's Bill, and his story will help other children living in Missouri.



Texas Adds Greyson's Law

June 19, 2009 was a bittersweet day for Bill and Nicole Morris when Governor Rick Perry signed HB1795, Greyson's Law. The law is named for their son, Greyson, who died from Krabbe disease just days before his first birthday. The Morris family's 9 year old son, Seth, has PKU and is living a healthy life because his disease was detected at birth through newborn screening. Seth asked his mom and dad why his disease is more important than his brother Greyson's disease. The only answer they could provide him was that his disease wasn't more important than his brother, and that they were determined to fight hard to get Krabbe disease added to the Texas mandated newborn screening list. The law expands the number of diseases the Texas Newborn Screening program mandates from 29 to 52. This does not yet include Krabbe disease. Greyson's law also established the Texas Newborn Screening Advisory Committee of which Greyson's father proudly serves as a committee member. The Morris family hopes that Krabbe disease will soon be added to Texas newborn screening. Because of their efforts hundreds of lives will now be saved through a tiny heel prick at birth. The law went into effect September 1, 2009.



Arizona Reinstates Funding for Newborn Screening

Hunter's Hope met with Arizona legislatures and Governor Janice Brewer, educating them on the critical importance of Newborn Screening, and, successfully convinced them to reinstate funding for the state's newborn screening program.

Family & Medical Symposium



The Hunter's Hope Annual Family and Medical Symposium was held at Beaver Hollow Conference Center in Java, New York, from August 10th through 16th.

The Medical component was attended by more than fifty prominent researchers from around the world. They gathered to address the role of hematopoietic cell transplantation (HCT) in neurometabolic diseases. The experts were from the following fields: child neurology, genetics, oncology (transplanters), neuropsychology, neurodevelopmental pediatrics, neuroradiology and basic science. This year's meeting built on last year's meeting that addressed the outcomes of pre-symptomatic infants transplanted for Krabbe disease. A summary of which was published in the June 2009 issue of *Genetics in Medicine*. The first session addressed the question of whether the late deterioration seen in some children transplanted for Krabbe disease, is also occurring in children transplanted for other neurometabolic diseases, including metachromatic leukodystrophy, adrenoleukodystrophy, nieman pick disease, and MPS 1. The second session concentrated on the long term consequences of intensive chemotherapy in infants. We compared these consequences to infants transplanted for leukemia. The leukemia infants have normal nervous systems compared to children with Krabbe disease, in whom damage to oligodendroglia and myelin is already present at the time of transplant). Finally, the last session focused on the need for, and initial development of, a standardized protocol for the evaluation and follow-up of infants transplanted for early Infantile Krabbe disease. Standardized protocols for evaluation and follow up contained, inclusion/exclusion criteria, neurodiagnostic testing, developmental and neuropsychological testing, endocrine follow-up, pulmonary and cardiac function as well as the development of late malignancies.



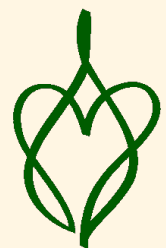


Room and board was provided by Hunter's Hope for all thirty-one families attending this year's symposium. The Foundation also covered travel expense for 10 families who otherwise would not have been able to come. Hunter's Hope has never turned a family away because of their inability to pay.

Several researchers and medical professionals stayed on to share with the families the latest developments in scientific research and medical care. Along with times of learning, the families enjoyed entertainment, games, sharing with other families, and relaxing.

The agenda included a variety of topics of interest to the families.

- ♦ Secretary Advisory Committee – Krabbe Evidence Review - Dr. Rodney Howell
- ♦ Cord Blood Transplant – Dr. Joanne Kurtzberg
- ♦ Translational Research Network – Dr. Michael Watson
- ♦ Lysosomal Disease Network – Dr. Chester Whitley
- ♦ Supplemental Newborn Screening – PerkinElmer – Bill Slimak
- ♦ World Wide Registry and Clinical Research – Dr. Patti Duffner
- ♦ Families Engaged – Panel of Leukodystrophy Families



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.



Hunter's Homes



Johnson Family - *"Thank you Hunter's Hope for caring enough for our family to provide us with a place to stay."*

To lighten the financial burden, Hunter's Hope offers three 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.



