

IVUN

International Ventilator Users Network

An affiliate of Post-Polio Health International (PHI)

“Ventilator Users Can Survive the System With Your Help”

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International Ventilator Users Network (IVUN) www.ventusers.org

IVUN RESOURCES

- **Resource Directory for Ventilator-Assisted Living.** www.ventusers.org/net/vdirhm.html
- **Home Ventilation Guide.** www.ventusers.org/edu/HomeVentGuide.pdf
- *Ventilator-Assisted Living*, newsletter. www.ventusers.org/edu/valnews/index.html
- Post-Polio Health International (PHI). www.post-polio.org
- Polio Place. www.polioplace.org;
- Post-Polio Experts Present. <http://www.polioplace.org/post-polio-experts-present-video-series>

LINKS RELATED TO VENTILATOR USERS

- **Chronic Critical Illness** “Chronic Critical Illness.” Daniela Lamas. *N Engl J Med* 370; 2: 175-177. www.nejm.org/doi/full/10.1056/NEJMms1310675
- **CoughAssist.** <http://coughassist.respironics.eu/>
- **Disability Rights**
[Centers for Independent Living. www.ilru.org/projects/cil-net/cil-center-and-association-directory](http://www.ilru.org/projects/cil-net/cil-center-and-association-directory)
- **Hospital Tales**
<http://dredf.org/healthcare-stories/2012/06/24/carol-gill-and-larry-voss/#more-165>

From the ICU to Homecare: a Patient’s Perspective, funded by the Chest Foundation.

<http://www.polioplace.org/resources/icu-homecare-patients-perspective>

- **IVUN Educational Conference Calls.** www.ventusers.org/edu/confcalls.html#pas
“Switching from the PLV-100, 102 (or other volume vents) to the Trilogy.”
www.ventusers.org/edu/PhilipsIVUNwebinar.pdf

“Understanding how new generation portable ventilators can lighten your load.”

www.ventusers.org/edu/valnews/val_26-6dec12p6-8.pdf

“Making a smooth transition and adding mobility.”

www.ventusers.org/edu/valnews/val_27-1feb13p4-5.pdf

“Tell me about a trach before I need one.”

www.ventusers.org/edu/valnews/val_27-2apr13p4-7.pdf

“How polio survivors can avoid tracheostomies.”
www.ventusers.org/edu/valnews/val_27-3jun13p3-5.pdf

“Dr. Braun Answers Ventilator Users’ Questions.”
www.ventusers.org/edu/valnews/val_27-4aug13p4.pdf

“Simple solutions.” www.ventusers.org/edu/valnews/val_27-4aug13p5.pdf

“Protecting every breath and improving patient comfort, SV9, VPAP, Stellar, and ResMed interfaces.”
www.ventusers.org/edu/valnews/val_275oct13p45.pdf

“My continuing medical education as a post-polio patient/physician.”
www.ventusers.org/edu/valnews/val_276dec13p15.pdf

“Biphasic cuirass ventilation and the United Hayek RTK ventilator.”
www.ventusers.org/edu/valnews/val_27-6dec13p3-4.pdf

- **European Survey**

“Patterns of home mechanical ventilation use in Europe: results from the Eurovent survey.” *Eur Respir J* 2005; 25: 1025–1031. <http://erj.ersjournals.com/content/25/6/1025.full.pdf>

- **Frogbreathing**

“Frogbreathing: A forgotten breathing aid.” www.ventusers.org/edu/valnews/val_24-3jun10p3-7.pdf

Frog Breathing by Gary McPherson. <http://www.inforesp.org/en/frog.html>

- **Guidelines & Consensus Statements**

Australia

2011. “Domiciliary Non-Invasive Ventilation in Adult Patients.”
www.health.nsw.gov.au/gmct/respiratory

Canada

2011. Canadian Thoracic Society. “Guideline. Home Mechanical Ventilation.”
www.respiratoryguidelines.ca/2011-cts-guideline-hmv

Germany

2010. “Guidelines for Non-Invasive and Invasive Mechanical Ventilation for Treatment of Chronic Respiratory Failure.” www.thieme.de/pneumologie

United Kingdom

2009. “Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient.” *Thorax* 2009;64 (Suppl I).

