

Family faces tragedy of child with rare illness

By DAVID EMANUEL
Staff Writer

Maris Walker of Bowie is doing all she can for her grandson and family, Bowie natives now living in Frederick.

She wants to share a story of "a horrid disease that our family wishes we had never heard of before."

Her 3 year old grandson, Dillon Papier, is a perfectly happy, full-of-life and full-of-smiles child. He loves baseball, Bob Dylan music and gourmet food.

A perceptive and delightful young boy, he may not live long enough to even see a first day of school.

Dillon was recently diagnosed with Niemann-Pick disease Type C, a rare, devastating and always fatal disease that has affected only 500 children worldwide.

The symptoms include enlarged spleen and liver, and perhaps most tragically, the loss of muscle control, deterioration of speech, seizures and progressive neurological and intellectual decline.

Eventually, Dillon won't be able to

even recognize his own grandmother, parents and friends.

Doctors sometimes call it a child's form of Alzheimer's disease, and many children die before age 10, or within five or 10 years of being diagnosed.

Dillon was diagnosed close to three years ago.

"The horror of Niemann-Pick disease is too great for most of us to imagine," according to Hunt Ozmer, chairman of the National Niemann-Pick Disease Foundation. "This rare, deadly disease robs a child of our most precious gift — life. At the same time, parents must suffer through the gradual decline and certain death of their child."

Researchers have worked hard to learn as much as they can, but it is an uphill battle, said Ozmer. NPD is dangerously unpredictable, striking without warning. Symptoms are also similar to dozens of other conditions.

"Diagnosis is still difficult, and a treatment has yet to be found," according to Ozmer. "Research is our only hope."

Niemann-Pick disease is actually a small group of diseases. They all work

at a genetic level, and most prove fatal at an early age, anywhere from 3 years old to late teens.

There are three types of NPD that are most common. For NPD Types A and B, researchers have identified that the cause is the deficiency of a specific enzyme activity within cells. Type A is more severe, and leads to neurological damage and death, usually by age 3. Type B patients can survive into late childhood or even adulthood, because there is little or no neurological activity.

Type C, which has struck Dillon, is completely different, according to Ozmer.

It is responsible for the buildup of cholesterol in such areas as the spleen and liver, and for the accumulation of "gangliosides" in the brain. That buildup results in eventual damage to the nervous system, causing neurological deterioration.

And like the other types, Type C is always fatal.

Yet with incredible faith and hope, and much denial, as Walker said, everyone is going to get through this — most especially, Dillon.



Courtesy photo

Bowlette Maris Walker spends precious time with her grandson Dillon Papier, 3, who is battling a disease called Niemann-Pick. He is one of only 500 children in the world afflicted with this rare, fatal, illness.

"There will be a cure," she said. "I know it."

Right now, Dillon just survives on "gag-awful" medicine.

"It's all just heartbreaking, and

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CHILD

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"We're just hoping this experimental medication will prolong his life — long enough until they find a cure," said Darrile, Dillon's mom, and a 1981 graduate of Bowie High School. She was clearly trying to remain positive during the interview as dad Mark tossed a baseball with his son and great-grandmother Charlotte watched with pride. "It's really not denial, I guess. It's just reality, a reality we are living with. And what the researchers need right now is funding."

With much generosity from the community, Walker and the family hope the Niemann-Pick Foundation can achieve the necessary funding for critical research "in hope of a successful treatment in time to spare Dillon and the other children the devastating affects of this fatal disease."

"All we can do, literally, is take things one day at a time," said great-grandmother Charlotte Mesnik.

"Thank you for making a difference," the family states in a flier. "Your generosity and heartfelt support provide us encouragement and strength knowing we are not alone in our struggle for a cure."

The Papier family may be contacted at 301-607-4439.

Donations can be made to the National Niemann-Pick Disease Foundation or Ara Parsoghian Medical Research Foundation, c/o Dillon Papier, 9741 Royal Crest Circle, Frederick, MD 21704.

Locally, Walker is accepting donations at 3900 Winchester Lane, Bowie, MD 20715. Make checks payable to the National Niemann-Pick Foundation. Call her if you would like to make a donation, at 301-464-8935 or 301-529-6481.

And she is also selling Baysox tickets to her grandson's first "Fight For a Cure" benefit for Niemann-Pick Disease.

The event will be Sunday, July 30, at 6 p.m. Gates open an hour earlier for "Family Fun Day" as well.

Walker has already purchased several tickets for the event, including a few box seats, and is looking for any groups, organizations, churches, families, businesses or individuals to contact her at to purchase them.

"All money over the price of the \$12 ticket will go into research for the foundation," she said, explaining that there is a discount which will go into research as well.

So far, she has sold 122 tickets.

"Please come and support America's favorite sport, as well as Dillon's," said Walker.

And with a smile with so much emotion behind it, she said, "Every day with him is a joy and a blessing. I believe in miracles. Anything can change. But no matter what happens, I am glad to have him in my life than never to have had him in my life."