Zoey Moore

Moore Family - *"There will never be enough ways to thank Hunter's Hope for this apartment and for my daughter's life. Thanks to them, we truly have 'Hope and a Future.' Every time I see my child doing something new, I will remember how blessed we are to have Hunter's Hope to make our transplant journey possible. With every ounce of gratitude I possess, thank you for the gift of life."*

Hunter's Wish Gift

A very special part of the Family Programs is our Hunter's Wish Gift. This gift is granted to a family when there is an apparent need. In 2009, Hunter's Hope helped a family acquire an appropriate vehicle for their wonderful young son, Dalton, who requires transportation on a daily basis. With the Foundation's assistance, Dalton's family purchased a handicapped accessible conversion van. Through the continuous giving of our supporters, Hunter's Hope is honored to have helped Dalton's family with a gift that appeared 'unattainable.' We are trusting that we can help more families in the future.



"Thank You to all of you for your kind gift. The van has already been a blessing to our family. Words can not 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." - Dianna, Dalton's very proud Mother.





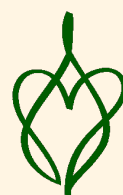
Kaden's
Kisses

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

Kaden left behind so many of his little footprints in people's lives. Some of these footprints were his contagious smile, laughter, hope, joy, comfort and mischief, but the most important footprint he left with us was his love.

Kaden was filled with an abundant amount of love. One of the ways he showed it was by giving many kisses and hugs, which he called "kiss/hugs," to his Mama, Dada, and little sister on a daily basis. Actually, he loved to give kisses and hugs to almost everyone! Every time someone receives a little "sign" from Kaden in heaven, we call it "kisses from Kaden" Kaden was such a loving little boy; we know he would want to share his "kisses" with other families who experience the tragic loss of a young child. We know too that when Kaden greets that child in heaven, he will welcome him or her with a lot of "kiss/hugs," take them by the hand and ask them to "come play with me."



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's and other leukodystrophies, but also patients with Multiple Sclerosis, stroke, and other diseases in which there is white matter destruction of the brain.

Center for Krabbe Disease



The Center for Krabbe Disease is part of the Clinical arm of the HJKRI. It was formalized in 2009 with the following mission:

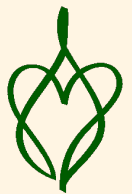
- Develop initiatives to maximize the success of the Newborn Screening program for Krabbe disease
- Increase understanding of the various types of Krabbe disease and determine which biochemical, genetic, and/or neurodiagnostic tests predict phenotype
- Educate physicians about Krabbe disease and the Newborn Screening program
- Develop clinical evaluation and treatment protocols for Krabbe disease

“Newborn Screening for Krabbe disease: The NYS Model was published by Dr. Patricia Duffner in Pediatric Neurology in April 2009. Dr. Duffner is the Clinical Director of the HJKRI/Center for Krabbe disease.

Darien Lake Theme Park Resort and the PARC Foundation Announce Recipient of Inaugural Jack Kemp Community Service Award



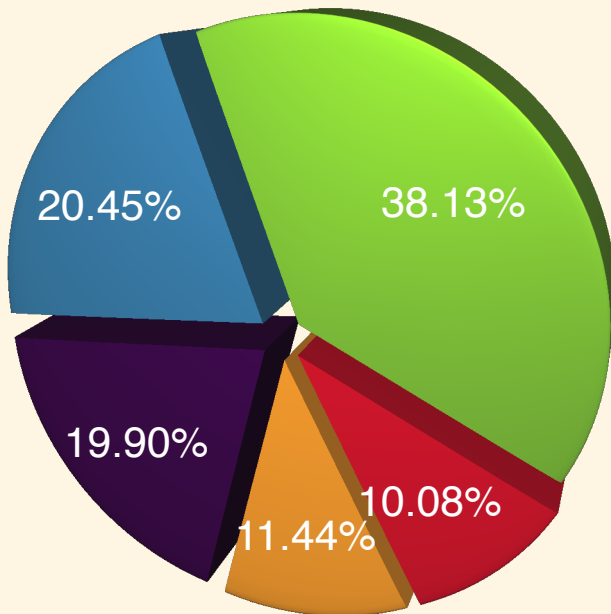
In August of 2009, at a presentation celebrating the life and work of Jack Kemp, PARC Management Chairman and CEO Randy Drew, spoke of the inspiration for the award as well as the selection of Hunter's Hope to receive this recognition. "Jack Kemp served both the Western New York community and our country as a role model, public servant and tireless advocate of those less fortunate, especially children and families," said Drew. "We are honored that the Kemp family has joined with the PARC Foundation to inaugurate an annual award that will both honor Mr. Kemp and inspire community service strengthening children and families through organization such as Hunter's Hope."



