

# INSPIRING HOPE

## Howard and Ellen Nikkel - "A Journey From Heart Failure to Transplant"

In 2008, my wife and I were teaching elementary school in Maturín, Venezuela, when my journey started. We were in the States for summer vacation when, in mid-July, I began to experience what I thought was a summer flu or something similar. But I didn't get better, and in fact, began to have trouble functioning. This was a problem since I was trying to get ready to start a new school year. Eventually I ended up in an emergency room in a private hospital one day before school was to start. The original diagnosis was a lower pulmonary infection based on fluid in my lungs, with an anomaly noted in an EKG the doctor ran. About 5 weeks later, when I wasn't improving, I ended up in a cardiologist's office who, after doing an echocardiogram, told me I had an enlarged heart with an ejection fraction of 25%. He said the most probable cause was a virus that especially liked heart tissue. A second opinion in the U.S. 3 months later showed the same thing, only this time the doctor read the ejection fraction at 20%. His opinion about the cause was the same. With medication, over a six month period, the ejection fraction improved to 37%. I stayed relatively stable there for several years, but in 2012, another echo showed my ejection fraction had dropped back to 20%. At that time I received an ICD at the Ross Heart Hospital. A few weeks later, the ICD saved my life when I went into fibrillation and the device fired.



My downhill journey continued, until in 2014, when we were back in the States for summer vacation, my cardiologist told me that I was very sick. I was going to the hospital immediately and I wasn't returning to Venezuela. I left the doctor's office in a wheel chair, and my summer/fall journey of hospitals began. I ended up receiving an LVAD in September of 2014 on my third visit to Ross. Without the LVAD, I wouldn't be here today. I slowly recovered my strength after physical and occupational therapy at Dodd Rehab Hospital and more therapy at a local hospital once home. While I wasn't as energetic and strong as I once was, I was still alive and reasonably independent, other than always having to carry a bag with extra batteries and controller everywhere I went. After 17 months on the LVAD, I received a call to come to the Ross for a heart transplant. On February 20, 2016, I got a new (to me) heart, and life has returned pretty much to normal.

A support group told me that I should write down my story because I needed to keep busy, I needed to see how far I had come from the beginning, and possibly our story could encourage others. I found out that I couldn't write the full story without Ellen writing several chapters about how being put into the role of caregiver on call 24/7 changed her life as well. While I was coasting through, just getting by due to my weakened heart, I didn't realize what it all meant for Ellen to suddenly have to take over all responsibilities. She had a major part in keeping me alive so that I was there to receive the LVAD and transplant. So this story is as much hers as it is mine.

*If you've had a similar experience, or would just like to talk to Howard about living with heart disease, his contact information is listed below!*