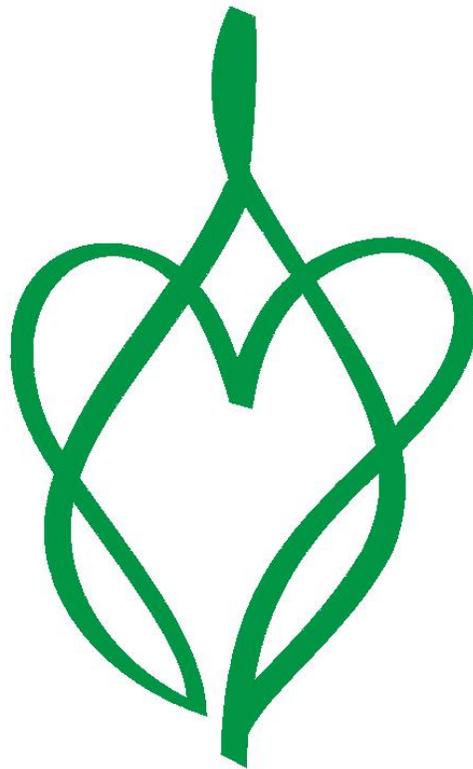


Hunter's Hope Foundation

2020 Annual Report



Leukodystrophy Care Network
Expanded Newborn Screening

Our 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 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 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 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.

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

...in respecting the right of privacy of all individuals

Education and Awareness

Hunter's Hope's commitment to increase awareness and understanding of Leukodystrophies and Newborn Screening provides important and potentially lifesaving information to the medical community and general population. This widespread knowledge will enable more timely diagnoses, as well as better treatments and therapies for children affected by Leukodystrophies and result in expanded newborn screening.

When news of Hunter Kelly's diagnosis broke, Jim and Jill Kelly received an outpouring of support from people all over the world, including families affected by Leukodystrophies. They knew they needed to make a difference for future children born with Leukodystrophies. As a result, Jim and Jill co-founded Hunter's Hope and dedicated themselves to helping the countless children and families affected by Leukodystrophy.

As public figures in the Western New York Community and beyond, the Kelly family uses their platform to share their story and the work of Hunter's Hope.

In 2020, Jim and Jill were able to share the work of Hunter's Hope through radio, social media, and television interviews. The pandemic led to the creation of a new virtual event, Tailgate with Jim Kelly & Friends. This new event allowed Jim & Jill to share Hunter's Hope mission with attendees from all over the world.

Community and Family Partners

Throughout 2020, Leukodystrophy families and friends of the Foundation raised awareness and funds for Hunter's Hope by hosting events and campaigns.

Wendy's of Buffalo raised funds for the twelfth year in a row, through its *Give a \$1, Get a \$1* campaign. The promotion, which ran from early January to Mid-February, was executed at Wendy's restaurants throughout the Western NY and Erie, PA area. As a result of the campaign, Wendy's of Buffalo presented Hunter's Hope with a check for \$43,239, making their 12-year total funds raised a little over \$721,000! In addition, members of the Wendy's of Buffalo staff donated their time and product to serve complimentary food and drink at the 2020 Hunter's Day of Hope & Prayer for Children event.

Believing for Bryleigh donated \$20,000 to Hunter's Hope in 2020 for a total of \$286,000 over the last 4 years. The Jackson Project donated \$20,000 to Hunter's Hope in 2020 for a total of \$79,000 over the last 3 years.

Ralph C. Wilson Jr. Foundation continues to support our Wish Gift program, with a donation of \$25,000 each year.

Expanded Newborn Screening

Newborn Screening (NBS) is a state-based public health system that is essential for preventing the devastating consequences of a number of medical conditions that would not otherwise be detected at birth.

All of the four million babies born in the U.S. year undergo NBS, yet the diseases screened for vary greatly by state. Since 2005, Hunter's Hope has partnered with Leukodystrophy families, lawmakers, and key decision-makers in an effort to expand every state's newborn screening panel to include every disease possible so that every child has a fair chance at a healthy start at life.

