

December 2012

Dear Friends,

Warm holiday wishes from The Global Foundation for Peroxisomal Disorders! We are excited to share the accomplishments of **THE** organization for individuals affected by Peroxisome Biogenesis Disorder – Zellweger Spectrum Disorder (PBD-ZSD). For two years, the GFPD has brought families together, supporting the successes and hurdles that come with a diagnosis of PBD-ZSD. Our community has 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 disorder.



The GFPD has many reasons to celebrate. Some of our notable accomplishments for 2012 include:

- Hosting a successful conference in Orlando, Florida for nearly 150 family members, friends, and medical professionals passionate about this spectrum of disorders, including twenty-eight individuals with PBD-ZSD. Physicians were available for individual consultations, and twenty-three children were seen in clinic. Families of children with PBD-ZSD, both living and deceased, were supported through group workshops and individual counseling with Marlyn Minkin, LMFT/LMHC, from Bellevue, Washington.
- Coordinating a medical symposium for physicians and scientists passionately working for ways to help children with PBD-ZSD. Part of the symposium included the development of a treatment algorithm, which is a step toward streamlined care for patients with PBD-ZSD.
- Assisting Dr. Nancy Braverman (McGill University, Montreal, Quebec, Canada) with her efforts to coordinate a Natural History Study (the first of its kind) to collect longitudinal data on PBD-ZSD.
- Working to develop a drug trial for patients with PBD-ZSD. A pharmacological agent tested in the lab has shown to improve peroxisome function in skin fibroblasts, which holds promise for those affected with a common PEX1 mutation.
- Supporting numerous community events that promote awareness and funding for the GFPD family & scientific community. Events included:
 - **Pound the Pavement for Peter**, a 5K race held in Atlanta, Georgia in memory of Peter Hopkins, son of Anne Park and Matt Hopkins, that had over 500 registered race participants, over 40 corporate sponsors, and 42 family sponsors.
 - **Art for Archer**, in Meridian, Mississippi, showcasing photography, crocheted items, jewelry, art contributions, and other handmade goods, honored Archer Maple, son of Ashley & Ryan Maple, and was a huge success.
 - **GFPD Dinner Dance in Memory of Adrian and Diego Alfaro**, in Turlock, California, planned by Carolina and José Alfaro in memory of their two sons who lost their lives from the degenerative effects of PBD-ZSD. Nearly 300 adults enjoyed dinner, dancing, and an auction that benefitted the GFPD while remembering and celebrating the lives of Adrian and Diego.



Angie & Jackson Jinright, Ashley & Archer Maple, Anne Park Hopkins, Melissa Gamble, Sam & Shannon Butalla at Pound the Pavement for Peter

- **Pancakes for PBD**, hosted by Pamela and Jeff Marshall in honor of their son, Ethan, brought support from their community in Decatur, Illinois, with a pancake breakfast. Table displays gave attendees information about the disorder and pictures of children affected by PBD-ZSD.
- **Painting for PBD**, hosted by Bethany and Jeremy Barno in Louisville, Kentucky, in memory of their son, Chase, brought friends together to make beautiful paintings while benefitting the GFPD.



Dr. Joe Hacia from USC and Dr. Nancy Braverman from McGill University

While hope is on the horizon, these are difficult times for scientists studying rare diseases. Two scientists, Dr. Nancy Braverman (McGill University – Montreal) and Dr. Joe Hacia (The University of Southern California – Los Angeles) actively participate in the GFPD and focus on identifying practical medical interventions that can improve the lives of patients with PBD-ZSD in the near term. Federal funding for PBD-ZSD research is scarce and thus they depend upon our support to continue their work to identify better treatments for PBD-ZSD.

If you have been touched by someone with PBD-ZSD, please consider contributing to the GFPD this holiday season. To earmark your donation specifically to Nancy Braverman or Joe Hacia's research projects, please make this designation on the enclosed card.

Best wishes for a wonderful holiday season & blessed New Year,

Shannon Butalla

Shannon Butalla, President
The Global Foundation for Peroxisomal Disorders



Archer Maple, son of Ashley & Ryan Maple



2012 GFPD Family Support Conference – Orlando, Florida

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. The GFPD helps children and families faced with a diagnosis of a Peroxisome Biogenesis Disorder – Zellweger Spectrum Disorder and assists family members and professionals through educational programs, research, and support services.

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