

The Waiting is the Hardest Part

By LEROY BOISON

CAS member LeRoy Boison faced the toughest trial of his life. Now he's on a mission to pay it forward.

Boison's new license plate features his "new birthday" and promotes a cause that is dear to his heart.

“

I hate the wait.”

If you see this slogan, you would probably think this is counterproductive in our fast-paced world. But the [New York Organ Donor Network](#) has adopted this catchphrase to impress upon people how long and difficult it is for those waiting for life-giving transplants. I now have firsthand experience with this wait, but after a series of unfortunate events my journey was faster than that of many others I met along the way.

Last April I had a massive heart attack deemed the “widow maker.” It came on abruptly and left me with a 20% chance of survival. Winthrop University Hospital in Mineola, NY, my local medical center, was fortunately able to stabilize me enough so I could be transported 25 miles away to New York Presbyterian Hospital (NYP) in Manhattan. During my month-long stay, three different machines were implanted in me to help the right side of my heart function and keep

the blood pumping on the left side. The final apparatus, a left ventricular assist device or LVAD (what Dick Cheney had), was effectively an artificial heart with a lead coming out of my side and connecting to a computer or control unit worn around my waist. This unit was connected to a power module by my bedside at night, and during the day could be connected to a pair of three-pound batteries for ease of mobility. Luckily for me, I met the criteria to be placed on the list for a



heart transplant, so the LVAD became a temporary device that served as a bridge to transplant rather than something I would have to live with for the rest of my life.

My initial reaction of excitement as I looked forward to the transplant quickly dissipated, however. I learned that people with type O blood like me typically have a two- to three-year wait for a heart. This is due not only to the factors in matching the donor organ to the recipient, but also because my geographic area of New York state unfortunately ranks 48th among the states in donor registration. The number of donor hearts cannot keep up with the demand. I tried to remain positive, resign myself to the fact that I would have to be patient, and make some modifications in my life to adjust for the LVAD—but I was already beginning to “hate the wait.”

Two and a half months into my “new life,” the complications began. I started to have multiple gastrointestinal bleeds, a possible side-effect of the LVAD, which required numerous blood transfusions and stays at NYP. One time my heart stopped, and my local hospital did not know that the LVAD could keep me alive for an extended period of time. The doctors reacted to my nonexistent EKG by administering the paddles without anesthesia. (Boy, does that hurt!) A minor surgery was then required to outfit me with a defibrillator. All of these incidents involved being readmitted to NYP seven times in total between July and November 2012.

The last bump in the road occurred right before Superstorm Sandy when my LVAD had to be replaced because blood clots had formed. This was actually a blessing in disguise, since our home lost power for almost two weeks and I relied on electricity to survive. Fortunately, my son and his family had power, and when I was finally discharged from the hospital I wound up taking a cab to his house, since gas was at a premium during this period.

Our worst nightmare was probably when my wife and I discovered that our insurance company would only allow my transplant to be per-

Donors Needed!

The latest statistics from the [United Network for Organ Sharing \(UNOS\)](#) dramatically demonstrate the need for more donors. There have been only 8,200 donors during the first seven months of this year countrywide!

Waiting list candidates as of 10/7/2013	120,056
Active waiting list candidates as of 10/7/2013	77,017
Transplants January-July 2013	16,669
Donors January-July 2013	8,215

formed in Philadelphia (120 miles away) as opposed to New York City. On the surface, this doesn't seem like much of a problem, but when you include all of the pre-surgery trips that are required before transplant, coupled with a year of follow-up visits and biopsies, the enormity of it all becomes evident.

They say that every cloud has a silver lining, and it turned out to be true in my case. Because of all these complications,

I was moved up to 1A status on the transplant list, which meant that my need for a new heart had become more critical. At the beginning of December, I learned that I was number one on the list at NYP for type O hearts, and suddenly the wait began in earnest. Every time the phone rang, my wife and I jumped to see who was calling.

On February 7, 2013, after one false alarm in late January, I received my new heart. I am doing fantastically, and words cannot express how grateful I am to the donor family for my new life. Now I want to pay it forward.

Since my new birthday, I have advised NYP in updating their LVAD patient manual and counseled LVAD



The author shows off his promotional T-shirt from the New York Organ Donor Network.

Spread the Word About Organ Donation!

