**INTERNATIONAL VENTILATOR USERS NETWORK**
AN AFFILIATE OF
POST-POLIO HEALTH INTERNATIONAL

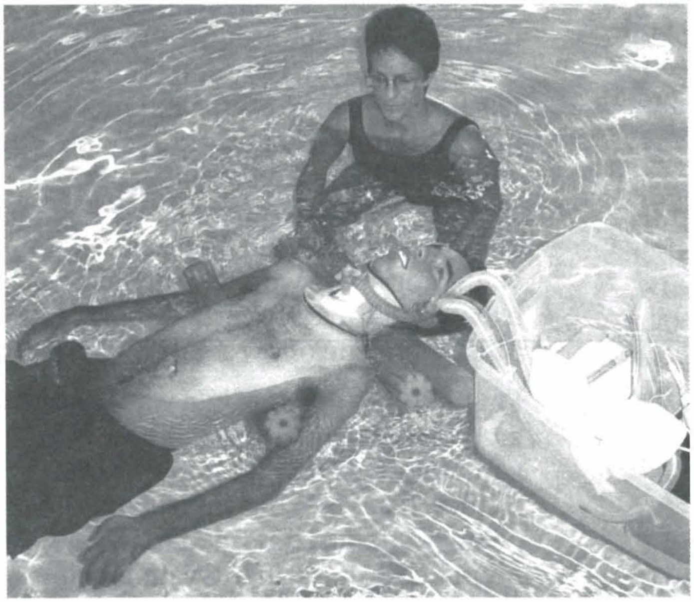
VOLUME 18, NO. 4, WINTER 2004

VENTILATOR-ASSISTED LIVING
SAINT LOUIS, MISSOURI
WWW.POST-POLIO.ORG/IVUN

# The Ventilator Boat: Will It Float?

Eric S. Obermann, Huntsville, Alabama (eric.obermann@comcast.net)

I was only 18 when the first symptoms appeared. I noticed that my tongue was getting harder to move. The next thing I detected was air leaking from my nose while playing my clarinet. Before I knew it, I was off at college and having a great time. Then I vomited and aspirated. I did not know it then, but I had just given myself my first case of pneumonia.



I was barely able to drive home (four hours) from college with this pneumonia. Two weeks later, we drove to Saint Louis to see a neuromuscular specialist. I was not feeling well, and by the time I saw the doctor, I was in respiratory distress and was admitted directly to the neurological ICU where I was intubated for my first vent experience. Even though I now had a trach with a cuff, I continued to get recurring bouts of pneumonia. I then decided to undergo a laryngectomy in order to prevent any possibility of aspiration.

I remember that after this procedure the hospital nurse told me that I could never take another shower ever again, and I became very depressed. Fortunately for me I have very determined parents who figured out how I can shower with my vent: I wrap a hair stylist's water-resistant apron around my neck.

Last summer we went on a family vacation to North Carolina, and we had a private pool. I decided that I wanted to take a dip and asked my uncles to lower me into the pool in my shower chair while keeping my neckline above the water. When I first hit the water I became alive! It is an amazing feeling to be immersed in water when you haven't been for over two years. One of the big benefits of being in the water is that I can move my limbs, which I normally can't on land. It also refreshes my sore back after days in a wheelchair.

I am now a quadriplegic at age 23. The specialists think I have a progressive ALS-like motor neuron disease but are still hesitant to label it ALS. I wear a cervical neck brace at all times because I have no muscle control in my neck. I use the LTV® 900 (Pulmonetic Systems, Inc., www.pulmonetic.com) ventilator with volume control 24 hours/day. My pulmonologist, Daniel Goodenberger, MD, Washington University in Saint Louis, suggested the LTV for traveling – an Alaskan cruise – and swimming. The LTV's laptop size and light weight give it the portability for travel and for activities like aquatic therapy.

