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Urbana boy with rare disease celebrates birthday with Orioles first pitch

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Dillon Papier had a rare opportunity to throw out a first pitch at a Baltimore Orioles game Sunday, but the Urbana youngster has had so much interaction with players in the past that the moment seemed almost old hat.

"He's done it at spring training games and at least twice a year at minor league games," said Dillon's mother, Darrile Papier. "He's a pro at it."

Dillon was diagnosed in 2005 with Niemann-Pick disease type C, a rare and fatal condition with only 500 known cases worldwide.

According to the National Niemann-Pick Disease Foundation, the majority of those diagnosed don't live past age 10. Sunday was Dillon's 11th birthday.

"He's tough. Whatever he's going through, he just gets back up," said his father, Mark Papier.



Dillon took the field at Camden Yards on his birthday for the first pitch to a favorite player, second baseman Brian Roberts.

Roberts has known Dillon ever since the boy came to Orioles spring training in Florida seven years ago. "They're like buddies," Mark Papier said.

The birthday party was held at Camden Yards' Camden Club, which was rented out for about 275 friends, neighbors, community members and others.

This year's birthday was emotional for many, who see that Dillon is still able to walk and talk despite the debilitating disease, Darrile Papier said.

"It's difficult for us. Other people each birthday are thinking of the future and college and high school. We're thinking, 'Oh, he's 11. Is that going to be his last birthday?'" she said. "We don't want to think that, and we don't think that, but it's hard."

The symptoms of Niemann-Pick disease type C, known as "childhood Alzheimer's," include an enlarged spleen and liver, clumsiness, loss of muscle control, speech deterioration, seizures and intellectual decline.

Mark Papier is an assistant coach for the Urbana High School baseball team.

He took his son to a fall league practice Tuesday evening. Dillon began watching baseball when he was 2 years old, and he has loved the game ever since. He accompanies his father to nearly every baseball event.

"I don't know," Dillon said with a smile, when asked why he loves baseball.

He then began naming the players on Urbana's team while intently watching their practice.



Mark Papier said Dillon, now in fifth grade, plays Little League but isn't as active as he was when he was younger. "Now, if he hits a ball, he runs to first base, and then that's all he can do," Mark said. "He's slowing down."

The family and their supporters remain hopeful, Darrile said.

Dillon is enrolled in a clinical trial through which doctors hope for a treatment that will slow the symptoms or prevent them from worsening. The disease cannot be reversed, she said.

The Orioles have been an integral part of Dillon's life, and he has frequently met players and team staff, the Papiers said. The Camden Yards caterers provided free food for his birthday party, and the Orioles also donated merchandise for a silent auction that day.

The Papiers have raised almost \$500,000 over the years to fund type C research through the National Niemann-Pick Foundation.

"Through this, we've seen such good in people," Darrile said. "They just give from the heart."

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