

# VENTILATOR-ASSISTED LIVING

SAINT LOUIS, MISSOURI

WWW.POST-POLIO.ORG/IVUN

## Living on Your Own in College and Beyond

Scott Bennett, Taunton, Massachusetts (srbenny@yahoo.com)

I have Duchenne muscular dystrophy and am now 40 years old. I have been living on my own since I was 18 years old. Before I graduated from high school, I began to make arrangements to live on my own and attend college.

I had applied to the University of Massachusetts-Boston and for various scholarships and a Pell Grant (federal college grant). I applied to the Massachusetts Rehabilitation Commission, a state vocational rehabilitation agency, for additional funding for college and any additional adaptive equipment I might need. I also applied to the Boston Center for Independent Living (BCIL), which provided training in the skills individuals with disabilities need to live on their own.



BCIL then had a nine-month program where you lived in an apartment supplied by them and where you learned independent living skills, including hiring, firing, training personal care attendants (PCAs), managing your finances, setting up your own personal care physician, transportation needs, etc. Upon completion of the nine-month program, the independent living center would assist you in finding your own permanent apartment. I do not believe the independent living center still has this nine-month program, but I do know that they still provide in-home training for independent living skills.

When I found my own permanent apartment, I was completely responsible for advertising, hiring, firing and training PCAs, managing my own finances, and managing my own health-care needs. Generally I tried to maintain a staff

of five to seven PCAs, each one assigned to a different time slot. I tried to keep a flexible schedule for myself as well as for my PCAs, in case of illness or vacations.

To find my PCAs, I started with paid advertising in the "Help Wanted" section of the local newspaper. But when the cost of advertising in the newspaper became too high, I began advertising at some of the local universities and colleges, including my own college. I found that often the best PCAs were nursing students or physical therapy students.

The salaries of the PCAs were paid for (and still are) by the Massachusetts Medicaid PCA program. The hours per week allocated to me were determined by Medicaid, with input from me and a nurse from the independent living center. The time slots

that I set up were two hours in the morning (7 am–9 am), one hour at lunchtime, two hours at dinnertime (5 pm–7 pm), and two hours at bedtime (10 pm–12 am). At 18 years old, bedtime was 12 am or 1 am; at 40 it is more like 11 pm. I was allocated additional money for an overnight assistant who was also a live-in assistant.

Generally my live-in assistant/roommate was also a college student, who performed both the bedtime shift and the overnight shift. The live-in assistant, in addition to wages, also was able to live rent-free – a big incentive for a college student – because the apartment was federally subsidized (Section 8). Recipients paid 30% of their income toward the rent, and the subsidy supplied the remaining 70%. With Supplemental Security Income (SSI) as my only source of income while in college, my rent was only about \$150 per month.

The State of Massachusetts maintained a publicly-funded transportation service for residents with disabilities that I used to get back and forth to college initially. Later I bought my own used van through vocational rehabilitation and hired a driver to drive me to college. The Disabled Students Center of the University of Massachusetts would assist with note-taking in class (if you were unable to take your own notes) and with making arrangements for any special needs in the classroom.

One piece of advice I can offer is that when you start taking classes in your first year of college, you should consider only taking half the regular course

load. Then take three-quarters of the course load in the second year, and finally in the third year work your way up to a full load. This way you do not get overwhelmed with schoolwork while you are learning to live on your own. By the third year of college you are generally into a routine, and managing your PCAs and your care become second nature. Of course taking classes in this manner means it may take you six or seven years to finish college instead of four, but I believe it is well worth it in the long run.

The more support you have from your family and the more support services you have make it that much easier to live on your own. Many resources and support services are available: SSI, Medicaid, subsidized housing assistance, independent living centers, vocational rehabilitation services, transportation systems. You should investigate and enroll in as many of them as possible.

I graduated from college at the age of 25 (seven years of college) with a Bachelor of Science degree. After college I began employment as a software engineer for a relatively large company where I'm still employed today. Shortly after starting my career, I met and fell in love with a wonderful woman. We're still together after 14 years.

