

November 2013

Dear Friends,

Holiday greetings from The Global Foundation for Peroxisomal Disorders! We have many reasons to celebrate this year, with advancements and discoveries that could help children with Peroxisome Biogenesis Disorder – Zellweger Spectrum Disorder (PBD-ZSD) in the near future. The GFPD marked its three-year anniversary in October, and we're ecstatic about the impact we've had on families and science in this short time. Our community of parents, children and professionals thank you for your emotional and financial support. We have greater hope for the future of our children because of your generosity, compassion, and commitment to the GFPD.



The GFPD has had many noteworthy accomplishments to celebrate in 2013. Some highlights of the year include:

- Awarding \$110,875 in grants to:
 - Dr. Nancy Braverman of McGill University, Montreal, Canada, \$10,875, *"A Pilot, Multi-Center Open-Label Trial Assessing the Safety and Efficacy of Betaine in Children with Peroxisome Biogenesis Disorders."*
 - Dr. William Rizzo of the University of Nebraska Medical Center, Omaha, Nebraska, \$25,000, *"A Pilot, Open-Label Trial Assessing the Safety and Efficacy of Betaine in Children with Peroxisome Biogenesis Disorders."*
 - Dr. Joseph Hacia of the University of Southern California, Los Angeles, California, \$50,000, *"Neural Cell Resources for PBD-ZSD Drug Testing."*
 - Dr. Steven Steinberg of the Kennedy Krieger Institute in Baltimore, Maryland, \$25,000, *"Pilot Treatment of the PEX1-G844D Mouse with Diosmetin."*
- Hosting a family & scientific conference in Lincoln, Nebraska for nearly 130 participants, including 21 affected individuals, their families, volunteers, and more than a dozen medical professionals passionate about PBD-ZSD. Participants had the opportunity to hear the latest medical and scientific information from a number of professionals specializing in PBD-ZSD research and disease management. Clinic was provided at Children's Hospital & Medical Center in Omaha, Nebraska for children participating in a trial of the drug Betaine, and for others needing specialized care unavailable to them at home. Additionally, free consultations at the conference center were available with the medical team to all families who sought individual appointments and second opinions. Marlyn Minkin, LMFT/LMHC joined us for the second year and provided individual counseling sessions and support for families throughout the conference.
- Becoming a member organization of The National Organization for Rare Disorders (NORD).
- Planning & hosting medical & scientific symposiums in Baltimore, Maryland, in April 2013 and another in conjunction with the Family & Scientific Conference in Lincoln, Nebraska, in July 2013.



Award recipients Joe Hacia, PhD, Nancy Braverman, MD and William Rizzo, MD with GFPD Treasurer, Melissa Gamble and GFPD President, Shannon Butalla at Embassy Suites Hotel & Conference Center, Lincoln, NE

- Providing support to Canadian researchers, Dr. Richard Rachubinski, Dr. Andrew Simmonds, and Dr. Nancy Braverman to obtain a five year, 2.5 million dollar grant from the Alberta Innovates Health Solution CRIO Competition for their research project titled, “An *Interdisciplinary Program to Develop Therapeutic Interventions for Peroxisome Disorders.*”
- Developing treatment guidelines for children with PBD-ZSD through the collaborative effort of the GFPD Medical & Scientific Advisors.
- Continuing our equipment exchange program by sharing equipment between families and reimbursing shipping costs for durable medical equipment worldwide.
- Supporting numerous community events that promote awareness and funding for the GFPD family & scientific community, including:
 - **Pound the Pavement for Peter**, a 5K race held in Atlanta, Georgia, in memory of Peter Hopkins, son of Anne Park and Matt Hopkins.
 - **Ilan-a-thon**, a 5K race held in Baltimore, Maryland, in memory of Ilan Betzer, son of Mousumi Bose and Andrew Betzer.
 - **GFPD Dinner Dance**, in Denair, California, hosted by Carolina and José Alfaro, in memory of their sons, Diego & Adrian.
 - **Pancakes for PBD**, in Mt. Zion, Illinois, hosted by Pamela and Jeff Marshall in honor of their son, Ethan.



The Menard Family,
Ilan-a-thon 2013



Phoenix & Anaru Smith from Australia befriending Archer & Ryan Maple from North Carolina at the 2013 conference

In three years, the GFPD has made tremendous impact supporting families devastated by PBD-ZSD and researchers committed to help our children. On behalf of all families impacted by Peroxisome Biogenesis Disorder-Zellweger Spectrum Disorder, thank you for prioritizing the GFPD as a part of your annual charitable giving. 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 PBD-ZSD.

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

Shannon Butalla

Shannon Butalla, President
The Global Foundation for Peroxisomal Disorders



2013 GFPD Family & Scientific Conference Family Participants

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. The GFPD is an organization that relies on the efforts of volunteers and private contributions. All of the work of the GFPD is contributed by volunteers.

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GFPD gratefully acknowledges all those who contributed over the past year allowing us to continue our mission: supporting families faced with a diagnosis of Peroxisome Biogenesis Disorder-Zellweger Spectrum Disorder (PBD-ZSD) and the physicians and scientists dedicated to the study and treatment of PBD-ZSD.

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Abby Simpson
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Adrian and Lisa Salinas
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