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.

Ventilator-Assisted Living

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Special thanks ...
Judith R. Fischer, MSLS

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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

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

New Products

Amara, a new full-face mask from Philips Respironics, is smaller and lighter than most traditional full-face masks. The mask cushion snaps into the mask frame. Available in petite, small, medium and large sizes, only in the USA.

www.healthcare.philips.com/us_en/homehealth/sleep/amara/index.wpd

Quality of Life Grants

CMMS Deshae Lott Ministries is accepting quality-of-life grant applications from individuals needing funds to live outside of an institution or to supplement their medical coverage (if grant would not disqualify the individual from his or her other means of medical coverage). Deadline is November 1. Grant awards will be announced by the end of the year. www.deshae.org/cmms/qlgrant.pdf

Care and Management of Ventilator-Assisted Children

Guidelines for Pediatric Neuromuscular Weakness

Recently released is an excellent and comprehensive resource: "The British Thoracic Society (BTS) guideline for respiratory management of children with neuromuscular weakness." Lead author is Dr. Jeremy Hull, Oxford University Hospitals, NHS Trust.

Sections include respiratory complications of neuromuscular weakness; identification of children at risk of respiratory complications; airway clearance and respiratory muscle training; types of assisted ventilation; planning for surgical procedures; scoliosis; feeding and swallowing difficulties and transition to adult care. Also included are social and ethical considerations such as quality of life, palliative care and end-of-life care, in addition to an extensive bibliography and appendices.

The guidelines are available to everyone at www.brit-thoracic.org.uk/ Guidelines/Children-with-Neuromuscular-Weakness.aspx. For more information, contact jeremy.hull@ouh.nhs.uk.

"Home Noninvasive Ventilation: What Does the Anesthesiologist Need to Know?" is a good companion to the BTS pediatric guidelines above. There are no practice guidelines on perioperative management of ventilator-assisted children, but this article, by a group of Canadian pediatric pulmonologists led by Karen Brown, MD, Montreal Children's Hospital, is a good beginning. It appeared in Anesthesiology 2012, 117(3), but is only available free to subscribers. Nonsubscribers can purchase it online at http://journals.lww.com/anesthesiology

The ways in which home noninvasive ventilators work in children (also relevant to small adults and those with poor respiratory muscle strength and drive) are thoroughly explained: triggers,

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QUESTION: I have seen pictures of mouthpiece ventilation, but would like more details on how to set it up. Can someone describe theirs?

ANSWER: Jacob Gapko, Eau Claire, Wisconsin, gapkoja@ yahoo.com

Here is the setup I use with my LTV® 950 ventilator which has specific settings for the NIV mode.



My setup starts with an air tube straw, connected to a 3.5 mm adapter ET, connected to a patient circuit, connected to a bacterial/viral filter and

finally to an elbow adapter. A microphone gooseneck supports the setup and holds the straw close enough to reach.

Manufacturers, part numbers, and contact information:

- air tube straw (disposable), part # 32698 (10 Pack), part #32662 (100 Pack) from Therafin. www.therafin.com/ controlaccessories.htm. I obtain mine drop-shipped from Express Medical, 636-349-8448. Ask for Kris Winston.
- 3.5 mm x 15 mm adapter ET, part #501003035 from Rusch, part of Teleflex Medical. www.teleflex.com
- patient circuit with PEEP, 22 mm, from CareFusion SPU (P/N 10820X10). www.carefusion or Customer Service, 877-754-1914.
- elbow adapter, standard 22 mm I.D. x 22mm O.D., Cat. No. 1641, from Hudson RCI, part of Teleflex Medical. www.teleflex.com
- bacterial/viral filter, Cat. No. 1605, from Hudson RCI. Go to www.hudsonrci.com/How/locator.asp for distributors near you, plug in your ZIP code or contact Teleflex Medical directly, 866-246-6990.



Marilyn Keen, the respiratory therapist at my home health company, Reliable Medical Supply, will be glad to answer questions about the setup. Call her at 763-255-3853. www.reliamed.com.

Since secretion clearance is an important part of NIV, I have incorporated the CoughAssist® and the InCourage™ airway clearance systems into my daily routine. Using both takes 30 minutes per session three times per day when I am healthy. I use them more often when I get a respiratory infection. I also have a standing order for antibiotics in case I cannot get in to see my doctor. Without antibiotics, it is very easy for a respiratory infection to develop into pneumonia, even when it starts as a viral infection. In the last decade I have been hospitalized only twice.

From Around the Network continued from page 2

interfaces, leaks, circuitry, rebreathing, to name a few. In addition, the design features of home ventilators as Class I and Class II Medical Devices by the Organization for International Standardization are listed.

Recommendations include both preoperative and postoperative management of these children (involving close monitoring of oxygen saturation and cardiorespiratory status); and transition back to home NIV system and liaison with home ventilation program before dis-

charge. To contact Dr. Brown, email roula.cacolyris@muhc.mcgill.ca.

Flu Vaccine 2012-2013

The U.S. Food and Drug Administration (FDA) voted to adopt the World Health Organization's recommendation for the Northern Hemisphere's 2012-2013 seasonal influenza vaccine. The vaccine viruses include: H1N1 virus (same as used in the 2011-2012 vaccine), H3N2 vaccine and B vaccine.

To meet estimated demands of the upcoming flu season, drug manufacturer Novartis launched delivery

of more than 30 million doses of its seasonal flu vaccine – Fluvirin® – to provide the earliest possible protection against the flu. Fluvirin vaccine, reformulated to include the two new strains, is FDA-approved for patients 4 years of age and older. www.cdc.gov/flu/about/season/upcoming.htm

People are advised to get the vaccine as soon as it becomes available, and local pharmacies are already advertising "flu shots."

For more on how you can protect against flu, go to www.flu.gov.