About 10 years ago, I was able to purchase a new wheelchair-modified van, with the assistance of the same vocational rehabilitation agency that assisted me in college. About five years ago, I moved out of my apartment and – through the Massachusetts Housing



## Scott Describes His System

The noninvasive ventilation system that I use includes a volume ventilator with a lipseal mouthpiece interface (with headgear) during the night and mouthpiece intermittent positive pressure (also known as sip intermittent positive pressure ventilation) during the day. The 45-degree angle mouthpiece and tubing are held in place with a microphone gooseneck and clamp assembly mounted on my wheelchair. I use the ventilator more than 22 hours per day, but not when I'm transferring, brushing my teeth, and doing other routine tasks that take only five to ten minutes to perform.

I also use a CoughAssist™ and a pulse oximeter to monitor my oxygen saturation at home whenever I have an upper respiratory infection. My frequency of respiratory infections averages one per year, and the CoughAssist™ and pulse oximeter are instrumental in minimizing hospitalizations due to respiratory infections. I also make every effort to minimize exposure to respiratory infections by not allowing PCAs to work for me when they are sick and making sure they frequently wash their hands.

When I think I'm getting a respiratory infection, I occasionally take prophylactic antibiotics and use chest physical therapy and manually assisted cough, also known as the quad cough technique (<http://calder.med.miami.edu/pointis/asscough.html>) to assist in clearing secretions.

I have maintained a very healthy lifestyle with noninvasive ventilation, so much so that after my pulmonologist – who first started me on noninvasive ventilation – retired, I did not replace him. I manage my own pulmonary needs and visit my primary care physician annually.

### EQUIPMENT:

PLV®-100 Volume Ventilator (Respironics, [www.respironics.com](http://www.respironics.com))

Bennett Lipseal Mouthpiece Assembly (Puritan Bennett, [www.puritanbennett.com](http://www.puritanbennett.com))

CoughAssist™ (J.H. Emerson, [www.coughassist.com](http://www.coughassist.com))

Onyx® 9500 Finger Pulse Oximeter (Nonin Medical Systems, [www.nonin.com](http://www.nonin.com))

Finance Agency, which provides low-interest mortgages to low-income and disabled residents of the state – purchased my own home.

Now I am a taxpaying citizen, no longer dependent on subsidized housing or SSI income benefits. The only government benefit I still receive is Medicaid for my medical needs and PCA salaries. Section 1619(b) of the Social Security Act allows any disabled individual to continue receiving Medicaid as a SSI beneficiary even after beginning employment and owning a vehicle and a home.

Technically I am still receiving SSI even though my SSI income is zero, and I can continue receiving SSI Medicaid as long as my medical expenses are such that I would not be able to continue working without Medicaid.

There are many agencies and assistance programs available to individuals with disabilities that can provide you with the means to live on your own, get an education, gain employment, purchase your own home, have your own family, and achieve all of your goals and dreams. ●



# The Experiences of Families with Ventilator-Assisted Children at Home

Franco A. Carnevale, RN, PhD, Eren Alexander, RN, MSc (A), Michael Davis, MD, Janet Rennick, RN, PhD, Rita Tronini, RRT, MA, Montreal Children's Hospital and Montreal Chest Institute/McGill University, Montreal, Canada (frank.carnevale@muhc.mcgill.ca)

The aim of this study\* was to learn about the moral experience of families with children requiring assisted ventilation at home. We wanted to learn about the struggles over “right and wrong” that these families faced. We recruited twelve families through the Home Ventilatory Assistance Program in Quebec, Canada.



Two-year-old Daphne and her mother following insertion of a diaphragmatic pacer.

Thirty-eight family members participated in the study, including the children, their parents and siblings. Ventilator-assisted children ranged in age from 1.8 to 19 years of age.

Their diagnoses included central hypoventilation syndrome, muscular dystrophy, spina bifida, obstructive apnea, spinal amyotrophy and various myopathies. About half of the children used invasive ventilation; the other half used noninvasive ventilation.

We studied family moral experiences by using interviews and home visit observations. The entire study was conducted in the homes of these families. A number of important issues were identified.

**FINDINGS.** Most importantly, it was found that the overarching theme that best characterized these families' experiences is “daily living with distress and enrichment.” In other words,

the lives of these families are clearly very stressful, but the magnitude of this stress did not appear directly related to whether the child required invasive or noninvasive ventilation.

However, these ventilator-assisted children also provide families with important possibilities for enrichment. It would be simplistic and mistaken to conclude that these children should not have been kept alive just because their care is stressful for everyone. Not having allowed these children to live would not make everything better.

