



Tony Villiotti and his daughter, Gina Madison, Executive Director of NASH kNOWledge, on the one-year anniversary of his liver transplant.

ON A MISSION TO HELP OTHERS

Through a documentary and nonprofit organization, liver transplant survivor hopes to pay it forward.

BY JENNIFER BROZAK

Like many people who are raised in an Italian family, Anthony Villiotti of Scott Township grew up surrounded by food. Hearty pasta dishes and loaves of bread were staples at his dinner table, and Villiotti and his family enthusiastically devoured every bite. Despite the heavy caloric intake, Villiotti was able to keep his weight in check by maintaining an athletic lifestyle; he graduated from Penn State in 1968 weighing around 200 pounds, which he carried easily on his 5'11" frame.

After college, Villiotti found a job in accounting and finance, where he spent long hours behind a desk, indulging in fast, unhealthy foods. Shortly before he was married in 1978, he learned he had high blood pressure. By 1988, as a father of two and weighing more than 290 pounds, he would be diagnosed with Type 2 diabetes. On medication to control his blood sugar, he vowed to lose weight and eat better. He lost around 30 pounds and, as he states, "I felt good and life moved on."

A few decades later, at age 57, he retired. With more time to devote to health and fitness, Villiotti began walking, and felt like he was in the best shape of his adult life. Then, unexpectedly, everything changed.

While he was out walking one day in 2004, his heart began to race and he broke out in a cold sweat. Anxious, he called his doctor and soon found himself being rushed to the hospital in the back of an ambulance. At the hospital, he was told he had atrial fibrillation, which causes an irregular heartbeat. He had also suffered a mild heart attack. A cardiologist performed a catheterization and, thankfully, no open-heart surgery would be needed. He was given a prescription for a beta blocker to lower his blood pressure and sent home the next day.

Then, at a checkup in 2005, Villiotti's primary care physician told him his liver enzymes were elevated and that he had a fatty liver, or, more specifically, Non-Alcoholic Fatty Liver Disease (NAFLD)—a disease that affects an estimated 100 million Americans. His doctor told him to lose weight, and since his doctor didn't make a big deal out of the diagnosis, neither did Villiotti. For the next few years, his weight ping-ponged up and down, and the fatty liver silently continued to worsen. Then, in 2014, following routine bloodwork, his doctor called with troubling news: he was concerned that Villiotti might have cirrhosis and wanted him to get an MRI.

Villiotti soon learned he not only had cirrhosis but also Non-Alcoholic Steatohepatitis, or NASH, the most severe form of NAFLD. It's estimated that NASH affects approximately 25 million people—nearly a quarter of those who have NAFLD—and most people don't know they have it.

"I was diagnosed with NASH and liver cirrhosis basically on the same day in 2014," says Villiotti. "The first emotion I felt with the diagnosis was confusion. What was NASH? I had never heard of it. And cirrhosis—I didn't drink, how could I have cirrhosis?"

He was astonished by the lack of information he and his wife, Betsy, had about the potential outcomes of the disease. Cirrhosis,

which is irreversible scarring of the liver, almost always leads to a transplant—or worse.

“People are surprised to learn that non-alcoholic liver disease is a more common cause of liver cirrhosis than alcohol abuse. Also, they are surprised to learn there are usually no symptoms,” says Villiotti. “The day I was diagnosed with cirrhosis was the first day I knew that NAFLD could lead to cirrhosis. I had NAFLD for nine years before I was diagnosed with cirrhosis.”

Dr. Cristina Strahotin, a transplant hepatologist with Allegheny Health Network who treated Villiotti after his cirrhosis diagnosis, says she was not surprised to learn that Villiotti was not told how far the disease could progress.

“This is a disease that starts slowly and that can progress over 30 years or longer,” Dr. Strahotin says. “It develops slowly, without symptoms. All you need is excessive body weight. Patients may present with high blood pressure or diabetes, and they’re simply told to exercise and to lose weight. They’re rarely told how serious this condition could become.”