In addition to advocating for expanded newborn screening across the U.S., we also advocate for NBS advancements federally, and from the scientific and medical perspective to continually improve outcomes for children with Krabbe Disease.

Newborn Screening for Leukodystrophies

In 2020, Indiana officially launched their Krabbe newborn screening program and Pennsylvania passed a law to ensure the implementation of statewide Krabbe NBS later in 2021. Currently, eight states include Krabbe on their NBS panel - NY, MO, KY, OH, TN, IL, NJ, and IN. We continually partner with family advocates across the U.S. to help add Krabbe NBS in additional states.

Krabbe NBS Council

In order to ensure that babies who receive a positive screen for Krabbe Disease have the best possible outcomes, Hunter's Hope partnered with medical and scientific experts to launch the Krabbe NBS Council. This independent council meets monthly to discuss updates in best practices, advancements, and to determine the best course of treatment for patients. Clinicians, state lab staff and other stakeholders from states currently screening for (or in the process of implementing) Krabbe NBS participate in the Council. This builds on the foundation's role as a leader in the Krabbe NBS community established through our annual symposium and various working groups.

NBS Clinical Practice Guidelines

Our LOKD NBS CPG and KD NBS Case Study workgroups completed and submitted manuscripts for review and publication. An additional workgroup's manuscript was published, called *Family Attitudes Regarding Newborn Screening for Krabbe Disease* to inform the medical and scientific community of affected families' experience regarding Krabbe NBS.

Leukodystrophy Care Network

When Hunter Kelly (2/14/97 – 8/05/05) was diagnosed with Krabbe Disease, his parents were told there was nothing that could be done, he would not live past his second birthday, and to take him home and make him comfortable until he took his last breath. Hunter lived to be eight and a half years old. Since 1997, an overarching goal of the Foundation has been to fund research into the cause, prevention, treatment, and clinical care for children suffering from Leukodystrophies.

Hunter's Hope established the *Leukodystrophy Care Network (LCN)* in 2015 and continues to make significant strides toward its mission to revolutionize the health and quality of life for individuals affected by Leukodystrophies with proactive, innovative, and comprehensive medical care standards and specialized centers throughout the U.S., Canada and eventually the world.

Revolutionizing Medical Care

Although currently there is no cure for Leukodystrophies, they are all treatable. However, with an occurrence rate of 1 in 7,000, Leukodystrophies still remain virtually unknown, even in the medical community. As a result, families often receive numerous misdiagnoses, as well as insufficient therapies and treatment options once a correct diagnosis is reached.

A substantial inequality exists in the care of individuals affected by Leukodystrophies. Twenty-one years after Hunter's diagnosis, families are still told to take their child home and make them comfortable until they take their last breath. Through collaboration and multidisciplinary care, the LCN is transforming the approach and outcomes of medical care for Leukodystrophy patients.

Establishing Standards of Care

In 2020, six workgroups, comprised of LCN clinicians and family advocates, continued work on Leukodystrophy Clinical Practice Guidelines (CPGs) in the areas of Krabbe Newborn Screening, Treatment, Neurology, Diagnosis, Respiratory, and Musculoskeletal. These guidelines establish a peer-reviewed standard of care based on the latest research, medical evidence, and best practices, to ensure that individuals with Leukodystrophy have the best possible medical care, improving length and quality of life.

Ensuring Excellence Through Collaboration

Individuals affected by Leukodystrophy and their families are at the core of the LCN and remain a key component in every aspect of the Network. The LCN is led by a Steering Committee consisting of 15 Leukodystrophy family members, representing 8 different Leukodystrophies. In addition, the LCN works collaboratively with Leukodystrophy family advocates, medical providers, and organizations to ensure patient care remains the LCN's primary focus.

Family and Medical Symposium

Each year, Hunter's Hope gathers the world's leading medical and scientific Leukodystrophy experts together with families affected by these diseases for a week of learning, sharing and relationship building. Due to COVID, Hunter's Hope held a Global Virtual Leukodystrophy Symposium in July 2020. This was an exciting opportunity to welcome individuals from all over the world to participate virtually in the Symposium. This format allowed more medical experts and families to participate than ever before. Hunter's Hope received support for this event through a grant from Passage Bio.

