

# VENTILATOR-ASSISTED LIVING

FORMERLY IVUN NEWS

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## Passy-Muir Speaking Valve: Improving Voice in Children and So Much More

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**D**avid Muir, a young ventilator user due to Duchenne muscular dystrophy, conceptualized a one-way valve that would allow him to speak while using his ventilator. In 1985, David met Patricia Passy who partnered with him to form Passy-Muir, Inc. ([www.passy-muir.com](http://www.passy-muir.com)) Together, they developed his idea into the Passy-Muir Valve (PMV) that is now used by children and adults in more than 30 countries.

When David died in 1990 at the age of 23, he knew his invention would help those who knew how to speak but were unable to produce voice. But could he have foreseen that his invention would help infants and young children to learn communication?



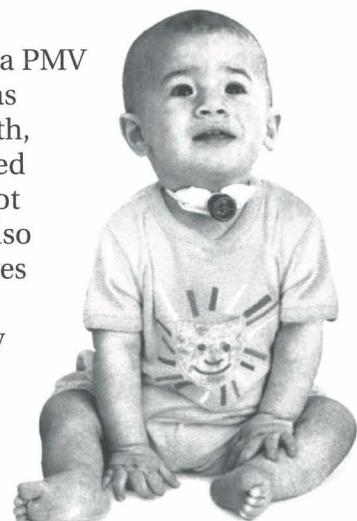
Elizabeth Pinel

Infants and children with a tracheostomy lose their ability to make sounds, produce differentiated cries and form words that are critical to language development. The earliest vocalizations, such as babbling, cooing and crying, enable infants to interact with their world and bond with caregivers. These also trigger formation of neurodevelopmental pathways. Wearing a PMV restores the ability of infants and children to vocalize, enabling them to perform these critical vocal behaviors. In addition to improving vocalization, the PMV may also improve swallowing ability and eliminate and/or reduce aspiration.

Lloyd and Renée Pinel claim that placing a PMV on their 9-day-old daughter, Elizabeth, has been pivotal in her development. Elizabeth, born with Pierre-Robin syndrome, required

immediate tracheostomy after birth. Wearing a PMV all day not only allows Elizabeth to babble to her heart's content, but it also provides an avenue for oral stimulation even though she receives non-oral tube feedings. Elizabeth sucks on a bottle during tube feedings to take advantage of the increased upper airway sensation caused by exhaled airflow. This promotes normal oral development. Her parents claim that one of the greatest benefits of using the PMV is that it enables Elizabeth to cough and clear her own secretions more effectively, decreasing suctioning needs. Renée states it is nice to drive her boys to hockey games without having to repeatedly pull over to suction baby Elizabeth.

Many parents struggle with the emotional impact of having a child born with medical complications, and health care practitioners must bear in mind how early placement of a PMV can help the parents. Lynne Lockey, whose son was born with vocal cord paraly-



Willie Lockey

## Passy-Muir Speaking Valve

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sis, states, "The experience of delivering a child who had to be trached at birth was so overwhelming and so draining. I felt like I had been cheated. When little Willie got his PMV, I felt lucky to hear my son cry for the first time. I only wish we could have gotten the valve sooner."

Clearly the PMV is more than just a speaking valve. It facilitates a more natural use of the upper airway for improved sensation, secretion management, swallowing and voice production. It allows the youngest of patients to audibly laugh, cry, coo, babble and connect with the world around them by communicating in a way that transcends words. ●

## How the Passy-Muir Valve Works

Although other speaking valves are available, the PMV is the only speaking valve FDA-approved for in-line use with a ventilator. Because of its bias-closed feature, it is also the only one found to have a positive impact on swallowing and oxygenation in addition to facilitating voice.

