Wilbraham resident battles for ALS cure

Andrew Spirito of Wilbraham and two friends to compete in Ironman Triathlon

By Joan Paris Turley Publications Correspondent

WILBRAHAM – Resident Andrew Spirito of Wilbraham and his friends Mike St. Pierre and Steve Miller will be racing against the clock in the grueling Ironman Triathlon in Louisville, Kentucky on Sunday, Aug. 29 in a test of endurance to complete the 2.4 mile swim, 112 mile bike and a 26.2 mile run sequentially without stopping, by midnight.

With a time limit from start to finish of 17 hours, the triathletes will add their names to a list of those who fight for the cause of amyotrophic lateral sclerosis (ALS or "Lou Gehnig's disease"), a terminal muscle-wasting illness.

In a sea of caps and goggles and powerfully kicking legs; frenzied bodies kick back engulfing water, then mount their cycles to pedal against the wind, jumping off to pound the pavement in the relentless run that makes them triathletes and testifies to the magnificence of the human form.

"Swim 2.4 miles! Bike 112 miles! Run 26.2 miles! Brag for the rest of your life", is a registered trademark slogan of the event.

Warrior-Poet

Spirito is a finance major and a senior at Bentley University, planing on a career in the venture capital and private equity industry. Miller is an engineering student at the University of Maine; and St. Pierre is studying entrepreneurship at the University of New Hampshire. These collegiate warriors will carry the memory of Dave Monette and Jon Blaise into their battle against ALS by joining Team Blazeman – a nationwide team of multisport athletes who compete for a cause that is larger than they are. Spirito said that Monette was a family friend and a heroic example of human strength under adversity. The Blazeman Foundation for ALS

The Blazeman Foundation for ALS is a charity started by Jon "The Blazeman" Blais of Seekonk, Massachusetts.

"Jon passed away three years ago, but not before completing the legendary 'Kona Hawaii Ironman', 'explained Spirito. Jon Blais, sometimes referred to as the "Warrior-poet" because of his love for the movie "Braveheart" and his work with special education students, was the first person with ALS to enter and complete the Ironman Triathlon in Hawaii, a life-long dream. He died on May 27, 2007.

Community Support Vivian Toman, of Wilbraham passed

Vivian Ioman, of Wilbraham passed away from the disease in November of last year at age 68. The vibrant, energetic mother of three and grandmother to eight succumbed to her diagnosis after only 18 months. She was an invaluable volunteer in the community and her friends from United Church were with the Toman family "every step of the way," according to her husband of 41 years, Tom. People who struggle with the sheer helplessness of Lou Gehrig's disease tell each other,



TIMES photo submitted

Andrew Spirito trains and runs hard in competition. (Inset) Tom Toman of Wilbraham, whose wife Vivian had ALS, wishes him success.

"Today's the best day of the rest of your life," Tom explains. Toman joined a support group with

the family of Dave Monette and observed, "That's fantastic that Andrew felt strong enough about his relationship with Dave to support the cause."

Toman participated in the first ever walk in memory of his wife in Springfield in the spring and the first in Western Massachusetts. He is interested in the current progress made by the Massachusetts Department of Public Health as they compile a state registry of locale and characteristics of all those stricken with Lou Gehrig's in the state. The work of the registry is estimated to cost \$150,000. A higher incidence of the disease has been noted to occur in military personnel, for example, and Toman is hopeful that the military may find some similarities among their men and women that would be useful for the general population.

Orphaned Disease

ALS is a progressive neurodegenerative disease that attacks nerve cells in the brain and spinal cord resulting in muscle weakness and atrophy. The life expectancy of someone diagnosed with ALS usually averages three to five years, but many people live longer. Physicist Stephen Hawking was diagnosed at 21, but has lived with ALS for more than 30 years. The chance of contracting the disease is one in 50,000 people.

"It's really an orphaned disease in terms of financial support," says Spirito. He explained that because it doesn't have as high a visibility as many other diseases, more fundraising needs to be done. Essentially, anyone with ALS is given the same option as Lou Gehrig who was stricken with the illness in 1939 – go home and prepare to die."

The men have set a fundraising goal of \$15,000. To contribute, log onto active.com/donate/teamblazeman/ironm anKY – or send a check payable to: Blazeman Foundation for ALS and mail it to Andrew Spirito, 17 Maplewood Drive, Wilbraham, MA 01095.



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