To swim, I sit in a wheelchair, and my physical therapist lowers me into the water via a swimming pool ramp. Then I float out of the chair. She supports my neck

continued, page 2

# My Dream: Scuba Diving!

Matt Johnston, Woodbury, Minnesota (www.scubadivingdream.com)

I'm 27 years old and use a custom tracheostomy tube and volume ventilation. I need to use a ventilator due to Duchenne muscular dystrophy. I have been working very hard at my dream to scuba dive and have contacted many people in the scuba diving industry. Other divers and people in the medical field say it is "do-able." I would be very happy just to spend 10 minutes and to go just 5 to 10 feet below the surface, because the underwater realm fascinates me.

I have made many friends in the diving world, especially through Divers Unlimited International (DUI) in San Diego whose president is Susan Long. Her company has been incredibly supportive of my dream and they plan to help at dive time. The biggest challenge is finding a way to dive with the right kind of ventilator underwater.

Project Innerspace, a Rhode Island-based nonprofit group whose mission is to address critical human health issues through ocean exploration, is sponsoring me with a contribution of first-stage program development and management. The group believes in advancing technology through the development of a new ventilator that can withstand submersion and with a system capable of operating at increased pressure.

In the meantime, I plan to experiment with the HT50® (Newport Medical Instruments, Inc., www.ventilators.com) inside a backpack strapped to my body inside a DUI dry suit. The HT50 has been tested to withstand pressures up to 2.1 atmospheres. Next, an air supply (either via an air line at the surface or via an air tank carried by another diver) would feed into the ventilator; there would be a one-way exhalation valve for carbon dioxide. This is just one of my many ideas.

I'm planning the dive in a warm water area (San Diego or Florida) in the summer of 2006, but I hope to do it sooner. If anyone has information or suggestions, I'd be glad to receive them: roadrunnermatt@yahoo.com. Thank you. ●

## The Ventilator Boat: Will It Float?

continued from page 1

above the water and uses two 'noodle' Styrofoam floats behind my neck brace to keep the trach dry. I inflate the trach cuff a few extra cc prior to the swim. Originally, we set the ventilator next to the pool but now use a plastic 9-gallon container to hold the ventilator and battery. This floats beside me while someone supports the tubing and assures that the "vent boat" floats. I can then swim and move about the entire pool and even do weight-bearing walking; in the gravity world, I can't even budge. Swimming with my ventilator boat – I look forward to it every week. ●

# PHI Grant Awarded to Johns Hopkins Team to Study Early Use of Noninvasive Ventilation

Post-Polio Health International, of which International Ventilator Users Network is an affiliate, announced that it has awarded a $25,000 research grant to a team from Johns Hopkins University. The researchers propose to determine whether early use of noninvasive positive pressure ventilation (NIPPV) prolongs survival in patients with amyotrophic lateral sclerosis (ALS) and to relate their findings to other neuromuscular diseases including polio and its late effects.

ALS, also known as Lou Gehrig's disease, is a progressive neurodegenerative disease that attacks nerve cells in the brain and spinal cord resulting in muscle weakness, atrophy and, eventually, death. The respiratory muscles are invariably affected, and respiratory failure is the most common cause of death in ALS patients.

NIPPV is becoming an increasingly standard treatment for patients with chronic respiratory failure, and observational studies suggest that NIPPV prolongs survival, but it is not known whether it modifies disease progression or simply provides support in the terminal stages of the disease. Currently, guidelines recommend starting NIPPV when a patient's forced vital capacity – a measure of breath exhalation – falls below 50 percent of the predicted value.

The Johns Hopkins study aims to determine whether NIPPV is more beneficial in prolonging survival if it is started earlier in the course of ALS. The study will also attempt to determine if a point can be identified at which survival is maximized.

"If our study demonstrates prolonged survival in patients who begin using NIPPV earlier than currently recommended, it will have profound implications for how patients with ALS and other neuromuscular diseases are managed," said Principal Investigator Dr. Noah Lechtzin, instructor of medicine in the Division of Pulmonary and Critical Care Medicine at Johns Hopkins University. "It will suggest that a more proactive approach is beneficial. This study could alter this passive approach to patient care."

