



Neighbors Team Up to Hit a Home Run for Dillon

Photos Courtesy Darrile Papier

By CARRIE DIETZ

Four-year-old Dillon Papier likes music and helping his mom cook. His favorites are pizza and ice cream although he won't say no to the more exotic hearts of palm and olives.

But when it comes to baseball, however, it's love. "Just being at a baseball game, Dillon's in la la land," said mom Darrile Papier, an Urbana Highlands resident. He likes being the umpire, too.

"Most kids get antsy by the middle of a game, but not Dillon," she said. "We don't know, it must be in his genes." Dillon's dad Mark Papier is a teacher at Walkersville High School and is the baseball coach at Thomas Johnson High School.

So when neighbors pitched in to send Dillon and his parents to the Baltimore Orioles Spring Training

in Florida it was the opportunity for a trip of a lifetime.

"He was going through baseball withdrawals," Darrile Papier said a few days before the late February trip. "Everyone is just so excited to go."

To everyone he meets, Dillon is one in a million.

Unfortunately he is also one in 500 people with Type C Niemann Pick Disease, an extremely rare and fatal form of the genetic disease.

Type C affects the body's organs such as the spleen and liver because of the inability to metabolize cholesterol and causes neurological issues including clumsiness and learning disabilities. Explaining the disease, Darrile said it's a storage disease. "Say you're recycling newspaper and then have no more room in your living room," she said. "That's what the cholesterol is doing in Dillon's body."

Dillon has seen his share of doctors starting at 1 month old when he was diagnosed with neo-natal Hepatitis. While working through that illness, the Niemann Pick Disease was discovered in August 2005, just before Dillon turned 3. By November it was determined that Dillon had Type C, the rarest of form of the disease.

"There are only 500 cases of this worldwide," Darrile said. Rare diseases are one in every 25,000, this is in a different league. "It would have been easier for us to win the lottery than have this disease affect our lives."

Since December 2005 Dillon has been on an experimental drug which Darrile points out is not a cure or treatment but will slow the progression of the disease. Darrile believes it is working. "In our

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eyes it is slowing the progress of the disease because it was moving very quickly," she said.

The drug is incredibly expensive — \$11,000 a month. "My insurance pays 10 percent of that and fortunately Mark's co-pay covers some, too," Darrile said.

Pitching in to do what they can, Papiers' neighbors in the Urbana Highlands presented a check for over \$1,000 to the Niemann Pick Foundation in Dillon's name at a holiday party last December. "I was speechless already, but when Mike Gilligan, Rich Bresee and Eric Scheidhauer told us about the trip I didn't know what to say," Darrile said. Scheidhauer called in a favor to Orioles owner, Peter Angelos and neighbors funded the rest of the trip.

For more information on Niemann Pick Disease, Type C, www.nnpdf.org.

Contributions to the National Niemann Pick Foundation can be sent in care of Dillon Papier to: 9741 Royal Crest Circle, Frederick, MD 21704.

The Papiers have a busy schedule during the five-day trip to Ft. Lauderdale: watching scrimmages, getting autographs on jerseys, hats and baseballs and meeting Orioles infielder Brian Roberts. "It's such a wonderful thing, it will be great," Darrile said.

Watch for a re-cap of Dillon's trip to spring training in the April issue of *The Town Courier*.