

YOUR VIEWS

Awareness day for children with PBD

Dear Editor,

October 5th is a special day for our family as we celebrate Pause for PBD, the annual awareness day for The Global Foundation for Peroxisomal Disorders (GFPD).

I invite the Jersey County Journal readership to join our family and do something meaningful to mark the day, like a random act of kindness.

Our daughter, Kenna, is 8 years old and is one of 175 children worldwide with Peroxisome Biogenesis Disorder (PBD). When Kenna is in your presence, you can't help but feel joy and unconditional love! Kenna enjoys singing songs, swimming, watching Elmo, and swinging. Peroxisomal Biogenesis Disorder (also known as Zellweger Spectrum Disorder), is a rare, genetic, condition affecting multiple organ systems in the body. PBD is generally fatal in childhood.

As a parent, it is difficult to express the sense of loneliness and feelings of isolation that enter your life when your child has a rare, genetic disease that most people have never heard of and has no cure. However, Pause for PBD, is a day that brings our family hope as we celebrate The Global Foundation for Peroxisomal Disorders (GFPD). The GFPD is an international nonprofit organi-

zation incorporated in 2010, that raises funds for research, supports families affected by Peroxisomal Biogenesis Disorders (PBD), and promotes awareness of PBD.

On October 5th, we are commemorating the GFPD's annual awareness day, Pause for PBD, and celebrating all that the GFPD has accomplished in the last seven years in moving toward a cure for PBD. Most importantly, Pause for PBD celebrates the beautiful children affected by this rare, terminal condition.

Raising public awareness truly makes a difference. It gives families hope and can lead to new, life-saving treatments. I encourage everyone reading this to get involved by visiting the GFPD website: www.thegfpd.org or finding us on Facebook and twitter @globalfoundpd or Instagram @thegfpd to learn about Pause for PBD events in your area and what you can do to support individuals and families impacted by PBD.

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