Medical Symposium

More than 150 Leukodystrophy researchers and medical experts from throughout the world attended the 2020 Global Virtual Leukodystrophy Symposium. Newborn screening staffers and NBS follow-up physicians from ten different states provided updates on their state's protocols, outcomes, and upcoming plans. Up-to-date information was shared by Leukodystrophy NBS Workgroup members who have been diligently working on addressing gaps in Leukodystrophy newborn screening follow-up. Attendees also heard from Leukodystrophy disease experts, LCN Coordinating Center staff, LCN Steering Committee members, LCN Certified Center Directors, Care Coordinators, Clinical Practice Guideline Authors, and workgroup members, Family Advocates, and other active members of the LCN to learn more about the latest advances in Leukodystrophy treatments and care.

Family Symposium

Over 50 Leukodystrophy families from around the world attended the 2020 Global Virtual Leukodystrophy Symposium. Several weeks before the Symposium, families were sent a welcome package with t-shirts, bears, crafts, and other fun items. A virtual Family Welcome Dinner was held and families were able to introduce themselves via video. Medical and scientific updates were presented to the families from LCN medical providers, family advocates, and Hunter's Hope staff. Hunter's Hope presented their Family Programs through a detailed video presentation and families were shown how they can easily apply for available assistance and support. A virtual walk, talent show, and chat rooms provided fun for all families throughout the week.

Family Programs

Hunter's Hope was created, in part, to confront the overwhelming needs families face as they care for children affected by Leukodystrophies. Through its Family Programs, Hunter's Hope services hundreds of families affected by Leukodystrophies. Hunter's Hope strives to give every family affected by Leukodystrophy love and support during the most trying time of their lives.

In 2020, over 688 notecards and 55 care packages were sent to affected children and their families throughout the year – to celebrate a birthday, in remembrance of a child's heaven date,

to welcome a new family to Hunter's Hope, or just to let someone know we were praying for them as they walked through a particularly challenging time.

The names and photos of more than 500 children affected by Leukodystrophies are displayed on the Wall of Fame page of the Hunter's Hope website. The Wall of Fame gives families an opportunity to honor their loved ones. Their faces serve as a constant reminder of why Hunter's Hope exists – for the strong, courageous children and adults affected by these diseases.

Hunter's Hope Wish Gift

Leukodystrophy families face tremendous stress, emotional pain, and financial hardship as they care for a child with a debilitating and fatal disease. Affected children require around-the-clock medical care, which often requires one or both parents to give up their job for an extended period of time. Hunter's Hope assists Leukodystrophy families during unique or extreme circumstances so they may provide the best possible care to their child. In 2020, Hunter's Hope fulfilled seven family "wishes" totaling over \$116,000.

Equipment and Supply Exchange

Children affected by Leukodystrophy require tens of thousands of dollars in equipment and supplies just to live each day. Unfortunately, many insurance companies do not cover these necessary pieces of equipment and most families cannot afford to purchase them on their own.

Through the Equipment and Supply Exchange program, the Foundation facilitates donations from families who offer their no-longer-needed equipment to bless other families in need. Hunter's Hope pays for one family's equipment to be shipped to another and in 2020, provided approximately \$10,000 worth of equipment and supplies to affected children and their families.

Hunter's Day of Hope and Prayer for Children

Hunter's Hope and the Kelly family believe all children should be celebrated every day. Each year, the Foundation celebrates *Hunter's Day of Hope and Prayer for Children (HDHPC)* as a day to remember the *gift* that all children are and to pray for children all over the world.