The valve consists of a plastic shell that attaches to the external end of the tracheostomy. Inside is a thin, pliable plastic diaphragm that attaches at its center to a set of "crossbars" traversing the valve face. This diaphragm remains closed until the individual actively inhales. When air is no longer being inhaled, the valve automatically closes. The exhaled air then flows past the tracheostomy (if a cuffed tube is used, the cuff must be deflated) and through the vocal cords enabling speech. This bias-closed feature causes a column of air to remain inside the tracheostomy which acts as a buffer to prevent secretions from traveling up the tracheostomy to block the valve.

The original version of the PMV (PMV 005) is still available, and four additional versions have been developed. The best way to determine an individual's candidacy for a PMV is to employ a team approach with a respiratory therapist, speech-language pathologist, nurse and physician.

## 2004 Camps for Ventilator- Assisted Children

- JUNE 6-11:** **Trail's Edge Camp.** Mayville, Michigan. Contact Mary Buschell, RRT, C.S. Mott Children's Hospital, 734-763-2420, mdekeon@med.umich.edu, [www.umich.edu/~tecamp](http://www.umich.edu/~tecamp)
- JUNE 6-12:** **Camp Pelican.** Lions Camp, Leesville, Louisiana. Contact Cathy Allain, 985-764-0343, [cathyallain@cox.net](mailto:cathyallain@cox.net)
- JUNE 10-13:** **Camp Inspiration at Double H.** Double H Hole in the Woods Ranch, Lake Luzerne, New York. Contact Kathleen Braico, MD, 518-696-5676, [theranch@doubleranch.org](mailto:theranch@doubleranch.org)
- JUNE 12-17:** **Fresh Air Camp.** Hiram House Camp, Moreland Hills, Ohio. Contact Kathy Whitford, CNP, Cleveland Clinic Foundation, 216-721-7159, [whitfok@ccf.org](mailto:whitfok@ccf.org), [www.freshaircamp.org](http://www.freshaircamp.org)
- JUNE 21-25:** **CHAMP Camp & CHAMP Camp Adolescent Retreat.** Recreation Unlimited, Ashley, Ohio. Contact Nancy McCurdy, 317-415-5530, [nmccurdy@champcamp.org](mailto:nmccurdy@champcamp.org), [www.champcamp.org](http://www.champcamp.org)
- JUNE 27-JULY 1:** **Pennsylvania Vent Camp.** Camp Victory, Millville, Pennsylvania. Contact Lois Marshall, Pediatric Critical Care Department, 717-531-5337, [lmarshall@psu.edu](mailto:lmarshall@psu.edu)
- JULY 4-9:** **Camp Inspiration.** Rocky Mountain Village, Empire, Colorado. Contact Monte Leidholm, RRT, The Children's Hospital, 303-837-2502, [leidholm.monte@tchden.org](mailto:leidholm.monte@tchden.org)
- SEPTEMBER 2-5:** **SKIP Camp.** Seashore Methodist Assembly, Biloxi, Mississippi. Contact Judy Abney, SKIP of Louisiana, 985-649-0882, [skipofla@aol.com](mailto:skipofla@aol.com)

**A frequent topic of concern for ventilator users is what to do should the ventilator malfunction or quit, or there is a power failure. Here are some suggestions from veteran ventilator users. More are available at [www.post-polio.org/whatwks.html](http://www.post-polio.org/whatwks.html).**

## Ventilator Backup: Are You Prepared?

**Larry Kohout** (lkohout@mn.rr.com) is a respiratory polio survivor in Minnesota who uses tracheostomy positive pressure ventilation.

I have used a ventilator 24/7 for the past three years. I have two ventilators — the LTV950™ (Pulmonetic Systems, Inc., [www.pulmonetic.com](http://www.pulmonetic.com)) that I use both day and night, and the LP10 (Puritan Bennett, [www.puritanbennett.com](http://www.puritanbennett.com))



that I keep as a backup unit. I also have an Ambu® resuscitator bag and three external batteries (U1, 35 amp-hour batteries by EverOn, model EVA 12-33) supplied by my

home health care provider. Each battery will power either of the ventilators for up to nine hours, and in this way I have survived two power outages lasting 19 hours and 23 hours respectively. In both cases my wife took the battery charger and dead batteries and walked down the five flights of stairs from our condo to use a power source at her parents' home where she could plug in and recharge the dead batteries. We thought about purchasing a small generator but can't afford it.

