

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.

Ventilator-Assisted Living

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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.



From Around the Network

Judith R. Fischer, MSLS, IVUN Information Specialist, info@ventusers.org

Product News

Pixi™ is a new nasal mask from ResMed for children over 2 years of age or weighing more than 13 kg (28.6 lbs). A soft silicone cushion minimizes pressure on the face, tubing has two positions for sleeping, and headgear has flexible stabilizers and quick release latch. Available worldwide. www.resmed.com



ResMed's Pixi™

HT®70S from Newport Medical Instruments is similar to the HT®70 ventilator but it does not provide pressure support or trends. For equipment specifications, visit www.ventilators.com.



Vent-Strap[®], from Pepper Medical, is used with the Trach-Tie[®] to provide extra security for the T-piece. www.peppermedical.com

Pepper Medical's Vent-Strap® Trilogy100, the Philips Respironics ventilator replacing the PLV®-100 series, is comprehensively reviewed

by vent user John Gugie, who has Duchenne muscular dystrophy. Go to www.associated content.com/ article/6073240/trilogy_100_ventilator_ from_philips.html?cat=5.



Philips Respironics' Trilogy100

NeuRx Diaphragm Pacing System (DPS)[™] from Synapse

Biomedical, Inc., recently received "Humanitarian Device Exemption" approval from the FDA for use in select patients with ALS. These individuals must have a stimulatable diaphragm, and their hypoventilation cannot have progressed to a forced vital capacity less than 45 percent of predicted.

For a clear explanation of how ALS affects breathing and how the system works, go to www.synapsebiomedical.com/ als/als-patientInfo.shtml.

MORE on www.ventusers.org

See "Update: NeuRx Diaphragm Pacing System (DPS)."

www.ventusers.org/edu/val news/val_24-1Feb10p4.pdf

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Muscular Dystrophy

Presentations from the Parent Project for Muscular Dystrophy's Connect Conference in July are available for downloading from PPMD's website. Several sessions were also streamed live, and those broadcasts are also available to view. Visit www.parentprojectmd.org and click on Connect, then Annual Conference.

Chronic Conditions in Young Adults

Physician-Parent Caregivers (PPC) is a nonprofit organization dedicated to advancing the independence and quality of life of young adults with chronic conditions and disabilities. Many people are not aware that these conditions are controlled, rather than cured, or that when children turn 18, they often fall through the patchy safety net of social and medical services. Recently PPC launched "Campaign Emerge" to increase the public's understanding of the "lived experience" and needs of these emerging adults. The campaign also calls for a conference to be convened to develop a system to address the healthcare needs of these young adults. http://physicianparent.org

Emergency Personnel: Responding to Vent Users

"Ventilator Emergencies in the Home" is the title of an article in the journal *Fire Engineering*. Author Francis Califano, an emergency management coordinator in New York, does an excellent job of presenting what emergency medical personnel need to know when called to the home of a ventilator user. An article by vent user Sandy Stuban, RN, is cited as a reference. www.fireengineering.com/articles/print/volume-164/issue-9/departments/ fire-service_ems/ventilator-emergencies-in-the-home.html

Join IVUN! ...and receive Ventilator-Assisted Living, IVUN's bi-monthly newsletter.

The eight-page newsletter will be sent electronically in February, April, June, August, October and December. (IVUN Members without email access may request print copies by contacting IVUN). Members will also receive an electronic *IVUN Membership Memo* in alternate months. To become a Member, complete this form. *Memberships are 100 percent tax-deductible.*

□ **\$30 Subscriber** – Bi-monthly *Ventilator-Assisted Living* and *IVUN Membership Memo* (both delivered electronically).

Yes, I want post-polio news, too.

□ **\$55 Subscriber Plus** – *Ventilator-Assisted Living* (bi-monthly; electronic) AND *Post-Polio Health* (quarterly; print)

□ **\$100 Contributor** ALL the benefits of Subscriber Plus AND Resource Directory for Ventilator-Assisted Living and Post-Polio Directory; discounts on special publications and meetings sponsored by IVUN

□ **\$150 Sustainer** ALL the benefits of Contributor AND one additional complimentary gift membership to:

Person of your choice (include name and address) or

 $\hfill\square$ Person who has expressed financial need to IVUN.

Yes, I want to support IVUN's mission of education, research, advocacy and networking and its comprehensive website, www.ventusers.org.

Membership at the following levels includes ALL benefits PLUS special recognition in IVUN publications:

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□ \$500 Silver □ \$1,000 Gold □ \$5,000 Platinum

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