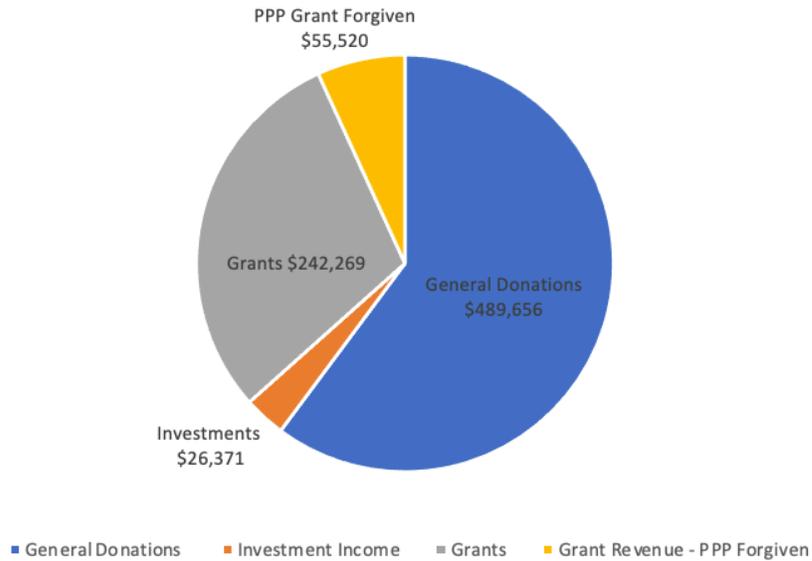
In Western New York, *HDHPC* is celebrated on the Saturday closest to February 14th, Hunter and Jim's birthday. In 2020, over 2,500 community members attended this free event and enjoyed an afternoon filled with kid-friendly entertainment and activities.

More than 25 organizations donated their time and services to host children activity booths, nine businesses donated food and drink for guests, and over 55 individuals volunteered their time to make the annual event a great success.

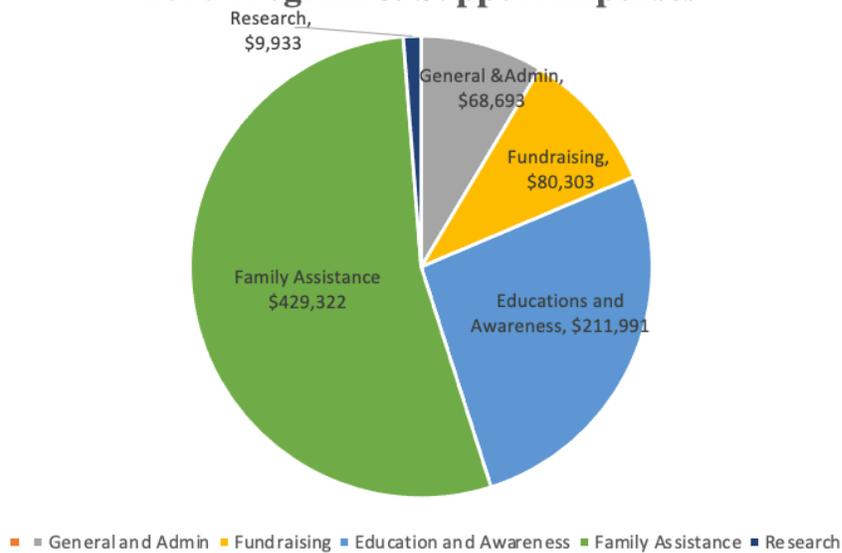
Most importantly, time was dedicated during the event for families to gather and pray for all children.

Financials

2020 Revenues and Other Support



2020 Program & Support Expenses



Total Income – \$813,816
 Total Expenses – \$800,242

Net Assets, beginning of 2020 - \$937,664
 Net Assets, end of 2020 - \$951,238

2020 Board of Directors and Officers

Jim Kelly
President
Co-Founder, Hunter's Hope

Jill Kelly
Chairwoman
Co-Founder, Hunter's Hope

Erin Kelly
Secretary
Hunter's Sister

Camryn Kelly
Board Member
Hunter's Sister

Paul Boser
Treasurer
Pyramid Brokerage Company
Cushman & Wakefield Alliance

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

Phil May
Board Member
VP & General Manager of Warner/
Chappell Music Publishing in Nashville

Brad Rye
Board Member
Senior Vice President, Mower

Steven Schmitt
Board Member
Marketing Manager,
Sherex Fastening Solutions

David Kern
Board Member
Founder,
Intrepid Automotive Enterprises, Inc.

Jacque Waggoner
Chief Executive Officer
Hunter's Hope Foundation