"Hunter's Hope is truly honored to be the recipient of the Inaugural Jack Kemp Community Service Award from the PARC Foundation," said Founders, Jim and Jill Kelly. "Jack Kemp was a man of great integrity with heartfelt compassion for his fellow man. He came alongside us when we founded Hunter's Hope, served on our Board of Directors and then continued as an Advisor until his passing," added the Kellys. "We feel incredibly blessed to receive this award that carries his name."

Financial Position

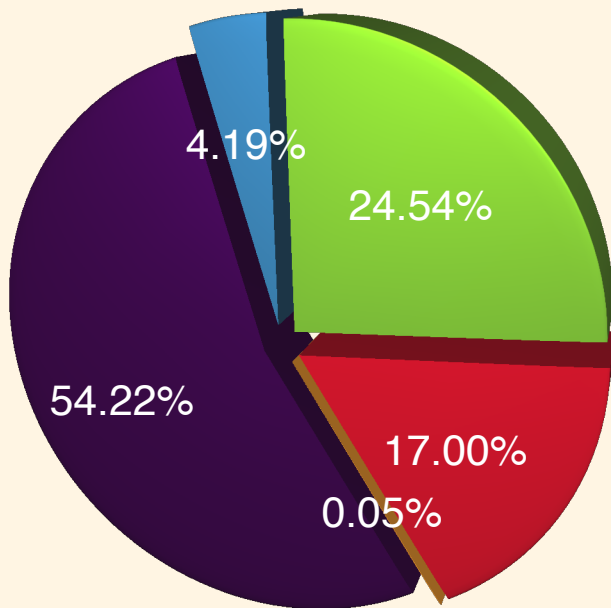
2009 Programs & Support Expenses



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.

- Education & Awareness (\$228,401)
- Family Assistance (\$234,661)
- Research (\$437,607)
- Fundraising (\$115,736)
- General & Admin (\$131,324)

2009 Revenue & Other Support



Hunter's Hope remains solid with continuing our successful Candlelight Balls, expanding our Radiothon locally, and expanding our Every Step Walk nationally. We are excited about our future and are more passionate with each new year in achieving our mission to help save the lives of children.

- General Donations (\$691,480)
- Investment Income (\$53,410)
- Federal Grants (\$312,936)
- Fundraising (\$216,847)
- Other (\$589)

Total Income - \$1,275,263

Total Expenses - \$1,147,729

Net Assets, beginning of 2009 - \$656,289

Net Assets, end of 2009 - \$783,822



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 C.O.O. Rosina Food Products, Inc.

Greg Connors

Board Member Esq. of Connors & Ferris, LLP

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Board Member Partner, Fessenden, Laumer & DeAngelo

David Janca

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Board Member Retired C.F.O., Gaymar Industries

Jack Martin

Board Member President/Founder, J. Fitzgerald Group, Inc.

David G. Young

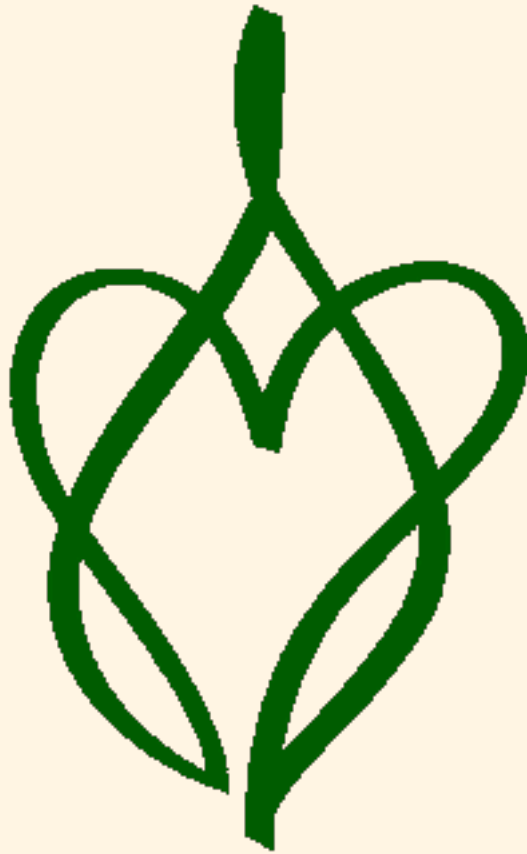
Board Member Founder, GENESIS PPG

Jacque L. Waggoner

Chief Executive Officer



Hunter's Hope Foundation



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