If you are formulating a disaster plan, you need to think beyond, "What do I do if my vent fails?" You also need to consider, "What do I do in case of a power failure?" Thinking about this shouldn't panic you. It's *not* thinking about it that ought to panic you. If you have made some sort of plan, the plan will probably work — at least as far as you have thought it through. Keep

playing "What if?" games to find holes in your plan.

I thought I had covered all the bases but then a clear-thinking respiratory therapist asked me what I would do if my vent failed while I was out on a short shopping trip. She knew that I did not take the backup vent along and suggested a second resuscitator bag to keep in my van. I followed her suggestion and also purchased one of those compact 12-volt devices (Husky Jump Start System, Model HSK020HD, Home Depot) that are used for jump-starting your car. It also has a cigarette lighter outlet on it that will run the vent if necessary.

Now when I leave my home, I have the external battery(ies), the power in the van, the 12-volt battery as backup and — if all else fails — the Ambu. I should emphasize that I take a sufficient number of external batteries to provide power for the time I expect to be gone. The 12-volt battery and the Ambu are purely for emergencies.

**Bill Miller** (MaxNWM@aol.com), C1/C2 quad, uses tracheostomy positive pressure ventilation and lives in Leesburg, Florida.

The emergency management services (911 people) know I'm a priority for power. If the power goes out for an extended period, I'm among the first to have it restored. My primary backup is my van which has a converter that runs off the van's battery to produce AC. If the van is running, the alternator keeps the battery strong (just like in regular vehicles) and I can have

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## Aging and Respiratory Function

Anita Simonds, MD, FRCP (a.simonds@rbh.nthames.nhs.uk), Royal Brompton Hospital, London, England

**M**any factors need consideration in the transition to old age. These include the physiological effects of aging, the progression or late effects of the neuromuscular disease/condition, the effects of medication, the increased likelihood of surgery, and the quality of ventilatory support in care/nursing homes.

### **Observations by older ventilator users**

Coming off the ventilator in the morning is much harder.  
I am more breathless after a meal.  
I have side effects from my medication.  
My hearing loss prevents me from hearing the ventilator alarms.  
I worry about what will happen when I am on my own.  
I feel weaker.  
Because my legs are less strong, I am more unsteady on my feet.  
I tire more easily.  
I don't want to lose my independence.

Social and psychological factors are also a major part of this transition. These include retirement, economic changes, loss of family ties, and the desire to retain one's autonomy and involvement in decision-making.

The effects of aging on respiratory function include:

- ◆ fall in lung volumes,
- ◆ decrease in area for oxygen exchange,
- ◆ reduced elasticity of chest wall,
- ◆ decrease in respiratory muscle strength,
- ◆ reduction in exercise level and deconditioning,
- ◆ osteoporosis, back pain, progression of scoliosis/kyphosis,
- ◆ cardiac problems that may add to breathlessness.

The increased likelihood of invasive procedures and surgery in later years necessitates careful risk/benefit assessment. Some ventilator users are

told they are "not fit for surgery," but the risks of not carrying out the surgery must be weighed.

Many procedures and scans can be carried out safely under sedation, and individuals can use their own home ventilators, but liaison with the anesthetic team is vital. For pre-operative assessment, the surgical/anesthetic team must know the complete medical history, ventilatory equipment needs and care plan.

Some ventilator users may also need management and treatment for cancer/malignant disease. They need to ask questions: "What is the ideal treatment for my cancer — surgery, chemotherapy, radiation and/or hormone therapy? Is there any reason why I should not have treatment? If problems are anticipated, can we work around them?"

