

Having enough heart to persevere

Local man fetes organ transplant with charity walk

By JOHN FLOWERS

MIDDLEBURY — The United Way of Addison County's May 7 "Race for the Rest of Us" was just one-third of a mile — billed as a 0.5 kilometer "race." It was a chance for participants to stroll, hop or jog while raising money for their neighbors in need of food, shelter, housing and other necessities.

But for Middlebury's Ken Scupp, the philanthropic jaunt was a symbolic cap to an at-times torturous, but ultimately miraculous, medical marathon. His prize for finishing that real-life race?

A new heart and a new lease on life.

"I've been trying to figure out why I was spared," Scupp, 68, said candidly during an interview on Monday.

Indeed, life can change in a heartbeat, something Ken Scupp learned more than a half century ago. A physician had delivered an ominous portend of his future health challenges at a time in his life when most people are checking out prom outfits and potential career paths.

"I was told at 17 that I was probably going to have to have my aortic valve replaced when I was 45," he said.

Scupp was able to postpone his predicted appointment with a scalpel until a few years ago, thanks to a very active life that included coaching and running in eight marathons.

It was a welcomed, extended run of good health, but it came to a halt on Nov. 11, 2021 — which happened to be his birthday. He underwent open heart surgery to deal with the faulty aortic valve and an aneurism (a balloon-like, blood-filled bulge) that had

(Continued from Page 1A) developed on the backside of his heart. Scupp had had a pacemaker installed a few years earlier to help deal with the aneurism.

The aortic procedure went well, but it came with some bad news.

"They fixed all the plumbing, but I still had 'electrical' issues, because of the aneurism," Scupp

said of a condition known as ventricular tachycardia, or "V-tach." V-tach is a heart rhythm problem (arrhythmia), caused by irregular electrical signals in the lower chambers (ventricles) of the heart, according to mayoclinic.org.

In an effort to remedy his V-tach symptoms, he submitted to three separate ablations — a procedure that scars tissue in the heart to block irregular electrical signals — and an experimental radiation therapy usually reserved for cancer patients.

"None of it worked," his wife and soulmate Josie solemnly recalled. "He continued to go back into V-tach."

Thanks to TLC and a strict regimen, Ken was able to go 40 consecutive days last summer without a V-tach episode. He appeared to be out of the woods and scheduled a checkup with his cardiologist at Massachusetts General Hospital.

"This was supposed to be a celebratory meeting," Josie said.

But on the very morning of his checkup — Aug. 12, 2022 — Ken went back into V-tach.

So instead of taking a victory lap, the couple detoured into the Mass General ER, where Ken was admitted. There he would remain for more than three months, submitting to numerous therapies, medications and procedures aimed at getting Ken's heart to beat normally.

In spite of the world-class care, Ken's prognosis only worsened. The ablation procedures had further weakened the structure of his heart, Josie said.

Suddenly, Ken was 17 again, receiving some shocking news.

Only this time the news was a lot worse.

"They came to us and basically said, 'We've done everything we can, and the only thing that's going to return you to a life of normalcy is having a heart transplant,'" Ken recounted.

"They told him, 'Your heart has given all it can give,'" Josie added.

PUT ON A LIST

Ken Scupp was put on a transplant list. His life would ironically depend on the tragic death of a stranger whose final act of selflessness would be a heart donation.

He buckled up for a potentially lengthy wait — perhaps a year or more.

But only a few days after being told he was living on borrowed time, Ken was thrown a bittersweet lifeline.

A 25-year-old man had died suddenly during Labor Day weekend, and his heart was available.

Mere hours later, Ken was again being rolled into an operating room. Only this time, surgeons would be installing a new engine instead of tinkering under the hood.

The operation, on Sept. 4 of last year, went well. Ken's body showed no signs of rejecting his new heart and he'd been told he could be discharged from the hospital within 10 days of the surgery.

The Scupps have learned, however, that good medical news often comes with a catch.

Ken's recovery was hampered by his lungs, which had collapsed during the operation and refused to reopen. He was diagnosed with acute respiratory distress syndrome (ARDS), which occurs when fluid builds up in the tiny, elastic air sacs in the lungs. He developed pneumonia, which almost killed him. Physicians plied Ken with

medications, put him on a ventilator, and eventually a tracheostomy tube, or trach.

"He didn't tolerate (the trach) very well," Josie recalled.

