December 2011

Dear Friends,

As we approach the holiday season, it is time to reflect and be thankful for all that The Global Foundation for Peroxisomal Disorders has accomplished in its first year. Upon incorporation, we hit the ground running, making up for the years the community of families and professionals did not have a non-profit public charity designated to rare disorders called Peroxisome Biogenesis Disorders (PBDs).

Many of the families affected by these rare disorders had reasons to celebrate. Other families had reasons to grieve. The Global Foundation for Peroxisomal Disorders brought families together, supporting the successes and hurdles that come with a diagnosis of Peroxisome Biogenesis Disorder. Our community had this opportunity **because of you**, people that believed in and donated to our cause. We are forever grateful and appreciate the confidence in our organization to provide support to our families and the professionals that treat and study patients with the disorders.

As we approach this special time of year, I hope you will consider a donation to GFPD to help more children and families facing this devastating diagnosis.

One of our first contributions to our families and professionals was hosting a conference in Omaha, Nebraska July 31 – August 2, 2011. Mother of Graham Whitney, who died from the degenerative effects of PBD at age nine shared:

Graham Whitney

"The Global Foundation for Peroxisomal Disorders is a Foundation that I wish did not have to exist, but since our children are affected by PBD's, I am so thankful that is does. This horrible disorder struck down our child and left us feeling hopeless, weak, and alone. The GFPD brought us together and gave us hope and strength so that we can fight this monster together. The conference allowed us to be together in person and united us as family… and this is one family reunion that I never want to miss. I will continue to attend… year after year… God (and money) willing. Thank you, GFPD, for giving me the love, understanding, and sense of belonging that no one else ever could." ~ Tracy Whitney

The conference benefitted families of children young and old, living and deceased. Maria McCarrick, mother of Katherine, wrote:

"When we signed up to attend, we weren't sure what to expect since GFPD is in its infancy and this kind of meeting is such a huge undertaking—both for those planning it and for those of us attending with our children in tow (from all over the world). My family and I were impressed with the quality of the speakers and the venue as well as the many helpful volunteers that staffed the event. Spending this precious time with people who understand the unique challenges that our families face was the highlight for me. I was also pleased to be able to consult with the leading doctors and scientists working in the field, particularly Dr. Gerald Raymond, who was instrumental in diagnosing my child 13 years ago and continues to devote himself to helping these children and furthering the research on Peroxisome Biogenesis Disorders.

…Finally, I wanted to sincerely thank you and GFPD for providing Katherine with her new (to her) wheelchair. She is riding in style in her cool raspberry Convaid transport chair thanks to the foundation's equipment exchange program--just one of the many important services GFPD provides… " ~ Maria McCarrick

Katherine McCarrick

Jordan Danielson, a four year old boy from Florida, suffered a major regression in a short period of time due to PBD. The wheelchair fit for Jordan was no longer useful, so the family utilized GFPD's equipment exchange program. Jordan's mom, Sarah, wrote:

"The Global Foundation for Peroxisomal Disorders has opened up the small world in which families affected with this disorder reside. The GFPD has brought companionship, help, knowledge, and hope amongst families. The GFPD has helped our

family in numerous ways for which I am very thankful.

Jordan Danielson

In June of 2011, The GFPD covered all shipping expenses and donated an Otto Bock Kimba Push Chair to my four year old son, Jordan. This could not have come at a better time since I received the new pushchair only days before Jordan was scheduled to have G-tube surgery. This was an imperative chair for Jordan to have since he has regressed over the past two years and requires more support. Unfortunately, if it were not for this program, we would have not received a new chair because my son's insurance will only cover a new chair every five years or so. The Otto Bock is a very pricey chair that our family could not afford to purchase for him since it is valued at approximately $6,000.00. We are forever grateful for the gift they provided for us. Jordan now has a chair which supports his head and body while keeping him comfortable and meeting all of his needs." ~ Sarah Danielson

These are a few of the many notes The Global Foundation for Peroxisomal Disorders has received sharing the impact we have had on their child and family. We are hopeful to continue growing our organization, providing awareness of our children's disorder and hope for those impacted by this devastating diagnosis. With your support, we have been able to:

- Create a website, www.thegfpd.org.
- Set up an equipment exchange program for families to recycle equipment & fund shipping for items being exchanged.
- Receive recognition by The National Organization for Rare Disorders as a resource for families and professionals who study or are devastated by PBDs.
- Establish a registry with families from eighteen countries.
- Host the 2011 GFPD Family & Scientific Conference with 120+ attendees.
- Provide clinic at Children's Hospital & Medical Center in Omaha, Nebraska for families that attended the conference.
- Manage an online family support network through social media networks (Yahoo! and Facebook).
- Provide support and information to parents seeking help from local, state, and national resources to ensure their child's health and educational needs are met.

On behalf of all families impacted by Peroxisome Biogenesis Disorders, I sincerely thank you for this year of support. We are humbled by the kindness of others and appreciate your commitment to help us make the lives better for children and families devastated by these disorders.

With warmest holiday wishes,

Shannon Butalla, President
The Global Foundation for Peroxisomal Disorders
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Scott & Landen Sinex

Ezra Burdick & Kenna Maag

The Global Foundation for Peroxisomal Disorders (GFPD) is a non-profit public charity and considered tax exempt under section 501(c)3 of the Internal Revenue Code. GFPD helps children and families faced with a diagnosis of a Peroxisomal Biogenesis Disorder (*in the Zellweger Spectrum of Disorders*) and assists family members and professionals through educational programs, research, and support services.

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