For ventilator users and people with chronic pulmonary diseases, pulmonary rehabilitation programs can improve exercise tolerance and increase quality of life.

Attributing new or progressive symptoms to "just getting older" without consideration of other possibilities is unwise. If you are a polio survivor, do not automatically ascribe new symptoms to the late effects of polio without eliminating other causes.

Aging brings changing goals and complex issues. There is often a lack of correlation between the views of the individual and those of the family and caregivers. Make sure your family, caregivers and health care team know your wishes — prepare advance directives and living wills. ●

# Transition: From Middle Age to Elderly

Lawrence C. Becker (lcbecker@bookwork.net), Roanoke, Virginia

For me, this transition is a work in progress. I never expected to make it, so I didn't start to think about it seriously until about 10 years ago. Life expectancy in 1952, when I contracted polio was two years. Now, at the age of 64, it is 80 % of normal.

Beginning in the early '80s, I experienced a significant decline in physical strength, balance and stamina due to the late effects of polio. I compensated with new technology, schedule changes, wheelchairs, etc., until 1999 when I ran out of options.

**Tipping point.** I expected a steady, gradual decline through my 50s and 60s, interrupted by lengthy plateaus of stability. What I got, much earlier than I expected, was a point in the decline beyond which there was a sudden, huge drop-off in functional abilities. I suspect this is characteristic of the aging process for people with a major disability. Facing this is difficult, because it may force major life changes before you are ready for them, and before you appear, to the outside, to need to make them. If you are unprepared for it, the tipping point looks like a medical emergency.

**Outliving support system.** Some of us, now in our 60s, are discovering that we are the healthiest members of our families. This makes retirement even more fraught with worry, particularly if work has been part of the support net.

**Secondary conditions.** Coping with major secondary conditions, such as heart problems, requires even more care and re-rehabilitation. Coping

with the increasing frequency of nagging, minor health problems also requires some adjustments.

## **Assisted living arrangements.**

Ventilator users face special problems in finding assisted living facilities. Many of these facilities are leery of ventilators, which are viewed as "life support." I don't think ventilator users can rely on finding a suitable arrangement when we need it.

**Core identity.** Many solutions that will be proposed by medical professionals, family and friends will not be aimed at protecting a ventilator user's core identity, but rather at keeping one "safe and comfortable." It is not wise to accept that uncritically.

As ventilator users, we need to consider what we cannot afford to lose, in the sense that such a loss would destroy our core identities. Next we need to insure that we preserve our core identities in any adjustments we make. For me, I was surprised that I could quite cheerfully lose my professorship, income, etc., as long as I could produce intellectual work in an office outside my home.

I do not think I will be able to adjust successfully to yet another major disability such as blindness or stroke. This has consequences for how I will deal with possible secondary conditions.

**Reciprocal relationships.** Beyond the tipping point, it is harder and harder to keep relationships with loved ones and colleagues genuinely reciprocal and "balanced" in the ways

*Facing the transition from middle age to elderly is easy to postpone, and almost everyone cooperates in helping you postpone it. The boundary between middle age and old age is very wide and fuzzy.*

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# Mouth Intermittent Positive Pressure Ventilation: An old technique revisited for a “sip” of fresh air

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The use of mouth intermittent positive pressure ventilation (M-IPPV) was first reported in 1969, although its use had begun over a decade earlier during the polio epidemics when iron lungs were opened to permit nursing care of the patient's body. Patients received ventilation by positive pressure with a mouthpiece used for pulmonary function testing. These patients often had no breathing tolerance and were encouraged to leave their iron lungs during the day and to use other alternatives like chest shells or intermittent abdominal pressure ventilation (pneumobelt). But M-IPPV was described as the most important method of daytime ventilatory support.<sup>1</sup> With the increasing availability of portable ventilators, the use of M-IPPV also increased.