2012. “Respiratory Management of Children with Neuromuscular Weakness Guideline Group On behalf of the British Thoracic Society Standards of Care Committee.” *Thorax* 2012;67(Suppl1).

USA

2010. American Academy of Sleep Medicine. "Best Clinical Practices for the Sleep Center Adjustment of Noninvasive Positive Pressure Ventilation (NPPV) in Stable Chronic Alveolar Hypoventilation Syndromes." *Journal of Clinical Sleep Medicine*, 2010. Vol. 6, No. 5.

2007. American Association of Respiratory Care. "AARC Guideline: Long-term Invasive Mechanical Ventilation in the Home, 2007 Revision and Update." *Respiratory Care*. 2007:52 (No 1).

1998. American College of Chest Physicians. "Mechanical Ventilation: Beyond the Intensive Care Unit: Report of a Consensus Conference of the American College of Chest Physicians." *CHEST*, 1998:.113:5 Supplement.
<http://journal.publications.chestnet.org/issue.aspx?journalid=99&issueid=21766&direction=P>

2007. American College of Chest Physicians. "Consensus Statement on the Respiratory and Related Management of Patients with Duchenne Muscular Dystrophy Undergoing Anesthesia or Sedation"
<http://journal.publications.chestnet.org/article.aspx?articleid=1085579>

2010. American Thoracic Society. "An official ATS Policy statement: Congenital central hypoventilation syndrome."
www.thoracic.org/statements/resources/pldd/congenital-central-hypoventilation-syndrome.pdf

2010. American Thoracic Society. Breathing in America.
<http://thoracic.org/education/breathing-in-america/index.php>

2004. American Thoracic Society. "Respiratory care of the patient with Duchenne muscular dystrophy." www.thoracic.org/statements/resources/pldd/duchenne1-10.pdf

- **Intermittent Mouth Positive Pressure Ventilation**

"My Experience with Setting up Day-time Ventilation."
www.ventusers.org/edu/valnews/VAL_23-3fa09p8.pdf

"Non-invasive Assisted Breathing" video, Josh Benditt and Louie Boitano, University of Washington. <http://uwtv.org/watch/F-Rgdbbtmrg/>

Snap-loc jointed tubing and connectors. www.cedarberg.com/

- **Iron Lung**

The Iconic Iron Lung and Polio Survivors in the USA."
www.post-polio.org/edu/pphnews/pph30-1b.html

- **Lung Volume Recruitment**

"Airway Clearance and Lung Volume Recruitment for Individuals with Neuromuscular Disease."

www.ventusers.org/edu/valnews/val_25-4aug11p1etc.pdf

- **Poliomyelitis: History and medical treatment.**

www.polioplace.org/history; www.polioplace.org/medical-articles

Networks: Home care. "Care for polio patients." Joan Headley. *CHEST Physician*, July 2014, 9:7; 24. www.chestphysician.org

- **Sleep**

Breathing and Sleep Symposium, 2009, The Salk Institute. http://poliotoday.org/?page_id=761

"Breathing and Sleep Problems in Polio Survivors." Nicholas Hill.

www.ventusers.org/edu/BreathingSleepProblems06-2010.pdf

"Tests for Breathing Problems If You Have a Neuromuscular Condition." Nicholas Hill.

www.ventusers.org/edu/TestsforBreathingProblems06-2010.pdf

Sleep Strategies: targeting the neuromuscular disease patient." Lisa Wolfe. *CHEST Physician*. March 2014, 9:3; 28, 31. www.chestphysician.org

- **Travel**

www.ventusers.org/adv/Flying-AirlineList.pdf

www.ventusers.org/adv/AirGovPoliciesResources.pdf

www.ventusers.org/adv/articles.html