

BRIAN'S HOPE

Hammerfest Triathlon part of 'ripple effect' of foundation named after Brian Kelley

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As the seconds ticked down to the siren that started the 17th annual Hammerfest Triathlon last Sunday, adrenaline-pumping rock music blared in the brisk morning air. Along with 200 or so participants, the favorites David Demres and David Ellis stood on the sandy crescent of beach, shaking out their arms and pulling tight on their swim caps.

On the line: \$20 each David had bet on himself to prevail as well as hundreds of dollars others had bet on each of them, with proceeds for the winner going to Brian's Hope, a charitable foundation named for 25-year-old Branford resident Brian Kelley to stop the progression of adrenoleukodystrophy (ALD), a genetic disorder that irreversibly causes rapid degeneration of the nervous system.

On their swim caps: the words BRIAN'S HOPE partially encircled with the logo of a ripple.

The logo is recent, as is the organization, which was founded in July 2012. The ripple effect it symbolizes, of the way Kelley and his family have spread awareness of the disease, has lasted over the last 18 years.

It all began in March 1995 when 6-year-old Brian, a typical healthy boy, crashed into a woodpile while sledding. By August, despite a bone-marrow transplant from his older brother, he could no longer walk, talk, or speak.

If that was the pebble, the first ripple came on Brian's return home after an 85-day stay at St.



Photos by Michael Marsland

David Demres crossing finish line as 2013 Hammerfest champion.

Raphael's Hospital. Hanging on the railing of the Kelley's house were welcome home signs hung by the family's neighbors. The second, the next summer: a lemonade stand set up by two of Brian's young friends who donated all of their profits to the Myelin Project, the research foundation for ALD.

Then there was the staff at Race Productions that in September 1996 staged the first Hammerfest Triathlon, naming, in Brian's honor, the Myelin Project as the beneficiary of that race and all future races, including Brian's Beachside Boogie, a duathlon competition each spring.

As the second Sunday of each September came and went, the ripple effect gathered force, with



See BRIAN'S HOPE, Page 4 Triathletes with ripple logo swim caps wait to begin Hammerfest triathlon.

Brian's Hope: Part of the ripple effect

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Zane's Cycles and an ever-increasing number of sponsors helping the Hammerfest grow in popularity and renown for its stunning venue and smooth-running operation, all the while raising nearly three-quarters of a million dollars toward research.

Then, in 2012, came a new and powerful undercurrent: an inexpensive test proven by pilot studies to be effective in detecting ALD in newborns. Until then, given the rare nature of the disease—it affects only one in 20,000 boys—there was no way for a family like the Kelleys to know that their child was at risk until symptoms appeared—in Brian's case, that sledding accident.

Until, in other words, it was too late to do anything to stop the ruthless progression of the disease.

Hence, the mission of Brian's Hope: to keep every child with the potential for developing ALD healthy and well and, more immediately, to codify that mission into law.

Hence, too, the groundswell of support for legislation requiring universal infant screen-

ing for ALD. There was the highly respected Kowalski Group, led by Linda Kowalski, offering to negotiate the legislative maze in Hartford for the Kelleys for free. There was Sen. Len Fasano, R-North Haven, throwing his weight behind the effort from the beginning. And the small bipartisan group of lawmakers informally caucusing on an early-March Sunday afternoon to ensure the bill would not get grounded in committee.

Not to mention Gov. Dannel P. Malloy, with one sweep of his pen on July 2, one day before Brian Kelley's 25th birthday, making Connecticut the second state in the nation to enact such a law, then celebrating that achievement with a signing ceremony in late August. And just this past Sunday, a proclamation by the General Assembly citing September 15, 2013 as "Brian Kelley Day" for "his inspiration in the passage of newborn screening for ALD."

Because here's the thing about a ripple effect: you can't stop it once the pebble drops. It keeps spreading. Not just to Florida and California, which are now beginning work to pass a similar bill. Or to other states,

now that Brian's Hope is in the process of developing a template to ratify the law so that, eventually, in the words of Brian's mother Jean Kelley, "no families throughout the United States will have to wonder whether their child has this or not."

It's also spread to Don Herzog, CEO and president of Guilford's East River Energy, who emblazoned his oil delivery trucks with the ripple logo. Unveiled in early September, the trucks will proclaim the existence of Brian's Hope to every motorist driving on roads up and down the shoreline and from Cheshire to New Haven to Woodbridge.

And to elite triathletes David Demres and David Ellis. As it happened, Demres overtook Ellis in the run. At the finish line, though, each seemed more elated about the funds raised for Brian's Hope by their friendly wager, "regardless," as Ellis put it, "of



Jean and Jack Kelley, with their son Brian, in front of an East River Energy "Truck of Hope."

who people bet on." Two days later, Demres reported that more still were pledging even after the race—including those who had put their money on second-place finisher Ellis.

It's just another manifestation of the ripple effect that is Brian's Hope and, in a larger sense, the legacy—and legend—of Brian Kelley.

For more information on Brian's Hope or to make a donation to stop the progression of ALD, visit www.brianshope.org or www.facebook.com/