

Niemann-Pick | Nashua man is one of 500 people with the disease

CONTINUED FROM | PAGE 25

pain on a daily basis, yet were so ready to give. And I watched their lives just slip away.”

The foundation raises money to support research to find a treatment and cure for Niemann-Pick. Because it is so rare, there was previously very little research done.

“NP stems from an inability to metabolize cholesterol,” said Parseghian. “Cholesterol is trapped in every cell of the body. The gene responsible for NP was discovered in 1997. Cholesterol has been found to play a role in Alzheimer’s disease (and many other conditions) and our research has the potential to have far reaching implications.”

According to the Parseghian Foundation Web site, NP causes cholesterol to accumulate in the liver, spleen and brain, leading to a series of neurological problems that are ultimately fatal. While the majority of cases occur in young children, there are some very rare instances when symptoms do not appear until adulthood.

Called adult-onset Niemann-Pick, this is what happened to Heikila. When his symptoms first began to manifest when he was 18, his parents and doctors were unable to determine what was wrong. It was not until he was 25 that he finally received an accurate diagnosis.

Marie Heikila, Guy’s mother, remembers the day well.

“The doctor said it was terminal, no treatment and no cure, and I wasn’t sure if Guy understood. It was a silent walk to the car until Guy told me, ‘Mom, if God wants to take



Staff photo by ED WOZNIAK

From left, Steve, Marie and Guy Heikila talk after sharing a dinner at their home Oct. 24.

me to heaven, OK, I’ll go.’ He never complains.”

Together with her husband, Steve, and their three teenage daughters, Stephanie, Lauren and Rachel, they are his primary caretakers. After a recent evaluation of his condition, it was determined that he now needs around-the-clock care; and a personal care aide was hired, a move that gives the family great peace of mind.

Caring for Heikila, who is now 27, is a big task, but it is a responsibility that the family embraces.

“It’s not easy,” said Rachel Heikila, “but it’s not like it’s a job. Some days are better than others, but we don’t mind.”

For Heikila’s parents, the greatest struggle has been letting go of their dreams for him.

“We have mourned a lot of losses over the past couple of years,” said his mother.

“Guy had a real entrepreneurial spirit. He was very business-minded. When he was

3 years old, he told me he wanted to become a doctor and take me to Hawaii. We thought one day he and his father would go into business together. That will never happen. He will never name a son after my husband.”

“It’s difficult,” said Steve Heikila simply. “It’s just difficult.”

The Heikilas hope that by sharing their story with others, some good will result.

“This disease is real . . . children are dying from it a couple of times a month. We need to raise awareness and we need to fund research,” said Marie Heikila.

“We need to make people aware that there are other illnesses out there that need our attention,” Steve Heikila said. “These rare diseases, and the families that suffer, need hope. We want to create hope for a cure, hope where there isn’t any.”

Guy’s parents carry their

heartbreak with grace, devoting their attention to their son, their efforts to making a better life for those who will come after him, and always, finding reasons to be grateful.

“We are so blessed that he had 18 normal years,” said Marie Heikila. “We are thankful we didn’t know sooner. It has been difficult for us, but Guy has always been very accepting.”

Guy seems to take each day in stride, in spite of his prognosis. Reading the newspaper and watching the news continues to be his favorite activity, because he enjoys the activity and drama expressed as each story unfolds.

His proudest moments have been working on both presidential campaigns for President George W. Bush, and he says that the president is the one person he would most like to meet. His focus, however, is also on making life better for others who suffer as he has. Asked what message he would most like to convey, he answered with great thought.

As always, Guy speaks with a smile, bright and warm, eyes clear and sharp. Even though he has begun to experience some difficulty speaking as a result of the progression of his disease, his message is clear.

“Strive in whatever you do to be your best. Watch your judgment about people who are out of the ordinary. You never know what is going on in their lives.”

If you would like to learn more about Niemann-Pick disease, or support the Heikila’s efforts to raise funds for research, go to www.parseghian.org.

BODY AND SOUL

Workshop teaches relaxation methods

MERRIMACK – Need a break from the stress of everyday life? On Friday from 7-9 p.m., join wellness professional Sandy Bothmer for relaxation and energizing techniques for improved vitality.

Wear comfortable clothes. The cost is \$35. Bring a notebook and a water bottle.

To register, call Moving

Spirit, the Center for Yoga, Dance and Wellness, Harris Pond, 32 Daniel Webster Highway at 886-7308 or visit www.movingspiritoyogadance.com.

YMCA yoga classes start this week

NASHUA – The Nashua YMCA will hold the following yoga classes starting in November. For more information, call 882-2011.

A morning yoga class will be held Wednesdays from 9:15-10:15 a.m. starting this week. This Kripalu-style class caters to all levels. Students will explore a variety of fundamental yoga components, focusing on the basic postures, breathing practices and relaxation techniques. In addition, students will gain flexibility and learn to alleviate unwanted stress. The cost is \$40 for members and \$52 for nonmembers.

Young at Heart yoga class for individuals age 55 and older will be held Wednesdays from 10:15-11:15 a.m. starting this week. Relax in a stress-free environment while learning to increase strength, flexibility and balance. Students will have the option of using a chair, standing or light mat work. Experienced as well as new participants are welcome. The cost is \$40 for members and \$52 for nonmembers.