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Meet Dillon Papier

Dillon Papier is a typical energetic six-year-old boy in many ways. His dazzling smile, fun-loving personality and extraordinary zest for life make a lasting impression.

He loves to have fun with his family and hang out with his buddies, go to parties, eat yummy treats and dance up a storm.

Above all, Dillon lives and breathes baseball! When he's not watching baseball or talking about baseball, Dillon can be found playing baseball with his Little League team. He enjoys sharing his vast collection of baseball memorabilia with everyone, but most of all, he never tires of practicing his southpaw swing with his daddy. All winter Dillon looks forward to baseball season and anxiously awaits his annual family trip to Florida to visit his two favorite teams, the Baltimore Orioles and the Washington Nationals, during their spring training.

However, one thing sets Dillon apart from other kids his age. Dillon has Niemann-Pick Disease Type C. This rare, genetic disorder will progressively rob Dillon of his ability to walk, his ability to talk, his ability to swallow, and ultimately, **WILL TAKE HIS LIFE**, unless treatments or a cure can be found in time.

From fear to empowerment

Though Dillon was born healthy, he began displaying symptoms at six weeks. It wasn't until Dillon was three years old that his parents were given the dreadful diagnosis -- Niemann-Pick Disease Type C (NPC). Dillon's mom, Darrile, recalls how shattered she and her husband Mark were when they learned about this debilitating, terminal disease. They went through, "...shock...disbelief... it was soul-crushing." They were devastated.

The Papiers decided they could not **"stand by and do nothing"** in the face of this cruel killer. They had to take action; they had to battle this disease which threatens to steal Dillon from them. They learned that research is the only hope to find treatments and a cure for NPC -- research which must move forward quickly -- for Dillon's sake, and for the sake of other children who share his diagnosis.

The Papiers connected with the National Niemann-Pick Disease Foundation (NNPDF). The NNPDF is a non-profit organization that provides support to families like Dillon's and, more importantly, offers hope through research. The Papiers kicked into high gear and began, with their community's support, raising funds for vital research.

The Papier's efforts have paid off. In less than three years, their hard work has raised \$230,000 for the fight against NPD! And the research is making progress. Genes have been identified, experimental treatments are being assessed, and hope is on the horizon.

But a cure is yet to be found, and we must drive forward to find it in time to save Dillon and all others with NPD.

From desolation to a sense of family

Like other families who are part of the National Niemann-Pick Disease Foundation, the Papiers have found great comfort in the support the foundation offers. In addition to funding research, the NNPDF provides information, education, advocacy, referrals, and fundraising support for families affected by NPD.

Communicating with and meeting other families who face the same challenges, fears and hurdles offers a sense of community and strength not available anywhere else. Dillon's family attended the NNPDF's Annual Family Support and Medical Conference, and came away armed with new hope and friendships, as well as the latest in research and information. The Papiers rely on the NNPDF's support network as they strive to maintain a positive attitude despite the knowledge that if treatments and a cure are not found soon, their son's decline will continue until he needs a wheelchair and a feeding tube, and struggles for every breath he takes.

In a recent interview with CBS news, Mark Papier, emotion evident in his face, put it this way, "If I thought about it [Dillon's NPC] constantly, it would be like a poison and it would eat me up inside. We live in the present and we celebrate every game and every birthday." [View CBS video link at www.nnpdf.org]

Darrile Papier now serves on the NNPDF's Board of Directors and is a member of the NNPDF's Research Committee. The Research Committee works closely with the NNPDF's Scientific Advisory Board (the top researchers and experts on NPD) to determine where research dollars will best be spent in the quest to beat the relentless foe which is Niemann-Pick Disease.



From utter despair to ardent hope....



Like many six-year-olds, Dillon Papier dreams of growing up someday to play professional ball. And like most parents, Mark and Darrile Papier would do anything in their power to help Dillon achieve his dreams. For themselves, they dream of treatments and a cure -- the only things that can save the life of their only child, Dillon, and other children with Niemann-Pick Disease.

As Darrile Papier said, "There has to be a first child to survive this [NPC] -- why can't it be Dillon?" The NNPDF wants so very much to make this happen, for the Papiers, and for every family who faces NPD.

Scientific research is the key.

Please, will you step up to the plate and make a contribution toward the fight against Niemann-Pick Disease? In these tough economic times, we must all consider carefully where we apply our resources.

You can be assured your gift to the NNPDF will be greatly appreciated and faithfully stewarded to bring the greatest benefit to families dealing with NPD.

Thank you in advance for your help in our quest for a cure!

The NNPDF is a non-profit 501(c)(3). Federal tax exempt id #: 35-1844264. Your donations are fully tax-deductible.