

The Continuing Story of Michael Stanzone

November, 2011, USA

While living in the long-term care facility, I heard from a friend of mine about a device which stimulated the diaphragm so it can help a spinal-cord injured patient breathe on their own. Since Pompe Disease is a muscular dystrophy disease, and the diaphragm is a muscle, I wondered if this device would also help me to get off my ventilator and breathe on my own again. My friend got me the contact information of the doctor who pioneered this device. I sent him an email but did not get a reply. Not wanting to give up on this I sent an email out to a network of people I belong to who either have Pompe

Disease or are parents of a Pompe patient. I asked if anyone has heard of the diaphragmatic pacemaker. George Fox from Florida told me his son's doctor, Dr. Barry Byrne, is familiar with it and Dr. Byrne also is in touch with the doctor who I first tried to reach. George gave me Dr. Byrne's contact numbers and I proceeded to try to get in touch with him. I got a quick response from Dr. Byrne. We started a game plan of getting me down to Florida to evaluate my condition to see if I was a candidate for the pacemaker. About a year later and numerous emails and phone calls with Dr. Byrne and his staff, I was all set to get picked up by a medical recreational vehicle and start the trek to Shands Hospital at the University of Florida in Gainesville, Florida which took 21 hours. It would take some very sophisticated tests to determine if I was a candidate for this device. I was very happy to hear that I was cleared to have the surgery. I would be the first person ever with Pompe Disease to have the diaphragmatic pacemaker implanted.



Finally at home with my son and Welcome Banner.



Arriving home by ambulance and welcomed by the whole neighbourhood.

About 3 days after the 4 hour procedure, we started the weaning process to get me off the vent and onto the pacemaker, a very slow process for sure. I was told numerous times not to get discouraged with the lack of progress. It could take months before I saw any positive signs. I admit I was getting frustrated but I always reminded myself of what my doctors told me about how long the weaning might take. During the weaning process, my doctors were very encouraged by the results of our testing. My diaphragm was actually waking up from 4 ½ years of "being on vacation" as my doctors would say. When setting the ventilator on lower and lower settings my diaphragm would start working harder and harder which is exactly what we wanted to see.

It was now time to leave Shands and head back to New Jersey but not to my home just yet. First I needed to get some rehabilitation so I could learn to live home again and be as independent as possible. I went to Kessler Institute for Rehabilitation in West Orange, NJ. I felt very confident going to Kessler knowing their reputation of being one of the top rehab centers in the country. Along with getting physical therapy at

Kessler I was also going to continue weaning off the ventilator. I was told to get off the ventilator and see how long I could stay off. To my surprise I was able to stay off the vent longer and longer each day. First day an hour, second day 2 hours, third day 3 hours. Before long I was staying off the vent for 10 to 12 hours a day. I was amazed. After being on a ventilator 24/7 for 4 ½ years I was no longer tethered to it like a ball and chain. I was free to travel around in my wheelchair without lugging my vent with me. Everything I went through not only to get to Florida but to also have the surgery was all well worth it. Long ago I accepted the fact I would be confined to a ventilator for the rest of my life but now that is not the case. My quality of life has improved immensely. My next step after Kessler was to go HOME. That happened on October 18th, 2011. I was greeted by family, friends, TV and newspaper reporters and photographers. It was overwhelming to say the least.

I've had a few bumps in the road since I've been home but hopefully the worst is over.

Michael Stanzione, USA