

On the MOVE

Story by Mike Latona

Racing past a disability



Bill Hawken

Nick DeLucenay takes a water break during an Oct. 16 cross-country meet at Seneca Park in Rochester.

Nick DeLucenay had endured years of insensitive remarks about his disability. When he reached ninth grade, he set out to be treated and respected as an equal.

"One of the reasons I got involved was to prove to people that I'm not a nobody," said Nick, 17. "I thought that now I'm in high school, I should change how I act."

Nick has become a pretty tough act to follow. A senior at Greece Odyssey High School, Nick carries a 3.1 grade-point average. He is captain of his cross-country team. He belongs to student government and Varsity Club.

Nick is equally involved at Holy Cross Church in Charlotte. He's an altar server and eucharistic minister. He's a member

of the youth group. He serves as a religious education teacher's aide and has helped at Vacation Bible School.

Earlier this year, Nick was voted into the Greece Youth Hall of Fame. And this month, Nick is among more than 500 diocesan teens who will receive the 1999 Hands of Christ Award from Bishop Matthew H. Clark. The honor recognizes high-school seniors who have made outstanding contributions to their church, school and community. Nick is due to receive his plaque in an Oct. 23 ceremony at St. Lawrence Church in Greece.

Nick has made all these achievements while dealing with Tourette Syndrome, an acute tic disorder. Tics are involuntary, rapid and repetitive movements of muscle groups. Symptoms of Tourette Syndrome arise in movement, speech and behavior.

Nick has been on medication for Tourette Syndrome since he was 5 years old. His earlier symptoms, according to his mother, were excessive throat-clearing, head jerks and touching of people. In addition, he has been prone to echolalia — repeating sounds or words that he hears. He also prefers strict rituals, such as eating breakfast alone or having his parents drive him to church on the same route each time.

"For you or I, it doesn't matter if we put our socks on one way one day, and another way the next. For him it's really important. He's got to check the VCR three or four times to make sure the tape is in," said his mother, Mary Ann DeLucenay, who belongs to the Tourette Syndrome Association's Midwestern New York State chapter.

If these routines are interrupted, she said, "He really gets upset."

Tourette Syndrome can be congenital: Nick's brother Danny, 9, also has Tourette's. (Their brother Alex, 14, does not.) Many of Nick's symptoms have dissipated in recent years, a common pattern with Tourette's patients when they reach adolescence. He does remain on medication to control his hyperactivity, and continues to speak rapidly.

Yet his remarks are quite insightful. Take his reason for favoring the Old Testament, as well as later books in the New Testament, for his Bible reading:

"There's certain parts of our faith we don't focus on, like before Jesus was born and after he was crucified," Nick said.

At times, his mother observed, Nick still struggles for acceptance by his peers.

"He has said, 'Mom, why don't I get invited to birthday parties?'" she said.

"Chronologically he's 17, but he identifies more with younger children and older adults," she added.

However, Nick is making big strides toward blending in. He gave class presentations about Tourette Syndrome in seventh and 10th grades, he said, to let



Nick is captain of his Odyssey High School squad and was named last year's Most Improved Runner.

fellow students know "why I acted the way I did."

Nick is an above-average student who has blossomed into a genuine leader, according to Mary Miller, an Odyssey teacher who nominated him for his Greece Youth Hall of Fame award.

"He maintains a cheerful attitude and is always looking for new ways to involve himself in leadership activities," Miller wrote in her nomination letter. She noted that Nick was a unanimous selection by the Odyssey nominating team.

Nick is enthusiastic about the future, saying he looks forward to dating and getting his driver's license. He plans to attend college next year for studies in "cooking or something computer-related," he said.

Nick enjoys his part-time job at a nearby supermarket, where he collects shopping carts in the parking lot and aids customers who need assistance putting groceries in their cars.

"I like being with people and helping them. We can't accept tips, though," he remarked.

Nick lists "Family Matters," "Judge Judy" and "The X-Files" as some of his favorite TV shows, and Metallica as his top music group. His leisure interests include surfing the Internet, golf and playing the piano — and, especially, running. In addition to being captain this year, Nick was named Odyssey's Most Improved Runner his junior season.

"I'm pretty proud of doing all these activities," he said.

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