"Although the patients in the present study have ALS, we believe that the results will apply to a majority of the people we serve with post-polio syndrome, as well as to those with other neuromuscular diseases such as muscular dystrophy, spinal musclar atrophy and multiple sclerosis," said Joan L. Headley, executive director of Post-Polio Health International.

Others on the Johns Hopkins team in addition to Dr. Lechtzin include Nurse Coordinator Lora Clawson, director of clinical research in the ALS Center, and Research Assistant Anne M. Lang, in the Division of Pulmonary and Critical Care Medicine. Dr. Gregory B. Diette, assistant professor of medicine, and Dr. Charles M. Wiener, associate professor of medicine, both also with the Division of Pulmonary and Critical Care Medicine, will act as consultants to the study.

The Research Fund of Post-Polio Health International was established in 1995 to seek scientific information leading to eventual amelioration of

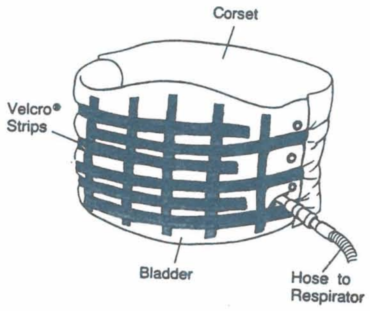
continued, page 9

# The Pneumobelt: Part of My Noninvasive Ventilation System

Tedde Scharf, MA, Tempe, Arizona (tedde@asu.edu)

I work fulltime as assistant dean at a large university and lead a full social life. The pneumobelt has made this possible because it provides hands-free assisted ventilation without any apparatus around my face. The only evidence that I use an assisted breathing device (due to limb-girdle muscular dystrophy) is the tubing around the side of my Permobile 2K wheelchair and the whooshing sound of the ventilator.

The pneumobelt, also known as an exsufflation belt, consists of an air bag or rubber bladder inside a cloth corset that is worn around the abdomen just under the diaphragm. It is connected by tubing to a ventilator that alternately inflates and deflates the bladder. As the pneumobelt inflates, it applies pressure up under the diaphragm to force air out of my lungs for exhalation. Then the bladder deflates, lowering the diaphragm, allowing air to rush back into my lungs passively for inhalation.



The ventilator settings can be set to provide a smooth, natural inhalation and exhalation, as well as a natural breathing rate for speaking. I use the LTV® 950 (Pulmonetic Systems, Inc., www.pulmonetic.com) to power my pneumobelt.

Because the pneumobelt works with gravity, it is only effective in the sitting and standing positions and cannot be used at night in the supine position. Other forms of noninvasive interfaces such as a face mask, a nasal mask, nasal pillows, or oral masks and mouthseals can be used for nocturnal ventilation. I use a custom Lyon nasal mask at night.

Commercial pneumobelt "corsets" and air bladders are available through Respironics, Inc. (www.respironics.com). The air bladder can be purchased separately from Respironics, the sole manufacturer. Many pneumobelt users have custom corset casings made by prosthetic/orthotic companies because the commercial corset is not very comfortable. The narrow nylon straps can cut into your sides. I wear a cotton T-shirt under the pneumobelt with thin foam pads to prevent pressure sores on my ribs and hipbones. Dr. Scholl's gel pads for shoes work well.

Currently, I'm experimenting with a new custom pneumobelt corset that utilizes 3" wide elastic belting found in low-back support belts. Its four straps are crossed in the back, attached to a sturdy but soft fabric that wraps partway around my sides (curved wider at the bottom to fit my hips). I've used this belt for about two months, sometimes up to 16 hours a day, and it's very comfortable – no extra padding needed.

During the day, I carry around a small mouthpiece attached to a short rubber flexible tube with common ventilator connectors. When I need to transfer out of my wheelchair, I disconnect the ventilator tubing from the pneumobelt (to prevent accidentally leaning on, overcompressing or blowing a hole in the air bladder) and attach the mouthpiece to the tubing. It's important to protect the air bladder from permanent damage from too much pressure when my caregivers lean me forward during caregiving. I also use this mouth intermittent positive pressure ventilation (MPPV) while bathing, dressing and undressing. MPPV is handy when I'm tired, need a little more ventilation or want to recline to watch television.