So Ken's physicians decided to sedate him in order to let the trach do its work. He remained unconscious — save for a few coordinated wakeups — for more than five weeks, according to Josie.

"They really weren't sure he was going to make it; his lungs were bad and still weren't opening up," Josie said.

At that point, physicians tried what Josie called a "Hail Mary pass" — a simple-but-rare procedure for an ARDS patient with Ken's kind of medical history: They elected to "prone" him, meaning they put him on paralytics and flipped him on his stomach for half the day, and onto his back the other half.

Gravity was being enlisted to open Ken's lungs.

"We had a family Zoom meeting (with our two grown children)," Josie said, her eyes welling with tears. "It was either going to work and he would make it, or it was over."

It worked. His surgeon was gobsmacked by Ken's perseverance and good fortune.

"(My surgeon) said to us, 'Mr. Scupp, I want you to know something; of all the patients I've ever had, you were the sickest one to ever survive,'" Ken said, shaking his head in disbelief.

With his lungs back in order, Ken was discharged from the hospital on Nov. 10 to begin a five-week stint at a physical rehab center in Cambridge, Mass. The surgeries and extended bed confinement had temporarily robbed him of his mobility.

"He had to learn how to do everything all over again," Josie said, noting it took him more than two weeks just to be able to stand up on his own.

Fortunately, Ken was a motivated patient who had set a goal of returning home before Christmas Day.

He and Josie made it back to Middlebury on Dec. 20. **COMING HOME**



JOSIE AND KEN Scupp cross the finish line after completing the United Way of Addison County's "Race for the Rest of Us" on May 7. Ken Scupp, who received a heart transplant last year, raised \$2,300 for the local nonprofit, which will use the total \$12,000 in race proceeds to help Addison County people in need.

Photo courtesy of United Way of Addison County

Now eight and a half months clear of the operation, Ken Scupp is counting his blessings. Topping the list is Josie, who's been with him every step of the way during his medical odyssey. She can recite the benchmark dates of Ken's surgical and recuperative experiences, and finished his sentences a couple of times during the interview.

Ken, who grew up in Philadelphia, also drew inspiration from film icon Rocky Balboa, the Philly boxer who went the distance in a title fight with fictional heavyweight champion Apollo Creed. Ken had a Rocky poster hanging on the wall in his room.

"I had that 'Rocky' mentality," Ken chuckled.

He's come a long way and is a veritable "cardiac kid" when one considers the age of his new heart, but Ken recognizes his limitations. He's lost 96% of the hearing in his left ear and developed a foot problem. Both ailments are side effects of his heart surgery. Ken

added he "takes more pills than I'd care to admit," and faithfully attends rehab sessions (including treadmill, stationary bike and rowing machine) at Porter Medical Center.

Ken will never run another marathon but is an avid walker.

He'll soon add fishing to his more restrained recreational repertoire.

He's also committed to giving back, including through the Boston-based Heart Brothers Foundation. It's a non-profit dedicated to helping heart failure patients and their families navigate the complex journey of cardiac ailments and recovery. The group gathers resources and folks like Ken who

can let future patients know what they can expect pre- and post-op. Ken saw this month's United Way "Race for the Rest of Us" as a way to give back at a local level. He asked a bunch of friends and family for a penny for every yard he walked in the 0.5-kilometer event. Small steps can pay big dividends, as Ken's sponsors had ponied up a combined \$2,300 for the United

Way as of this writing.

"I raised a lot more than I thought," he said gratefully.

Helena Van Voorst, executive director of United Way of Addison County, was thrilled with the Scupps' financial contribution and praised their courage in the face of Ken's medical predicament.

"There are times when we're just humbled by the heart this community has — pun intended," she said. "It's humbling to know that we have a community where people are going through difficult things, and their first reaction is, 'How do we give back?' And they think of the United Way. We're so grateful for Ken's and Josie's support..."

It's support that sadly couldn't have happened without another family's tragedy. Ken desperately wants to thank his donor's family, which has the right to remain anonymous. Ken has written a letter that'll be forwarded to the family, and they can choose to make contact.

"I'm attempting to express my gratitude," Ken said, though he knows mere words can't begin to describe his feelings nor the donor family's loss.

"It is really daunting that someone had to die in order for me to live."



JOSIE AND KEN Scupp of Middlebury are incredibly grateful following a heart transplant that has allowed Ken to live an active life after several months during which his survival was in grave doubt.

Independent photo/John Flowers