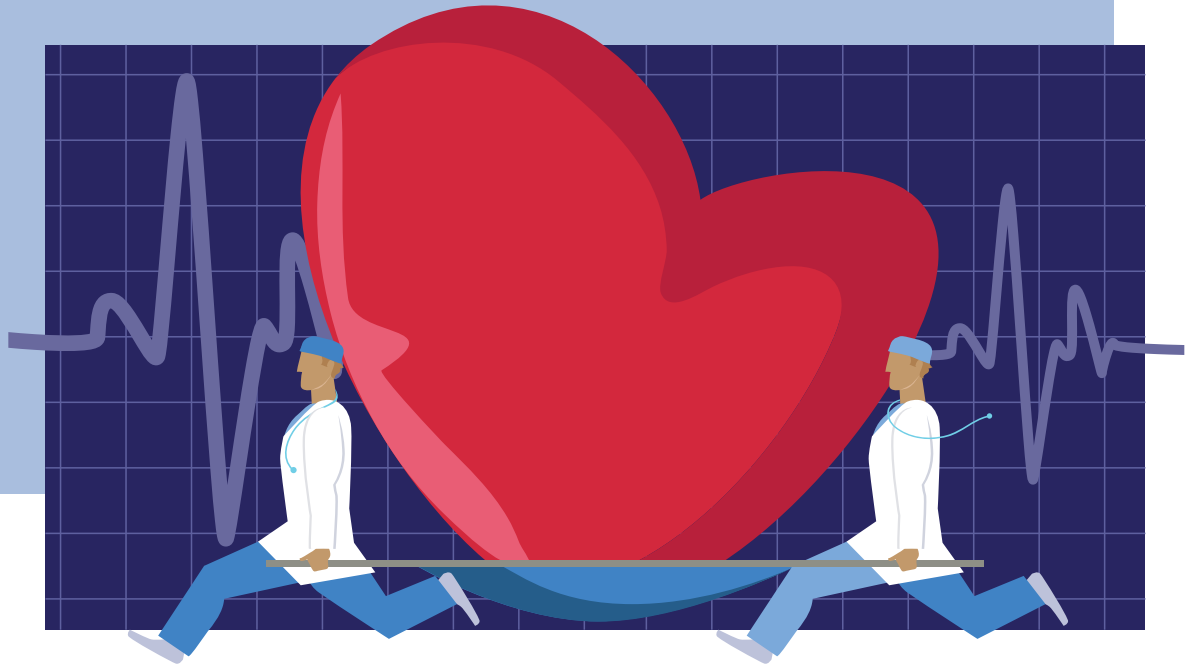
Information is available to employers free of charge from numerous sources, including:

<http://organdonor.gov/howhelp/workplacepartners.html>

<http://organdonor.gov/materialsresources/index.html>

<http://donatelife.net/spread-the-word/>

<http://www.unos.org>



patients to help them adjust to the sudden change in their

lives. I want to show

them there is a light at the end of the tunnel. I have also asked my current and past employers and other organizations to distribute donor awareness information. The CAS Board and Executive Council have very graciously allowed me to use this article to promote the cause.

Even the issue regarding the transplant site resulted in more than one positive outcome. A chance encounter my wife had with our neighbor, who is the president of Adelphi University, resulted in an intervention by our New York State Senator, Kemp Hannon, who is the head of the New York State Health Commission. After a six-month impasse, within 48 hours my insurance company approved the transplant at NYP. When I went to personally thank my neighbor, he inquired as to my occupation and we began discussing a potential actuarial science program for his university. I have volunteered to assist in any capacity so I can give back to the actuarial community.

Please consider suggesting that your HR department sponsor a donor awareness initiative, and if you should know

of anyone who could benefit

from talking to me, don't hesitate to have them contact me. Best of all, consider becoming a donor yourself. I have been a donor since I received my driver's license in 1964 and, although that didn't have an impact on my priority, it somehow makes me feel better about being on the other end of the deal.

The last year and a half has given me a new perspective on life and many things to be thankful for—in particular, all of the CAS members who reached out to me with their support. The actuarial community, while a bit larger than when I first joined, is truly a family. ●

LeRoy A. Boison, FCAS, MAAA is a consulting actuary living in Garden City, NY. He has served on numerous CAS committees and was the first CAS vice president-international. He is currently a member of the CAS Ratemaking Committee. He continues to pay it forward.