FAMILY STORY

Just over eight years ago, my husband and I learned that our son, Sam, had a rare condition called a Peroxisomal Biogenesis Disorder (PBD). We were told that Sam would be deaf, blind, globally developmentally delayed, and had a slim chance of living through infancy. The chance of him doing things kids normally do – walk, talk, learn, etc. - looked very bleak.

Sam turned nine July 1, 2011. He is extremely expressive, loving, social, and capable. With the right supports, he reached milestones that seemed impossible upon diagnosis, including walking and an understanding of verbal communication.

I look forward to hearing your story, and welcome you to The Global Foundation for Peroxisomal Disorders.

Sincerely,

Shannon Butalla

President, GFPD

GFPD
GLOBAL FOUNDATION FOR PEROXISOMAL DISORDERS

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GFPD
GLOBAL FOUNDATION FOR PEROXISOMAL DISORDERS

These are the faces of Peroxisomal Biogenesis Disorders.

Beautiful. Strong. Courageous. Happy.

Who We Are

The Global Foundation for Peroxisomal Disorders (GFPD) was founded in 2010 by parents whose children are impacted by Peroxisomal Biogenesis Disorders or PBDs. GFPD is a 501(c)(3) public charity committed to funding research to develop a greater understanding of Peroxisomal Biogenesis Disorders (PBDs). Additionally, GFPD organizes family support and informational conferences, connects families through an online support group, and provides an equipment exchange program. Our seven member Board of Directors is comprised of parents of children with PBDs. The nine member Medical & Scientific Advisory Board includes professionals from the United States and Canada who treat and study children with the disorders. They are committed to promote research and provide optimal care for children diagnosed with the disorders.

What are Peroxisomal Biogenesis Disorders?

Peroxisomal Biogenesis Disorder (PBD) refers to disorders in the Zellweger Spectrum of Disorders, which include: Infantile Refsum Disease (IRD), Neonatal Adrenoleukodystrophy (NALD), and Zellweger Syndrome. Collectively, these disorders, along with Rhizomelic Chondrodysplasia Punctata (RCDP) are called the Peroxisome Biogenesis Disorders, or PBDs. PBDs are rare, genetic, metabolic, terminal conditions affecting all major systems of the body. Children with PBDs commonly experience sensorineural hearing loss, vision loss, hypotonia (low muscle tone), seizures, developmental delays, liver and kidney issues, problems with bone formation, feeding issues, and adrenal insufficiency.

The Zellweger Spectrum of Disorders are inherited in an autosomal recessive fashion, and the incidence of these disorders is somewhere between 1/25,000 and 1/100,000 births.

Zellweger Syndrome
(most severe)

Neonatal Adrenoleukodystrophy (NALD)

Infantile Refsum Disease (IRD)
(least severe)

How Can You Help?

GFPD is a new organization that relies on the efforts of volunteers and private contributions. Since incorporation, GPFD has reached out to families around the globe to provide information, support, equipment, and a sense of community to families who must learn about these devastating disorders. GFPD has much more work to be done. Your donation can:

- Help a family with unforeseen medical expenses (durable medical equipment, prescription assistance, assistive technology).
- Assist in funding research grants for scientists and physicians passionate to improve the quality of life for children diagnosed with Peroxisomal Biogenesis Disorders.
- Provide funding for families to attend the annual GFPD Medical & Scientific Conference.
- Increase awareness of the disorders by providing funding for education materials & publications to physicians, educators, therapists, and families.
- Offset shipping costs for the GFPD Equipment Exchange Program to recycle medical equipment from families within the PBD Community.

LEARN MORE

We are here to help. If you are a family member, professional, concerned friend or neighbor who would like more information about Peroxisomal Biogenesis Disorders, please visit our website at www.thegfpd.org.