During M-IPPV, air is delivered to the individual via tubing or a circuit attached to a simple angled mouthpiece (Respironics, [www.respironics.com](http://www.respironics.com)) held in the mouth or just near it.

A mouthpiece is an inexpensive interface that requires no specialized fitting or maintenance. M-IPPV is ideal for seated individuals — a metal clamp attached to the wheelchair can be used to hold the circuit in place so that the person can easily grab the mouthpiece with his or her mouth. (It is also referred to as “sip” intermittent positive pressure ventilation.) For optimal use of M-IPPV, the individual must have sufficient neck rotation and oral motor and soft palate functions. Leakage must be prevented; in rare cases, nostril plugging is necessary.

Generally the ventilator is set for large tidal volumes, often 1000–2000 ml. The person, according to the physician's instructions, can vary the ventilator parameters (tidal volume and breath rate) to vary speech volume and cough flows as well as to practice air stacking for full expansion of the lungs. The low-pressure alarms of volume-cycled ventilators often cannot be turned off. To prevent alarm sounding during the day when the individual does not need every delivered volume, the angle of the mouthpiece creates adequate back pressure to prevent low-pressure alarm sounding. A humidifier can also be used for this effect.<sup>2</sup>

Although M-IPPV has been demonstrated to be ideal for 24-hour support, it has not gained widespread use. Individuals can learn to sleep with the mouthpiece without it falling out of the mouth. Nocturnal use can be accomplished with a lipseal (Puritan Bennett, [www.puritanbennett.com](http://www.puritanbennett.com)) or a wider gauge mouthpiece that prevents air leakage through the mouth. Sometimes customized dental appliances are required for better comfort. The recent introduction of the Oracle™, an oral interface designed for CPAP delivery with no need for headgear (Fisher & Paykel, [www.fphcare.com](http://www.fphcare.com)), may become popular for nocturnal M-IPPV.

Side effects of M-IPPV may include excessive salivation, abdominal distension and, in long-term users, mild orthodontic deformities. The former two, although initially a source of discomfort, generally improve and almost never constitute reason to discontinue M-IPPV.<sup>3</sup>

Based on the work of John R. Bach, MD, and his team (Center for Ventilator Management Alternatives, University of Medicine and Dentistry of New Jersey, USA, [www.doctorbach.com](http://www.doctorbach.com)), we have also been using M-IPPV as a technique for extubation and tracheostomy tube removal for patients with neuromuscular diseases (mainly spinal cord injury and ALS) and as first-line intervention during ventilatory failure caused by respiratory tract infections in ALS.

With this protocol, patients with unmeasurable lung function recover ventilatory autonomy using M-IPPV during the day and "high-span" bi-level positive airway pressure (BiPAP) during sleep. Moreover, in a sub-group of our ventilator users (>16 hours), M-IPPV has provided optimal ventilation without the need for invasive intervention, particularly when combined with airway secretion clearance techniques, both manually assisted cough and mechanically assisted cough with the CoughAssist™

(J.H. Emerson Co., [www.jhemerson.com](http://www.jhemerson.com)). ●

#### References

1. Bach, J.R. & Lee, H.J. (1993). New therapeutic techniques and strategies in pulmonary rehabilitation. *Yonsei Medical Journal*, 34(3), 201-211.
2. Bach, J.R. Alba, A.S. & Saporito, L.R. (1993). Intermittent positive pressure ventilation via the mouth as an alternative to tracheostomy for 257 ventilator users. *Chest*, 103(1), 174-182.
3. Bach, J.R. et al. (1987). Mouth intermittent positive pressure ventilation in the management of post-polio respiratory insufficiency. *Chest*, 91(6), 859-864.

