

## From Vent to Diaphragm Pacing System: Part III

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If you've followed my blog and pursuit of the NeuRx Diaphragm Pacing System™ (DPS), you know that I wanted to be using the DPS by now. However, I still don't have a surgery date, although that could be decided soon. Allow me to explain.

My pursuit of the DPS is slightly complicated by two things: (1) I take a blood-thinner medication to prevent blood clots, and (2) I also wish to have my cardiac pacemaker replaced during the same trip to the operating room.

Neither is all that complicated, but because I have to come off my blood thinner prior to surgery and get back to a therapeutic level afterward, I only want to have one surgery. Having two entirely separate surgeries would essentially double the chance that I could develop a blood clot or get an infection. I don't believe that my risk for developing a blood clot and/or getting an infection is very high, however, either could be fatal for person like me who is quadriplegic, since our immune systems are fairly compromised (and blood clots can be dangerous for people with fantastic immune systems).

My original choice of hospital – Shands at the University of Florida (my alma mater) – will not allow me to have both procedures concurrently. I think Shands wants to ensure that I'm medically stable on my cardiac pace-

maker before doing the DPS; however they did not explicitly state that. I believe I'm stable now; my pacemaker battery has been dead for several years, and even when working, it's only designed to kick in if my heart rate falls below 60 beats per minute, which I was told almost never happens. I even asked our state representative to encourage Shands and my insurance company to come to an agreement, but that was to no avail.

Fortunately, Florida has multiple facilities that are approved for DPS surgery. Two surgeons – one for the DPS and one for cardiac – at the Orlando Regional Medical Center (ORMC) are comfortable with concurrent procedures and recommended that to the pre-registration department. Pending approval, a surgery date may be set soon.

Like many things in life, this has been a lesson in both patience and perseverance – and I will NOT give up, even if ORMC cannot or will not do the procedures together. Stay tuned for Part IV ... ▲

**MORE on** [www.ventusers.org](http://www.ventusers.org)

For more on Bill's pursuit of the NeuRx Diaphragm Pacing System™, see Parts I and II:

[www.ventusers.org/edu/valnews/val\\_24-2apr10pAll.pdf](http://www.ventusers.org/edu/valnews/val_24-2apr10pAll.pdf)

[www.ventusers.org/edu/valnews/val\\_24-3jun10pAll.pdf](http://www.ventusers.org/edu/valnews/val_24-3jun10pAll.pdf)

**The NeuRx Diaphragm Pacing System™** provides electrical stimulation to the diaphragm (through the implantation of four electrodes) to cause it to contract, thus eliminating or reducing the need for a ventilator. It has been FDA-approved in the United States for people with spinal cord injury since 2008 and is awaiting FDA approval for use in people with ALS (it has been approved for ALS use in Europe). More information on the NeuRx DPS is available from Synapse Biomedical Inc., [www.synapsebiomedical.com](http://www.synapsebiomedical.com)