I have learned – the hard way – to always change the ventilator settings to lower volumes when transitioning from the mouthpiece to the pneumobelt to prevent accidental over-inflation and blowing a hole in the air bladder. The newer pneumobelt air bladders are tougher and less likely to overinflate. Generally, the air bladder lasts me a year or longer and, with the standard corset, costs about $800.

I augment my breathing during the day by frog breathing (gulping air into the back of my throat and forcing it into my lungs with my tongue). I can breathe this way for about 20 to 30 minutes if I'm sitting upright. In a reclined position, it takes more effort, but it is still life-sustaining. I highly recommend learning this technique; it is invaluable when equipment breaks down and for a change between other assisted breathing methods.

In emergencies, I use an Ambu® bag (manual resuscitator) and keep one handy in my office, near my bed and always take one when traveling. I also keep backup tubing, connectors and mouthpieces readily available. ●

Tedde's article, "Noninvasive Ventilation: A Successful Changeover," appeared in *IVUN News*, Spring 1996, Vol. 10, No. 1.

## "Strategies for Living Well"

### Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living

**June 2-4, 2005, Marriott Saint Louis Downtown, Missouri**

*Topics of particular interest to ventilator users include:*

- ✦ Maintaining Pulmonary Health: What You Can Do
- ✦ The Importance of Cough
- ✦ A Tracheostomy: What, Why and When
- ✦ Management of Neuromuscular Breathing Problems: The Danish Way
- ✦ Ventilator Users: Getting Your Act Together and Taking It on the Road
- ✦ Travel Tips
- ✦ Interfaces: New, Tried and True, and Custom
- ✦ Have a Pulmonary Function Test (PFT): It's Painless
- ✦ Anesthesia Precautions for People with Neurological Conditions
- ✦ The Latest in Ventilatory Equipment
- ✦ Service Dogs for People with Neuromuscular Conditions and Those Who Use Vents
- ✦ The Right Ventilation at the Right Time
- ✦ Analyzing Your Sleep: Is It Apnea, Hypoventilation ... or Both ... or Something Else?

*Complete program and registration information will be available online in late January: www.post-polio.org. Members of International Ventilator Users Network (IVUN) will be notified by mail or email.*

# Planning for Elective Surgery

Louie Boitano, MS, RRT, Northwest Assistive Breathing Center, Pulmonary Clinic,
University of Washington, Seattle (boitano@u.washington.edu)

Almost everyone who is scheduled for elective surgery needs a pre-operative evaluation in order to determine health status and to plan for pre- or post-operative care that will best support them through the surgery. A pre-operative evaluation for a person with a neuromuscular condition who is scheduled for surgery must include a thorough respiratory assessment and detailed medical history.

While physical limitations may be apparent to the evaluating physician, mild to moderate respiratory limitation can be overlooked if the person does not express any symptoms. An individual with slowly developing respiratory muscle weakness may not even be aware of respiratory limitations.

**Respiratory Evaluation.** Pulmonary function testing should include a forced vital capacity test in both sitting and supine positions if possible, maximum inhalation and exhalation pressure tests, a peak cough flow test, and an arterial blood gas test. These test results are used to measure respiratory muscle strength and to screen for lung or diaphragmatic problems that can affect breathing.

If you have questions regarding potential surgery and your neuromuscular respiratory status but do not have access to a pulmonary physician who is experienced in neuromuscular diseases and conditions, you may be able to find such a physician in your region by consulting IVUN's *Resource Directory for Ventilator-Assisted Living* (www.post-polio.org/ivun/d.html).

A history of sleep-related problems including snoring, frequent awakening during the night, frequent need to urinate more than once per night, nightmares, awakening with headaches in the morning or excessive daytime sleepiness can indicate sleep apnea and/or underventilation related to respiratory muscle weakness. The inability to sleep flat on one's back because of feeling short of breath (orthopnea) can indicate diaphragm muscle weakness.