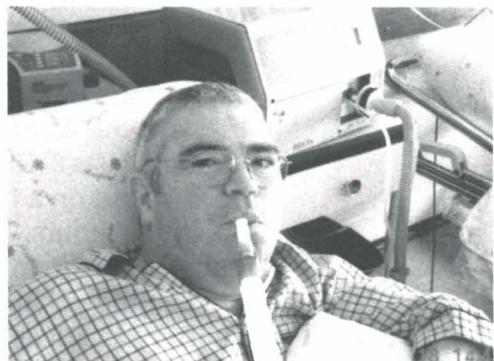


"I feel much better since I have been switched to M-IPPV. I had been using nasal high-span bilevel nasal ventilation for the past four years, and I felt that I needed more ventilatory support during the day. Using M-IPPV with the PV 501 (BREAS, [www.breas.com](http://www.breas.com)) was the best solution to ventilate my lungs during the day. Thanks to this technique I can take deep breaths whenever I want and that allows me to speak better and even achieve good coughs. I was taught to air stack several times a day, and now I can even lie down with no kind of shortness of breath. It's really very good!" *Pedro Miguel Silva, 29, who has Duchenne muscular dystrophy, uses long-term non-invasive ventilation at home.*

"I love my 'blower pipe!' It feels very good to take some deep breaths whenever I want to, and then leave it and try to breathe on my own. Thanks to this technique I am able to speak clearer and cough harder. I was very frightened with the possibility of a tracheostomy tube, but thanks to M-IPPV and other respiratory muscle aids (manual and assisted cough plus nasal bilevel ventilation overnight) that will never happen. The improvements on my respiratory symptoms are amazing." *Elsa Cristina, 22, who has a C3/C4 spinal cord injury, recovered from acute respiratory failure using noninvasive respiratory muscle aids.*

"When I came to the ER feeling breathless, I saw death in front of my eyes! I never thought it could be so simple to ventilate my lungs with such a small device. After a couple of days I can hear my voice and feel like I am breathing again."

*Manuel Correia, 58, who has nonbulbar ALS, started M-IPPV during hospital admission due to acute respiratory failure.*



## Ventilator Backup: Are You Prepared?

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electricity as long as I have gasoline in the tank. I try to always leave it full or at least above half of a tank. My van would also allow me to drive to another location that had electricity, if there was no power for several days.

I also keep a very long, heavy-duty extension cord with a 3-outlet expander in the back of my van. If I'm out in the van and need electricity, I can use an outlet at a store or restaurant. If I'm at home, I can run the extension cord all the way from the van to my bedroom.

For the van, I purchased a generator that can do two crucial things: it can start a dead vehicle battery with a jumper cable attachment, and it provides plugs for electricity. But it is gas-powered (loud, gives off fumes and needs to be used about once a month to keep it running well) and small, so it's only good in short-term scenarios

but ideal for a dead van battery. These generators can be purchased at Home Depot, Lowe's, Sears, etc. for about \$300-500.

For ventilator backup, I have two LP10s (Puritan Bennett, [www.puritanbennett.com](http://www.puritanbennett.com)) and each has its own internal and external battery. The internal battery lasts about 45 minutes. The external battery lasts 8-10 hours (manufacturer's claim) but on a full charge, I can get about 15 hours. To recharge it, I simply plug it in. For an emergency, it's wise to be plugged in to keep that external battery as full as possible. You never know when you'll need it.



Bill Miller

I keep an Ambu® bag on my chair at all times, just in case. These resuscitators can be found online at less cost, about \$20, no prescription required ([www.buyeremp.com/dept.asp?dept%5Fid=10213](http://www.buyeremp.com/dept.asp?dept%5Fid=10213)). Technically they are disposable, but mine have lasted years by adding a bacteria filter and changing it periodically. ●

### Ed. Note:

*Consumer Reports* (November 2003) contained an excellent review "Generators: power in a pinch." ([www.ConsumerReports.org](http://www.ConsumerReports.org))

