Hunters Hope Foundation, Inc.

GuideStar Nonprofit Profile Charting Impact Report * Last Updated on 03.18.2014

This report represents Hunters Hope Foundation, Inc.’s responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

Hunters Hope Foundation, Inc.
P.O. Box 643, Orchard Park, NY 14127
716-6671200 (ext. 202)
http://www.huntershope.org

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 four-fold: • To broaden public awareness of Krabbe Disease & other Leukodystrophies thus increasing the probability of early detection & treatment. • 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 and those afflicted with Leukodystrophies. Among the essential goa...
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1. What are we aiming to accomplish?

1. Hunter’s Hope is a “Household Name”
2. Annual National Day of Hope and Prayer for Children
3. Early detection implemented nationwide for Krabbe, Leukodystrophies and Lysosomol Storage Disorders
4. A Cure for Krabbe, Leukodystrophies and Lysosomol Storage Disorders
5. Clinical Care Centers of Excellence providing the best clinical care, family support and education for Krabbe, Leukodystrophies and Lysosomol Storage Disorders

2. What are our strategies for making this happen?

Co-Founders NFL Hall of Fame Quarterback Jim Kelly and his wife Jill, established Hunter’s Hope after their infant son, Hunter (2/14/97 - 8/5/05) was diagnosed with Krabbe Leukodystrophy. Krabbe is a rare, fatal genetic disorder that affects the central and peripheral nervous systems. Children affected by Krabbe suffer greatly and typically do not live beyond their second birthday. While Jim and Jill Kelly 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 plans to continue efforts to fulfill our mission through our Family Programs, by pursuing Expanded and Universal Newborn Screening throughout the U.S., and by supporting research for improved treatments and ultimately a cure for Krabbe and other Leukodystrophies. Since its inception, Hunter’s Hope has been dedicated to bringing hope to families affected by Krabbe and other Leukodystrophies as they cope with caring for and losing a child affected by these devastating diseases. This has primarily been accomplished through the Foundation’s Family Programs, which include the Hunter’s Hope Equipment and Supply Exchange, Hunter’s Homes, Hunter’s Wish Gift, and the Annual Hunter’s Hope Family and Medical Symposium. Additionally, Hunter’s Hope is actively pursuing improved Newborn Screening standards throughout the U.S. by advocating for states to include Krabbe and other similar disorders in their newborn screening panel. Currently, the treatment for Krabbe is only effective when administered before a child is symptomatic. Early detection through newborn screening for Krabbe is crucial. Hunter’s Hope is also involved in advocating for federal funding for newborn screening through the Newborn Screening Saves Lives Reauthorization Act. The bill is crucial to supporting states as they grow and expand their newborn screening programs, educating parents and healthcare providers about newborn screening, and funding research to identify new treatments for conditions detected through newborn screening. Finally, through the Hunter James Kelly Research Institute (HJKRI), the Foundation coordinates all funded research efforts to find improved treatments and ultimately a cure for Krabbe and other Leukodystrophies. The Institute is leading numerous research efforts aimed at improving the ability to detect and treat Krabbe early through newborn screening. A specific focus is on remyelination, which could potentially benefit those afflicted by stroke and patients suffering from Multiple Sclerosis in addition to those who suffer from Leukodystrophies. As the Foundation begins its 17th year, we remain as passionate as ever in fulfilling our mission as we serve the Leukodystrophy community and beyond.

3. What are our organization’s capabilities for doing this?

1. Provide information about Krabbe and other Leukodystrophies for families and the medical and science communities.
2. Provide support for families.
3. Fund research.

4. How will we know if we're making progress?

1. Increase in information available online for families and the medical and science communities.
2. Support for families including annual Symposium, Hunter's Wish Gifts, Helping Hand Grants, Families participating in World Wide Registry, etc.
3. Improved and expanded newborn screening for Krabbe Disease and similar disorders.
4. Increase in funding for research projects for Krabbe and similar disorders.
5. What have and haven't we accomplished so far?

Supporting over 30 scientists at the Hunter James Kelly Research Institute as they work to understand how myelin is formed, how it is damaged in disease, and how it may be repaired. Understanding myelin will not only help those suffering from Leukodystrophies, but also those affected by Multiple Sclerosis, stroke and other neurological disorders. Working with medical experts from across the country to analyze data from over 140 patients through the Krabbe World Wide Registry. A better understanding of the disease and its genetic mutations will help improve newborn screening standards as well as care for those diagnosed with Krabbe Disease. Hosting 39 Leukodystrophy families and over 60 scientific experts during the 16th Annual Family & Medical Symposium. Assisting families by exchanging over $42,445 worth of adaptive equipment and supplies, offering a home-away-from-home at the Hunter’s Home for children who need medical treatment at Duke Hospital, sending over 409 Care Packages to welcome new families, celebrate birthdays, remember children in heaven, help families grieve the loss of a child, and help more than 20 families with funeral costs after losing their child. Sending over 7,000 letters to Legislators in more than 10 states and to Congress, resulting in... - Support for newborn screening initiatives for Krabbe and other Lysosomal Storage Disorders (LSDs) in Tennessee, California, Oregon, North Carolina, Pennsylvania, New York, Maine, Michigan, Maryland, Arizona, and Texas. - Nationwide support for the re-authorization of the Newborn Screening Saves Lives Act; a bill that helps provide crucial funding to state newborn screening programs, federal programs aimed at expanding and improving newborn screening, and research to help create screens for additional diseases.