Night-time pulse oximetry to monitor blood oxygen saturation (optimal is >95%) and a diagnostic sleep study may be necessary to screen for sleep-disordered breathing. If a sleep study is found to be positive, an additional positive airway pressure (PAP) study should be performed to determine the level of noninvasive positive pressure ventilation (NPPV) needed to provide optimal night-time breathing support. Ideally, if the surgery is elective, there will be time to become comfortable using NPPV support prior to surgery.

Swallowing function must be evaluated before surgery to determine an individual's ability to prevent anything but air from entering the lungs. Weak swallowing muscles can limit one's ability to protect the airway following surgery. While poor swallowing function will not affect the ability to undergo some surgical procedures, it may determine the level of support in monitoring the individual's airway both during and following the surgery.

**Planning.** Once the pre-operative evaluation is completed, a plan of care can be developed that best supports the individual's needs during and after the procedure. The planning team should include the surgeon or physician performing the procedure, the anesthesiologist, if one is needed, and the individual's pulmonary physician. The care plan depends upon the type of surgery, the need to use either general

Ventilator user Larry Becker wrote about his experiences, "Sedation for Surgery," in *Ventilator-Assisted Living*, Fall 2003, Vol. 17, No. 3. (www.post-polio.org/ivun/val_17-3b.html#sed or contact IVUN).

anesthesia or conscious sedation during the procedure, and the individual's degree of respiratory muscle weakness.

Individuals who already use continuous noninvasive respiratory support are also viable candidates for most surgical procedures, if they do not have other complicating conditions such as heart disease. Additional pre-operative planning will be needed in determining the feasibility of using the individual's personal home ventilator and the coordination of respiratory support from noninvasive to invasive, if needed for the surgical procedure, and then from invasive to noninvasive back again at the appropriate time.

The type of procedure and the time it takes are important factors. Procedures such as a gastric tube placement or colonoscopy requiring conscious sedation are relatively minor and short in duration. They can be well supported using NPPV along with airway monitoring by someone experienced in noninvasive respiratory support. In almost all cases requiring general anesthesia, the person must have a breathing tube placed during the procedure to provide breathing support and to protect the airway.

**Post-operative care.** Noninvasive breathing support can be immediately started once the patient awakens from anesthesia and the breathing tube is removed. If the individual is already using NPPV, he or she should have consulted with the team about bringing his or her own ventilator to the hospital to use at this time. Depending upon the type and length of the surgery, resumption of NPPV can occur in the operating room, the post anesthesia recovery unit or in the ICU.

Post-operative pain can limit an individual's ability to breathe and cough adequately. This is especially true for individuals with neuromuscular conditions. However, post-operative pain control may often require pain medications that can also affect an individual's ability to breathe independently. For this reason, a person should continue to use NPPV following surgery with a backup respiratory rate that insures enough support if breathing becomes depressed by the amount of medication necessary to control the pain.

The placement of a breathing tube in the throat during general anesthesia often causes discomfort after the tube is removed. Because the breathing tube is a foreign object in the airway, the body often reacts to the tube by producing more secretions for a while after the tube is removed.

An individual with a weak cough, evidenced by a peak cough flow less than 200 L/minute, who is also taking pain medication, will have difficulty clearing secretions after surgery. A mechanical cough assist device such as the CoughAssist™ (J.H. Emerson Co., www.coughassist.com) should be available to aid in secretion clearance as needed during post-operative recovery.

An individual undergoing a significant surgical procedure requiring general anesthesia will be closely monitored in post-anesthesia recovery and in the ICU to ensure optimal respiratory support and cough augmentation during the first 24 hours following surgery. ●

# Home Care for Children in Holland

Trudi Taat-Krakeel, Home Ventilator Nurse, Sophia Children's Hospital, Rotterdam, The Netherlands
(g.taat@erasmusmc.nl)

It is better for children who need more care to live in their own home with their whole family. In Holland, most of the children who use 24-hour ventilation live at home with their parents. The responsibility of caring for these children is constant, but they can apply for a Person Committed Budget (PCB). A special committee looks at the total amount of care the parents must provide the child, and it determines a budget that the parents can use to hire people to help look after their child. (The parents' income is not a factor.) The people can be nurses or friends or a member of the family.