Pulmonetic Systems, Inc. recently introduced the LTV® Universal Power Supply with an AC/DC converter, backup battery and backup battery charger capable of four hours of rechargeable external power. ([www.pulmonetic.com](http://www.pulmonetic.com))

## Transition

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that have been so carefully worked out over the years. I believe it is crucial to maintain this balance. In my experience, trying to make incremental adjustments is useless — the entire relationship must be completely reconsidered. Schedules need to be reorganized around caregivers who are also aging. To some extent this requires a reversal of roles or exploration of alternatives that may be difficult for both parties. ●

# Arizona Respiratory Center Receives Grant

John D. Mark, MD, Director ([jmark@peds.Arizona.edu](mailto:jmark@peds.Arizona.edu)), Southwest Ventilation Program,  
University of Arizona Health Sciences Center, Tucson, Arizona

The Arizona Respiratory Center's Southwest Ventilation Program received a \$25,000 Quality of Life Grant from the Christopher Reeve Paralysis Foundation (CRPF) in late 2003.

The Southwest Ventilation Program (SVP) is a regional initiative to improve the health and quality of life of adults and children with complex respiratory and neuromuscular conditions. The SVP provides comprehensive family-centered care to people in southwest Arizona who require assisted ventilation to maintain normal breathing.

The grant supports the creation of a library of patient, family and professional educational materials in multiple formats. SVP is producing treatment protocols and guidelines for professionals and for families, such as edu-

cational booklets on complex topics including suctioning, noninvasive bilevel ventilation at home and use of the home ventilator via tracheostomy. "How to" tip sheets for such procedures as augmented cough, breathing stacking and airway clearance techniques will be provided. SVP is also developing videos, CDs and DVDs for training health professionals and for patient use.

The Arizona Respiratory Center (ARC) was designated the first Center of Excellence in the University of Arizona College of Medicine in 1971. This internationally known Center combines research, clinical care and training in the care of children and adults with respiratory problems. The Southwest Ventilation Program began in the fall of 2003 and has served 50 people. ●

## ALS Respiratory Care Resources

**Completing the Continuum of ALS Care: A Consensus Document.** "Promoting Excellence in End-of-Life Care" is a national program of The Robert Wood Johnson Foundation charged with the task of improving the end of life for dying patients. The program recognized ALS as a disease that requires special attention at the end of life. Working with The ALS Association (ALSA), an ALS Peer Workgroup was charged with identifying the current state of end-of-life care for people with ALS and establishing recommendations on how to improve the end of life for individuals and their families.

Primary authors of this report (January 2004) are Hiroshi Mitsumoto, MD, DmedSc, ALS Peer Workgroup Chair and The ALS Peer Workgroup Members. The Executive Summary and Report to the Field are available in HTML or PDF (44 pgs.) at [www.promotingexcellence.org/als/als\\_report](http://www.promotingexcellence.org/als/als_report).

**Douglas McKim, MD, FCCP**, and his team at The Rehabilitation Centre, Ottawa Hospital, Canada, developed respiratory protocols for treating people with ALS and other neuromuscular diseases. ([www.rehab.on.ca/mobile/present\\_e.html](http://www.rehab.on.ca/mobile/present_e.html); click on Therapy/Treatment, then select from the respiratory protocols.) Also on CD-ROM.

## Respironics Colorado Announces Discontinuation of Service and Repair Support for Certain Ventilation Equipment

In the fall of 2003, Respirationics Colorado notified affected physicians, caregivers and ventilator clients that, effective March 1, 2004, Respirationics could no longer ensure its ability to procure service parts or repair services for certain ventilation equipment. The equipment affected included the iron lung, rocking bed, Bantam, Zephyr blower, PVV, 170C Monaghan, Thompson Portable, Cascade humidifier, IPPB, Gomco 789 Aspirator, Gomco 400 Aspirator and the Huxley.

