



# East County TIMES

August 21, 2003 • Volume 8, No. 45

Serving Essex, Middle River, Chase, Rosedale, White Marsh, Perry Hall, Edgemere & Dundalk

## Worst-Case Scenario Becomes Reality for Dundalk Family

- by Allison H. McAlister -

Most every weekend from March through October, you can find the Heuchan family of Dundalk at one of Maryland's dragways, cheering on daughter Addie, 12, as she races for the National Hot Rod Association (NHRA) Jr. Drag Racing League, which consists of drivers ages 8 through 18. This is her first year racing, and it's really become a family affair. While Dad John starts her car and Mom Tina runs for tools, little brother Nick, 6, is a part of Addie's pit crew.

In addition to helping clean and wax the half-scale dragster, Nick is responsible for making sure that all of Addie's safety gear is in the car and ready for her before she goes to race.

John and Tina expected Nick to become involved in the league and start racing his own dragster in a couple of years. On June 16, the message left on the Heuchan's answering machine made it quite clear that Nick would never drive his own car in the NHRA. The family learned that Nick had a rare genetic disease, one that would quickly rob him of his eyesight and eventually take his life.

### *Getting a Diagnosis*

The Heuchan's story begins back in May 2002 when they received a letter from Nick's school, where he was currently enrolled in kindergarten, informing them Nick suffered from a color deficiency. Tina was skeptical; she

knew color blindness was something that was passed on by the mother with a colorblind father. Tina's father was not color blind. She says she wasn't comfortable with the determination but "sat on the letter for a couple months" before making an appointment for Nick with an ophthalmologist.

It was July when Nick went to the eye doctor, but the examination did not go smoothly. The doctor felt five-year-old Nick wasn't cooperating and suggested the appointment be rescheduled in three months. The Heuchans returned in October, only to be referred to a pediatric ophthalmologist, Dr. Dankner. This eye doctor told them that Nick's

*See Family, page 6*

## Family

*Continued from page 1*

vision was 20/100 in his right eye and 20/200 in his left. With such a significant amount of vision loss, the Heuchans were then referred to the Johns Hopkins Wilmer Eye Institute for additional testing.

At Hopkins, Nick saw Dr. Janet S. Sunness, a retina disease and low-vision specialist, as Nick's diagnosis at this point was macular dystrophy and ADHD tendencies. Nick was now considered legally blind. The tests Nick had to endure this day included wearing eye patches, then special contact lenses with probes while the doctor sent shocks of light into his eyes for two hours. After six grueling hours of testing, the doctor determined the pictures taken of Nick's eyes and the test results didn't add up. The tests needed to be redone.

In March 2003, this time with Nick under anesthesia, the eye tests were performed once again. At this time the doctors first brought up DNA testing. From here, the Heuchans were sent to a neurologist and a genetic specialist in April. Blood was drawn for genetic testing at the end of May. Dr. Raymond from Kennedy Krieger telephoned the Heuchans on June 16 to tell them Nick tested positive for Juvenile Batten Disease and he wanted to see them in his office the next day.

### *What is Batten Disease?*

Named after the British pediatrician who first described it in 1903, Batten Disease is the most common form of a group of disorders known as neuronal ceroid lipofuscinoses (or NCLs). There are four main types of NCL: infantile, late infantile, juvenile and adult. The symptoms are similar but they become apparent at different ages and progress at different rates.

Juvenile Batten's, which is the form Nick has, begins between the ages of 5 and 8 years of age. The most common early indicators of the disease are progressive vision loss, seizures, and a lack of coordination. This form progresses less rapidly than infantile and late infantile, although ultimately ends in death in the late teens or early 20s, with some living into their 30s.

Batten Disease is relatively rare, occurring in an estimated 2 to 4 of every 100,000 births in the United States. This statistic is evidenced by the fact that the Heuchan's pediatric neurologist has dealt with just six or eight cases throughout his career. Only two of those patients are still living. One is Nick.

### *How is Nick Now?*

Although rapidly losing his vision, Nick is otherwise okay for now. Describes Tina, "Things are getting darker for him and we're dealing with sleep issues." He still plays his GameBoy, though he has to hold the

illuminated screen right in front of his one eye in order to see well enough to play.

He's been taking Braille classes since the first week of July, and John and Tina report he's doing fairly well with that.

The Heuchans are using this time to indulge Nick in all sorts of events and activities while he still has his eyesight. One of the highlights of Nick's summer was getting to meet Ronnie Milsap at this year's Heritage Fair. "He sat glued through the concert," John remembers. "Meeting Ronnie Milsap just made his day."

Nick will attend Norwood Elementary School this year, even though the Heuchans have been in touch with the Maryland School for the Blind (MDSB), where Nick will go on Aug. 26 for an evaluation. "He'll have normal classes with Braille instruction at school this year," explains Tina. She says the MDSB wants him to stay in public school as long as possible, and they'll be happy to take him when public school is no longer feasible.

### *What's Next?*

"I don't need your sympathy; I need your help," Tina tells people these days. Although a cure for Nick would be nothing short of a miracle, the Heuchans plan to do all they can to fight for treatment for this deadly disease and hope that eventually a cure is discovered. John plans to dive head first

into fundraising efforts, but he insists on doing everything "above the table." The fundraising will get underway, he says, "once all the legalities are in place." He needs a lawyer to help him do it, so that he knows it's done right.

Right now, the Heuchans are in the process of setting up a website, which will be located at [www.nicksbattle.com](http://www.nicksbattle.com) when it goes online. "Most people will get information from us on that, but until it's up, they can get information by emailing [nicksbattle@msn.com](mailto:nicksbattle@msn.com)," explains John.

Tina is unhappy she has access to Johns Hopkins but they can't do anything for Nick. "We live in the medical capital of the world, and they can't help." Nick will travel to Durham, NC in September to visit a specialist at Duke University. Travel expenses for this trip are out-of-pocket for the Heuchans, so the teachers at Nick's school took up a collection at the end of the year to help with the trip's cost. Says Tina of the situation, "You don't realize how precious life is or how people touch you or react to you on a day-to-day basis. You don't realize how important friends are to you."

While the Heuchans root for their daughter Addie to win her races this weekend, countless caring souls will cheer for Nick, hopeful that he will find his miracle as he prepares for the most difficult race of his life.