There are also houses that have been adapted for ventilator-assisted children, who can stay for a few days while their parents have some time for themselves. The children can stay one or two weekends per month and even for a holiday vacation. The people who work in these houses are not nurses, but specially trained people taught by the nurses of the Center for Home Ventilation. An additional option is a house where children live during the week and go home on the weekend.

## The Story of Anouk

*As told by her mother, Danielle Vink*

Our daughter, Anouk, was born six years ago with Pompe's disease, a serious muscle/metabolic illness. It was estimated that she would not live beyond a year.

Because it was our last recourse, we enrolled Anouk in a trial of enzyme replacement therapy when she was seven months old. She started receiving weekly enzyme replacement therapy by an infusion at the Sophia Children's hospital. At that time, Anouk needed 24-hour assisted ventilation via tracheostomy.

Anouk spent the first two years of her life in hospital because our house was not adapted for her. When it became clear that Anouk was not getting worse, we decided to take Anouk home with us. The home ventilation team looked for a suitable home ventilator, which was difficult because Anouk weighed only 10 kilograms. Finally, we went home with the BiPAP® Synchrony (Respironics, Inc., www.respironics.com).

From the moment Anouk came home, we used PCB to engage nursing assistance to help us with her care so that now and again we can go out to "recharge our batteries."

When Anouk was 4 years old, her condition became stable, and we started looking for a suitable school. We found a special school in our neighborhood, but no one there knew how to use the ventilator sufficiently. So we created a team of people who could provide that kind of care. The team (three nurses) stays the whole time with Anouk – monitoring her equipment, suctioning her and helping with her schoolwork. I trained them myself, so that everyone provides care for Anouk in the same way.

Anouk has been attending school for two years. She spends four days a week at school. The taxi comes for her at 8:15 am and brings her home at 3:15 pm. I don' t go with Anouk to school –

she must learn to function without me and I can learn to release her. Of course, I always will be there in the background.

I provide Anouk's care when she is at home; it is a daily routine that I like to do in our family. For my other daughter, it is pleasant that we are a family and that there are not always other people in our home. Sometimes we have a short holiday together while someone else, paid by money from the PCB, looks after Anouk.

In the past few years, we have found a good balance, with everyone positive about this way of caregiving in the family. I recently started to work in the evening hours, and Anouk's father is looking after her very well.

The opportunity to apply for the PCB makes it possible to have Anouk with us at home, and we are together, one happy family. ●

---

### PHI Grant Awarded to Johns Hopkins

continued from page 3

the consequences of poliomyelitis and/ or neuromuscular respiratory diseases. This is the third grant to be awarded. Complete reports on the first two research studies – *Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life* and *Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress* – are available on Post-Polio Health International's website, www.post-polio.org (click on Research). ●

## Potpourri

**John J. Downes, MD, FCCP,** received the Margaret Pfrommer Memorial Lecture Award in Long-Term Mechanical Ventilation from the American College of Chest Physicians (ACCP) at its annual meeting in October 2004. Dr. Downes is Medical Director of the Pennsylvania Ventilator-Assisted Children's Home Program, which he established in 1979 at the Children's Hospital of Philadelphia. He is also Professor Emeritus of Anesthesia and Pediatrics at the University of Pennsylvania School of Medicine in Philadelphia. A well-deserved award to a caring, compassionate physician devoted to his patients and their families.

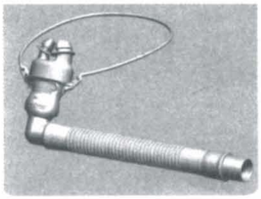
**Over 5 Years Club** is a project of Lee Kramer, who was diagnosed with ALS in 1992. Lee maintains an email network of people with ALS who have survived for five years or more. His network numbers more than 150 people and includes Professor Stephen Hawking, the renowned physicist, diagnosed with ALS at age 21 in 1963. To join Lee's club and network, email ranger-1@pacbell.net or visit http://home.pacbell.net/ranger-1.

