

From Vent to Diaphragmatic Pacing System: Conclusion

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Ultimately our trip for my surgeries was successful, though not as successful as hoped. The primary successes were: replacing my cardiac pacemaker, getting x-rays of my chest and neck that I was given to view on CD and having actual outpatient surgery for my procedures (no overnight stay required, which limited my chances for infection). I'm now more than two months post-surgery, and I've healed well with no infections.

Missing from that success list is implementation of the NeuRx Diaphragm Pacing System™ (DPS). Even when inside my chest, with the electrodes placed on my diaphragm, my diaphragm wouldn't fire when stimulated by the DPS. My surgeon, Dr. Michael Cheatham, tried everything – even calling DPS inventor Dr. Raymond Onders (who trained Dr. Cheatham to do the DPS) for additional suggestions. It wasn't meant to be.

Dr. Cheatham indicated that my diaphragm apparently has zero innervation, as it was completely atrophied and much thinner than he typically sees. Even if it had fired, he was a bit apprehensive about placing electrodes into my diaphragm because it was so thin and he didn't want to damage anything.

Though I could have received several benefits from the DPS, I stand by my statement that I already have a high quality of life, and I'm not limited by the vent in the most important ways: speech quality and infections.

For a quadriplegic like me, my ability to talk well is of extreme importance.

And if you've heard me talk in person or via phone, I think you'll agree that I speak well and typically clearly, at an appropriate volume (when well hydrated) and with little pause between breaths. Only having a brief pause is thanks to a speaking valve, and also the ability to initiate another breath sooner than programmed, and also receiving fairly large breaths.

With the DPS, I was concerned about matching that quality because breaths cannot be initiated with the DPS, and the size of breath is smaller than what I receive via vent (quite possibly 30 percent smaller for me). That could have been mitigated by increasing my breath rate on the DPS, but only doing it could answer that question.

Also, my lack of significant respiratory infections for a vent user is fairly uncommon, and is represented by zero respiratory-related hospitalizations in the 13.5 years since I was discharged from my initial hospitalizations and rehab. I'm certainly not saying that my number of infections would have increased on the DPS (it could have,

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NEV®-100 has been discontinued by Philips Respironics. (www.ventusers.org/edu/faqNEV-100mar11.pdf) People who have been using the unit to power the Porta-Lung are advised to use either the Hayek RTX Respirator, www.unitedhayek.com, 866-361-4839, or Pegaso V from Dima Italia, www.dimaitalia.com, distributed in the USA by Porta-Lung, Inc., 303-288-7575.

Home Care Workers

Jim Lubin, who uses a vent and hires his own attendant care workers, recommends an excellent website from the Home Care Referral Registry of Washington State. The site provides useful resources. “Hiring and Supervising Your Home Care Worker” is available as both a print download and YouTube video. www.hcrr.wa.gov/Consumers2010/videos_guides.html

Vent Users in Taiwan

In February, polio survivors in Taiwan demanded that the Bureau of National Health Insurance (BNHI) cover home respiratory equipment. Joined by representatives of the opposition political party, they want the qualifications for reimbursement of home respiratory support changed. Currently home ventilators are provided free to those who have undergone 21 consecutive days of tracheotomy or intubation. It is estimated that there are approximately 1,800 people in the government-funded home respiratory support program annually.

The annual cost of home respiratory support, including respiratory equipment, maintenance fees and a therapist to provide regular check-ups, is estimated at NT\$500,000 (USD \$15,625), but the cost is too high for individuals and families. The BNHI will evaluate and review the reimbursement plan. ▲

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because I’m breathing through three filters on the vent and would have had one filter at most on the DPS) but it’s hard to beat zero in 13.5 years.

I’m not disparaging the DPS; I have two friends in particular who are benefiting significantly from the DPS, and I wanted to try it and potentially benefit from it. But I don’t want anyone reading this to think that life with a ventilator is a necessarily bad.

If my diaphragm had fired when stimulated by the DPS, I would’ve continued to embrace the challenge of becoming a successful DPS user.

But that is/was a very significant challenge that included learning and teaching my caregivers different ways of providing for my needs. For example, it would’ve placed a port on my stomach where the DPS connected that would’ve required care and careful bathing around it, etc. The point being, I think that we, as a team, are already good at life with a ventilator and largely see it as not that big of a deal.

No worries and God bless! ▲

MORE on www.ventusers.org

For more on Bill’s pursuit of the NeuRx Diaphragm Pacing System™, see:

Part I
www.ventusers.org/edu/valnews/val_24-2Apr10p5.pdf

Part II
www.ventusers.org/edu/valnews/val_24-3Jun10p4-5.pdf

Part III
www.ventusers.org/edu/valnews/val_24-5Oct10p4-5.pdf