The frustrating part, Dr. Strahotin says, is that in its early stages, fatty liver disease can be reversed through diet and lifestyle changes. The liver is the only organ in the body that has the capacity to regenerate.

“If you’re in stage two or even stage three of this disease, it’s still reversible through diet and exercise,” she explains. “Once you develop cirrhosis, the condition is no longer reversible. At that stage, the goal is to preserve the liver in whatever state it is in for as long as we can.”

For Villiotti, that meant MRIs every six months to monitor his progress. And then, on March 17, 2017, he received devastating news: he had liver cancer. The only cure would be a liver transplant. He was added to the transplant list, and in the meantime went through several rounds of radiation to ensure that the tumor wouldn’t metastasize beyond the liver while he waited.

“That emotion was fear and uncertainty and it was the first time I really faced my own mortality,” he says. “I was either going to get a transplant or I was going to die.”

Over the course of the following year, Villiotti would experience a number of health emergencies—all related to his liver’s inability to properly function—that would land him in the hospital. He had bouts of hepatic encephalopathy (HE), which caused toxins to filter into his bloodstream and ultimately to his brain, causing extreme confusion; a bladder cancer scare; ascites, which causes fluid to build up in the stomach area; and shortness of breath from fluid building up in his lungs.

“There are four main complications that can arise from this disease, and Tony experienced every one,” says Dr. Strahotin.

On March 17, 2018—a year to the day from his diagnosis of liver cancer—Villiotti received a call that a donor liver was available. On March 18, he was wheeled into the operating room; six hours later, he was wheeled out with a new, functioning liver.

Villiotti was able to return home on March 26, 2018, following his recovery in intensive care. More than a year later, Villiotti, now 72, is keeping his weight in check, exercising daily and eating healthy foods.

“This is the best I have felt in at least 15 years,” he says. “I have plenty of energy and feel great.”

Now, Villiotti is on a mission to help others like him. Hoping to increase awareness of NAFLD, NASH and cirrhosis, he launched a nonprofit organization called NASH kNOWledge in September 2018.

“My experience with non-alcoholic fatty liver disease motivated me to start the nonprofit,” he says. “I believed that if I had known more about NAFLD I could have reversed my condition and it never would have advanced to the transplant stage. My successful transplant left me with the desire to ‘pay it forward’ and try to prevent others from repeating my experience.”

The organization’s website, www.nash-now.org, offers a gold mine of information and resources about all stages of liver disease, as well as Tony’s personal blog and articles about the latest research.

“There are still plenty of information voids that need to be addressed,” says Villiotti. “We hope to spend time developing information for parents and school nurses on childhood NAFLD and NASH, which is a growing problem. We also hope to provide more nutrition information on our website. Our overarching goal is to make more inroads, especially in Pittsburgh, on increasing awareness.”

Part of Villiotti’s efforts include a documentary, “Silent Epidemic: The Liver Disease NASH,” which was released to the public at a special screening on June 12, International NASH Day, at the Carnegie Science Center.

“We decided to do the film in order to make the general public more aware of NAFLD and NASH,” he says. “We are hoping that a person who otherwise would not be concerned about liver health will see the documentary and be alerted about the ticking time bomb that is NASH. We saw it as another way to increase public awareness.”

Villiotti and his family worked with Ron Bruno from The Videohouse in Green Tree to finish the project. Through Bruno, award-winning television veteran Susan Brozek Scott was hired as the producer and writer. The film features reenactments and interviews with Villiotti, his wife Betsy and his treatment team. He says the response to the project has been positive, and they’re now looking for ways to share it with more people.

“I hope others will learn how important good liver health is, and how liver disease can sneak up on you,” he says. “The tagline we use is ‘Awareness + Action = Control.’ If a person is aware of the dangers and increasing incidence of non-alcoholic liver disease, he or she can take steps to avoid it. If a person has one of the risk factors—Type 2 diabetes and obesity are major risk factors—they need to talk with their doctors and be sure to monitor their liver health.” ■