**Virginia Nelson, MD,** and her team in Ann Arbor at the University of Michigan Health System Pediatric Home Ventilator Program recently received recognition as Clinical Program of the Year for the health system.

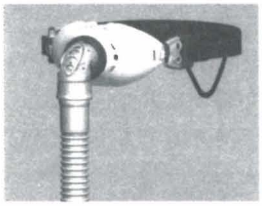
**CILB (Citizens for Independence in Living and Breathing)** disbanded as a formal organization in 2004, but the website is still being maintained: http://webhome.idirect.com/~cilb. Videos of CILB's 1996 and 2001 conferences are still available. Email Tom Wagner (tomwagner@sympatico.ca) for descriptions and order forms. To order, contact VCR Active Media, Ontario, Canada: 905-629-2553, 905-629-3437 fax, sales@vcractive.com.

**Paul Longmore, PhD,** is the recipient of the 2004 Henry B. Betts Award. A ventilator user due to polio, Longmore helped to establish and now directs the Institute on Disability Studies at San Francisco State University. Longmore is considered a major founder of the field of disability studies and is an internationally recognized spokesperson for the rights of people with disabilities. He has committed himself to changing the lives of people with disabilities who want meaningful work but fear loss of public benefits that pay for healthcare, disability equipment and personal assistance. ●

## Interfaces



**Infinity® 481**, the new nasal pillows interface from Fisher & Paykel Healthcare (www.fphcare.com, 800-446-3908), features a ball and socket-styled joint base with a contoured silicone seal anatomically shaped to the nostrils. The seal is available in four sizes.



**Oracle® 452**, the latest model of Fisher & Paykel's mouthseal, has been redesigned for better comfort and fit.

**The Aura™** nasal pillows system is manufactured by a new company called AEIOMed (www.aeiomed.com, 866-722-2507). The tubing follows the center of the face and does not interfere with vision or wearing glasses. The headrest helps hold the pillows in place, but does not touch the face at any point. Contact the company directly about distribution.

**7600 Vmask™ face mask** from Hans Rudolph, Inc. (www.rudolphkc.com, 800-456-6695) is made of soft silicone and available in five sizes. The mask features 360° dual swivel elbow port, holes for $CO_2$ exhaust, and quick-release lightweight headgear. It is also dishwasher safe.

## Equipment

**GoodKnight® 425**. This new bilevel ventilator from Puritan Bennett (www.puritanbennett.com, 800-635-5267) weighs 1.5 lbs, and is small and compact with dimensions of 3" high x 5.5" wide x 8" deep. It features an adjustable ramp time and automatic altitude compensation. Accessories include a portable battery pack and cigarette lighter adapter. Respiratory therapists and sleep physicians and technicians can use the hour and compliance meters to track patient use.

**Power Source Information for LTVs.** Pulmonetic Systems, Inc. issued a letter to customers in December 2004 notifying them that the company is replacing power boards in all LTVs affected by a recall caused by a power switchover problem. They also issued a product bulletin "Choosing and Using the Proper Power Source for the LTV." Visit www.post-polio.org/ivun/index.html.

## INTERNATIONAL VENTILATOR USERS NETWORK

AN AFFILIATE OF

POST-POLIO HEALTH INTERNATIONAL

## MEMBERSHIP OPPORTUNITIES

International and USA membership levels are the same.
(US dollars only)

### $15 Supporter

Access to home mechanical ventilation information at www.post-polio.org/ivun
Access to www.post-polio.org
Networking opportunities
Information about relevant events
Support of Post-Polio Health International's educational, research and advocacy efforts
Opportunities to participate in research
100% tax-deductible

### $25 Subscriber

**All of the benefits of *Supporter,* AND ...**

Quarterly 12-page newsletter of your choice: *Ventilator-Assisted Living* OR *Post-Polio Health*
100% tax-deductible

### $45 Subscriber Plus

**All of the benefits of *Subscriber,* AND ...**

Both quarterly newsletters: *Ventilator-Assisted Living* AND *Post-Polio Health*
100% tax-deductible

### $75 Contributor

**All of the benefits of *Subscriber Plus,* AND ...**

*Resource Directory for Ventilator-Assisted Living*
*Post-Polio Directory*
Discounts on special publications such as *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*
Discounts on meetings sponsored by Post-Polio Health International
100% tax-deductible

### $125 Sustainer

**All of the benefits of *Contributor,* AND ...**

One additional complimentary Subscriber Membership for another person designated by the Sustainer or to a person who has expressed financial need to IVUN
$100 is tax-deductible.

