

Sample Press Release

National Niemann-Pick Disease Foundation

Contact: Your name, phone number and email address

News Release

For Immediate Release

October Declared 7th Annual Niemann-Pick Disease Awareness Month Local Child Diagnosed with Rare Disease

Frederick, MD <September 17, 2008> -- Darrile and Mark Papier of Frederick had never heard of Niemann-Pick Disease (NPD). What could this cruel disease be, that doctors had just told them would rob them of their energetic little boy, Dillon?

The doctors told the Papiers that Dillon, now six-years-old, will likely not live past his teens. He will never drive, never date, never go to college, and his parents will be left to wonder how Dillon's life might have turned out, had he not gotten the diagnosis of Niemann-Pick Type C (NPC). The average lifespan of a child with NPC is 10 years, so time is not on young Dillon's side.

October marks the 7th Annual Niemann-Pick Disease Awareness Month – a time when families affected by Niemann-Pick, together with their relatives, friends, and the National Niemann-Pick Disease Foundation (NNPDF), work to raise awareness of this rare disease that robs parents of their children, and children of their lives, and to raise funds for research into treatments and a cure.

To that end, the Papier family and their team of friends, neighbors and co-workers are planning a NNPDF awareness campaign and all-city "Rake-a-Thon" on Saturday, October 19th, 2008. Individuals who would like their yards raked or who would like to volunteer for this event should contact Darille Papier at 123-456-7890. Raking by the team of volunteers is offered free of charge; however, tax-deductible donations to the NNPDF in honor of Dillon Papier will be gratefully accepted.

The Papier team is also challenging local businesses, school and civic groups to support this event via a sponsorship or through volunteer service. A backyard cookout sponsored by Bob's Burger Corner, and an educational presentation, will wrap-up the day's events at Riverfront Park.

Niemann-Pick is a disease that strikes children through accumulation of excess lipids in key cells in the organs. The cells malfunction, leading to failure in basic motor skills, including gait and mobility impairments, eventually requiring a wheelchair and hospital bed. As the disease progresses, other debilitating symptoms develop, such as the loss of the ability to speak and swallow, and seizure disorders. The health of a child with Niemann-Pick Type C (NPC) declines until ultimately, the disease claims his or her life.

Today, there is no cure for Niemann-Pick, but research is making progress. The National Niemann-Pick Disease Foundation works to fund research and to support families in their day-to-day care of children with NPD. Established in 1992, the NNPDF is an international, voluntary, non-profit organization comprised of parents, relatives and friends committed to finding a cure. www.nnpdf.org

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