Tim Murphy, Vice President and Controller of Respirationics Colorado indicated, "Respirationics Colorado representatives have and will continue to work with its clients, as well as their physicians and their caregivers, in an effort to transition these individuals to other equipment."

Murphy continued, "From the inception of this project, Respirationics Colorado shared the transition plan timeline and approach with the March of Dimes and the International Ventilators User Network. Respirationics

remains grateful to these organizations for their time, perspective and assistance during this project.

"All of the associates of Respirationics Colorado realize the challenge this change poses for our clients and remains committed to working with each of them, their physicians and caregivers to insure an orderly transition," Murphy concluded.

### IVUN Equipment Exchange

IVUN heard from several long-term ventilator users who are clients of Respirationics affected by the changes in servicing and parts for their older ventilator equipment. Some of them have used iron lungs and Bantams and Monaghans for decades and were understandably concerned.

IVUN attempted to educate them about more modern, alternative modes of ventilation, to connect them with others who successfully transitioned to newer equipment, and to facilitate an equipment exchange network for those who could not make the transition.

For more on the equipment exchange, connect to "Can You Help?" ([www.post-polio.org/netwkg.html](http://www.post-polio.org/netwkg.html)). People who want to donate ventilatory equipment and aids can advertise their offerings on that web page. People who need older equipment can view what is available and make arrangements for the equipment exchange and/or submit their equipment needs. Send your contact information and description of equipment donations or needs to: [ventinfo@post-polio.org](mailto:ventinfo@post-polio.org).

### NEW INTERFACE

The **ComfortLite™**, new from Respirationics, Inc. ([www.respirationics.com](http://www.respirationics.com)) offers two nasal interface options: the Direct Seal™ cushion provides a comfortable seal without insertion into the nostrils, and the Simple Cushion™ is a small, tip-of-the-nose interface. The ComfortLite has a unique headgear system that separates the hose from the mask area for greater stability and a 360° hose swivel. Multiple adjustment points on the headgear help to fit the ComfortLite to a wide variety of head sizes and ensure mask stability. Advantages include minimal facial contact, reduced pressure points, less claustrophobia and elimination of skin sensitivity problems.



# INTERNATIONAL VENTILATOR USERS NETWORK

AN AFFILIATE OF



## 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](http://www.post-polio.org/ivun)
- Access to [www.post-polio.org](http://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  
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- 100% tax-deductible

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

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- \$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



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Send to:

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

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

### 2004

- JUNE 18-20** Families of SMA Family and Professional Conference. Hyatt Regency Woodfield, Schaumburg, Illinois. Contact FSMA (800-886-1762, [sma@fsma.org](mailto:sma@fsma.org), [www.fsma.org](http://www.fsma.org)).
- JULY 8-11** The Parent Project for Muscular Dystrophy Research. Westin Hotel, Cincinnati, Ohio. Contact The Parent Project (800-714-KIDS, [pat@parentprojectmd.org](mailto:pat@parentprojectmd.org), [www.parentprojectmd.org](http://www.parentprojectmd.org)).

### 2005

- JUNE 2-4** Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: Strategies for Living Well. Saint Louis Marriott, Saint Louis, Missouri. Contact Justine Craig-Meyer, Post-Polio Health International (314-534-0475, [info@post-polio.org](mailto:info@post-polio.org), [www.post-polio.org](http://www.post-polio.org)).

## HOW TO CONTACT US ...

### INTERNATIONAL VENTILATOR USERS NETWORK

AN AFFILIATE OF



4207 Lindell Boulevard, #110, Saint Louis, MO 63108-2915 USA  
[www.post-polio.org/ivun](http://www.post-polio.org/ivun), [ventinfo@post-polio.org](mailto:ventinfo@post-polio.org)  
314-534-0475, 314-534-5070 fax

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Passy-Muir Speaking Valve ... Ventilator Backup: Are You Prepared? ... Aging and  
Respiratory Function ... M-IPPV: An Old Technique Revisited ... and more.



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