2024 NNPDF Persevere Award

Darrile Papier

NNPDF is thrilled to honor Darrile Papier as the 2024 Persevere Award recipient with our sincerest appreciation and gratitude for her compassion and incredible dedication in the fight against Niemann-Pick Disease.

Darrile and her husband Mark joined the community when their son Dillion was diagnosed with NPC. They hit the ground running. Dillion's life inspired them to fight for the trials and medications that are options for our families today. She put countless hours into advocacy, fundraising, as well as using their personal and professional connections to support our mission and values. Darrile served on the board of directors and for many years has led some of our breakout sessions at our family conference. Her outgoing attitude and loving heart will be felt when you meet her.

Darrile has spent many years with the foundation contributing her time and efforts to helping other families to manage their daily lives after a diagnosis of Niemann-Pick disease. She is the one that will sit and listen when you didn't realize you needed an ear. She takes the time to understand what you and your family are in need of and from then on, she makes it her mission to connect you to someone that can help. She leads you to where you need to be, even if you don't know it yet. Liz Heinze, NNPDF Board Chair, expresses "I don't know how many times I would have conversations with her, and she would think of something that I should have been looking into or fighting for and I just did not know that it was even a thing. Her heart of gold just wants to help and she does it all in memory of her sweet boy."

It is legacy members such as the Papiers that have blazed a path for where we are as a foundation and what we have to offer our newly diagnosed families. Without research, there is no treatment, without treatment, no cure, without a Darrile, there may not be that one connection that gets you and your family one step closer to what your loved one needed to make it through the next day.