

Organ donor advocate stays in the race

By Lorri Drumm Meadville Tribune

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Tom Hayden has been running long distances since his high school days on the track team.

Since his first marathon in Cleveland in 1982, he has qualified for the Boston Marathon 17 times and ran in it 13 times.

Whether it was a half marathon, marathon or a lap around a local track, it was always his feet hitting the pavement, his breath panting, his sweat dripping and his heart pounding in his chest — until a race in 2015.

"After my second open-heart valve replacement from a human donor, when I ran a marathon, it was not just me out there," said the former long-time Meadville Area Senior High girls volleyball coach. "Someone else was there with me."

Hayden, who retired from teaching earth science to Meadville students in 2006, said his run in the 2001 Boston Marathon went well. In fact, he qualified for the race in 2002, but some time after that he noticed that long runs were getting tougher. When he continued to slow down, he decided it was time to seek medical advice.

"The thought of not running any more was emotionally devastating," Hayden said.

"In 2009, tests showed I was born with a bicuspid aortic valve," Hayden said. "What happened was predictable. The valve was becoming more rigid and the build-up was slowing down the blood flow through my heart."

Bicuspid aortic valve is an inherited form of heart disease in which two of the leaflets of the aortic valve fuse during development in the womb resulting in a two-leaflet valve (bicuspid valve) instead of the normal three-leaflet valve (tricuspid).

Further testing at the Cleveland Clinic revealed the opening of Hayden's heart valve was down to nine-tenths of a centimeter and he had an aneurism on his aorta that was considered by his doctors to be "more than substantial."

His first open-heart surgery included replacement of his heart valve with a bovine valve and a sleeve was placed over his aorta.

"I still remember my comment when I was recovering in the ICU," Hayden said. "I said, 'It's nice to be able to breathe.'"

In just about two months after surgery, Hayden was back to running.

"It was great to be running again," he said.

Eventually, Hayden started slowing down again.

"By March 2013, I couldn't finish a quarter mile," he said. "Something was wrong."

That something remained a mystery until August that same year when his cardiologist discovered bacteria in his bloodstream, Hayden said.

He was diagnosed with endocarditis.

"It was explained to me that anything not native to your body, in this case the bovine valve, can be attacked by cells in your own body," Hayden said. "The bacteria made the valve smaller."

Hayden again underwent open-heart surgery to replace the valve, this time with a human valve.

"The surgeon said a human valve was preferred for the second surgery," he said. "He said there's a smaller chance a human valve will develop endocarditis."

Following recovery, Hayden not only returned to running, but after a 14-year absence, he returned to a race that signified a special moment in his time as a marathon runner.

In 1985, Hayden competed for the first time in the Niagara Falls International Marathon that runs from Buffalo to Niagara Falls. That 1985 race marked the first time Hayden qualified for the Boston Marathon.

Exactly 30 years and two heart surgeries later, Hayden returned to Buffalo to run that race again in October 2015. He won a medal. He couldn't shake that feeling that it wasn't just him out there alongside all those runners.

So, about a month after the marathon, he set out on a mission to get that medal to the family of the person he felt deserved credit for his win. He tracked down a public relations person at the Cleveland Clinic, who tracked down the donor bank that then made contact with the donor family.

"The lady who helped me worked so hard to help me get that medal to the family," Hayden said. "She just kept plugging away."

It took about 15 months before Hayden got confirmation that his letters and medal had reached the family.

So far, he hasn't had any contact from the donor family and he still knows nothing about the person who donated the heart valve that gave him the chance to compete again.

"I don't know how the donor family feels," he said. "They might be glad to know someone's doing well but it might bring back sad memories too. I'll understand if I don't hear back from them."

"Every donor family is different," said Colleen Sullivan, director of communications at the Center for Organ Recovery & Education (CORE) in Pittsburgh. "Some want to know how their loved one's organs have helped and some don't. There's no right or wrong way to move forward."

The staff at CORE do encourage donors and recipients to reach out.

"They can write letters that can be kept anonymous unless both parties agree otherwise," Sullivan said. "The bond between a donor and recipient is unlike any other. Sometimes the process just takes time so there's no time limit for a response."

Sullivan shared an example of that process.

"A number of years ago young woman from Erie was on the waiting list for a heart transplant," Sullivan said. "She kept coming back to Pittsburgh and each time her condition had worsened."

When the young woman finally received a heart transplant, she sent a letter to the donor family. After a year went by with no contact from the family, the young woman acknowledged the gift on the anniversary of her surgery again with a letter of thanks.

Each anniversary she continued to send letters, with no reply, until the fifth year after her transplant. After five years of silence, the donor family reached out to the young woman who received a heart from another young woman who had been a similar age when her life ended.

"The donor family told the woman they simply weren't ready to meet her, but they always looked forward to the card and letter of thanks each year," Sullivan said.

There are more than 118,000 people in the United States in need of donor organs, according to Sullivan. "Every 10 minutes another name is added to the waiting list for organs," she said.

"There's a significant need for human donors," Hayden said. "I just want people to know that whatever they've been through, they shouldn't give up."

Dr. Nicholas Smedira, Hayden's surgeon, shared some thoughts about the patient he admires.

"Organ and tissue donation provide patients with a chance for an active and full life. Patients like Tom understand the kindness and compassion necessary to proceed with donation and

he's showing he does not take that sacrifice for granted," Smedira said. "Seeing patients flourish after tissue and organ transplantation is one of the joys of my career. I want to continue encouraging more and more people to share their organs and tissue. This will save more lives and potentially help others cross the finish line as well."

Hayden has no intention of slowing down, but he may opt for a shorter distance between the start and finish lines.

"Between my wife and my cardiologist, they think it's time to put the marathons to rest," Hayden said. "There are lots of shorter races."

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