### Use the form below to join today!

**If you are a current member, give this form to a friend, family member or health professional.**

---

## INTERNATIONAL VENTILATOR USERS NETWORK

AN AFFILIATE OF

POST-POLIO HEALTH INTERNATIONAL

## MEMBERSHIP APPLICATION

Name ____________________
Institution ____________________
Address ____________________
City ____________________
State/Province ____________________
Zip/Postal Code ____________________
Country ____________________
Phone __________ (area/country code) Fax __________ (area/country code)
Email ____________________

### PAYMENT OPTIONS

☐ Enclosed is my check made payable to Post-Polio Health International. (US dollars only)
☐ OR, charge my: ☐ VISA ☐ MasterCard ☐ Discover
Card # ____________________
Exp. date ____________________
Name on card ____________________
Signature ____________________

### MEMBERSHIP LEVEL

☐ **Supporter,** $15
☐ **Subscriber,** $25
  ☐ *Ventilator-Assisted Living* OR ☐ *Post-Polio Health*
☐ **Subscriber Plus,** $45
☐ **Contributor,** $75
☐ **Sustainer,** $125 ...
  Please send the additional complimentary Subscriber membership with this newsletter,
  ☐ *Ventilator-Assisted Living* OR ☐ *Post-Polio Health, to:*
  Name ____________________
  Address ____________________
  ____________________
  City, State/Province ____________________
  Country __________ Zip/Postal Code __________
  ☐ Or, donate the additional complimentary membership to a person selected by IVUN.
☐ Other $__________

*Send to:*
**POST-POLIO HEALTH INTERNATIONAL**
4207 Lindell Blvd., #110, Saint Louis, MO 63108-2915 USA
314-534-5070 fax

VAL18/4

The mission of International Ventilator Users Network, an affiliate of Post-Polio Health International ... is to enhance the lives and independence of home mechanical ventilator users through education, advocacy, research and networking.

## Calendar

**MARCH 10-12. ALSA Leadership Development and Clinical Conference,** Saint Louis, Missouri. Contact ALSA, 800-782-4747, www.alsa.org.

**MARCH 19-25. VACC (Ventilator-Assisted Children's Center) Camp.** Miami, Florida. Contact Bela Florentin, VACC, Miami Children's Hospital, 305-662-8222, bela.florentin@mch.com.

**APRIL 7-9. Focus on Respiratory Care Conference,** Cleveland, Ohio. Contact Bob Miglino, RRT, 800-661-5690, BobM@foocus.com, www.foocus.com.

**APRIL 8-9. Tenth International Home Ventilation Conference,** Lyon, France. Contact Brigitte Hautier, +33 4 78 39 08 43, Brigitte.Hautier@free.fr, www.jivd-france.com.

## *In this issue ...*

**VENTILATOR-ASSISTED LIVING**

SAINT LOUIS, MISSOURI USA ISSN 1066-534X

VOLUME 18, NO. 4 WINTER 2004
Issued Quarterly

**EDITOR:** Judith R. Fischer, MSLS

**GRAPHIC DESIGN:** Sheryl Rudy

**EXECUTIVE DIRECTOR:** Joan L. Headley, MS

## HOW TO CONTACT IVUN ...

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915 USA
www.post-polio.org/ivun
ventinfo@post-polio.org
314-534-0475, 314-534-5070 fax

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 LINDELL BOULEVARD, #110
SAINT LOUIS, MO 63108-2915 USA

NON-PROFIT ORG.
U.S. POSTAGE
PAID
PERMIT NO. 210
JEFFERSON CITY, MO