# International Ventilator Users Network

An affiliate of Post-Polio Health International (PHI)

International Ventilator Users
Network's mission is to enhance the
lives and independence of home
mechanical ventilator users and polio
survivors through education, advocacy,
research and networking.

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Special thanks ...
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To be sure you receive email updates from PHI and IVUN, set your spam filters to allow messages from info@post-polio.org and info@ventusers.org.

# Networking

### From Around the Network

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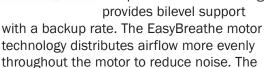
#### **Product News**

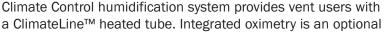
Ventilator users interested in changing their interface and/or ventilator should discuss the change with their pulmonologist and home health care provider.



Mirage<sup>™</sup> FX (*left*) is the newest nasal mask in ResMed's FX series. The lightweight mask utilizes the Spring Air<sup>™</sup> cushion for an even distribution of pressure and extra softness on the bridge of the nose. www.resmed.com/uk/products/mirage\_fx/

S9 VPAP™ ST, based on ResMed's S9™ series for sleep-disordered breathing, provides bilevel support









LTV® 1100 (left) is the latest portable ventilator in the LTV series from CareFusion. It is designed for vent users who need volume ventilation with pressure support; it does not provide pressure control. www.carefusion.com

**OPAP**, the oral interface described in *Ventilator-Assisted Living*, December 2010, aroused interest in ventilator users, but they experienced some difficulty in contacting the manufacturer. The OPAP Healthcare site – www.opaphealthcare.com – is being updated, but it provides the basic information on how the device works. Direct contacts are Larry Twersky, Ltwersky@1800snoring. com, 800-818-0598, and Scott Veis, Vice-President of Sales and Marketing, Appliance Therapy, scottv@appliancetherapy.com, 800-423-3270, ext. 4590.



 $\triangleright$ 

**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.

#### From Vent to Diaphragmatic Pacing System: Conclusion

continued from page 1

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\_24-3jun10 p4-5.pdf

Part III

www.ventusers.org/edu/ valnews/val\_24-5oct10 p4-5.pdf