As one mother stated, “She’s a sweet little girl. She’s really worth it. So I think when you look past her disability, well, even with her disability she’s a beautiful individual, and I couldn’t even begin to think of life without her. It is a bit more complicated but it’s worth every little bit of effort that you put into it because you receive so much back in return. It’s really nice to have her in our life – without her I think it would really be really, really sad.”

It is important that we attend to the additional issues identified by these families to help us find ways to facilitate their lives. These issues included:

**Confronting parental responsibility.** Parental responsibility was generally regarded as stressful and frequently overwhelming. Parents were required to devote an exceptional amount of care and vigilance toward their children's needs. They struggled with immense emotional strain, the significant physical and psychological dependence of the child, the impact on family relationships, living with the daily threat of death, and feeling that there is really

\*The Toronto SickKids Foundation National Grants Program and The Canadian Children and Youth Home Care Network financially supported this study.

“no free choice” in the matter (they could not really have chosen other than to keep the child alive).

**Seeking normality.** All of the families actively worked to normalize their experiences. They established common routines so that their lives resembled the lives of “normal” families as much as possible.

**Conflicting social values.** Families were hurt by the reactions they encountered in their everyday lives in their communities. They sensed that the child’s life was devalued by others – commonly regarded as a life not worth sustaining. They felt like strangers in their own communities, frequently feeling obliged to seclude themselves within their homes.

**Living in isolation.** Families experienced a profound sense of isolation. Given the complex medical needs of these children, neither the extended families nor the medical system could provide adequate respite.

**What about the voice of the child?** The children in this study, both patients and siblings, were generally silent when asked to talk about their experience. Some children referred to their ventilators as good things. They helped them breathe and feel better. Some siblings expressed resentment toward the attention that their ventilator-assisted sibling was receiving.

**Questioning the moral order.** Most families questioned the *moral order* within their lives. They wondered how “good things” and “bad things” are

determined in the world. Parents said that this is a very unfair situation but there is nothing that you can do about it.

**CONCLUSIONS.** These findings highlight the need for increased sensitization to the needs of this population among staff in critical care, acute and community settings. Integrated community services are required to help alleviate the significant distress endured by these families. ●

*Ed. Note:* The complete report will be published in a forthcoming issue of *Pediatrics*.

## Ventilator Conference in Lyon

More than 1,100 respiratory health professionals and ventilator users from 33 countries attended the Tenth International Conference on Home Mechanical Ventilation, JIVD, in Lyon, France, April 9-10, 2005.

Proceedings of the conference are available on CD-ROM for € 99 through One Science, 47, rue Marcel Dassault, 92100 Boulogne Billancourt, France. (Fax: +33 1 69 20 78 93, [contact@e-onescience.org](mailto:contact@e-onescience.org)).



Dominique Sebbane, ventilator user from Lyon, and John R. Bach, MD.



# Masks: Obtaining a Good Fit

## Part I

Diana Guth, RRT, Owner, Home Respiratory Care, Los Angeles, California (Diana@hrcsleep.com)

To obtain a comfortable and well-fitting mask and successfully use noninvasive positive airway pressure (PAP) ventilation, you and the respiratory therapist (RT) at your home health company need to establish a trusting relationship.

The RT should start with an interview to determine your history of breathing problems and needs, followed by an examination to determine your manual dexterity, ability to raise your arms to your head, and other physical limitations.

By answering the following questions, you can help the RT choose the best mask for you.

- ◆ Why are you seeking a mask for breathing assistance? Has your physician prescribed a PAP unit, generally a bilevel unit for use at night, based on the results of pulmonary function tests or sleep study? If you have those results, please provide them to your RT.
- ◆ Are you able to sleep/breathe lying flat on your back?
- ◆ Are you a restless sleeper?
- ◆ Do you have morning headaches?
- ◆ Do you have any allergies or sinus problems? If you do, you may need to use a heated humidifier with your PAP unit.
- ◆ Do you get up frequently during the night to urinate (medically known as nocturia)? If you do, you will be glad to learn that successful PAP treatment may decrease or eliminate nocturia.
- ◆ Do you breathe through your nose, your mouth, or are you a nose breather and mouth/lip leaker?

- ◆ Is your mouth open while you sleep?
- ◆ Do you sleep on your back, stomach, or side?
- ◆ Are you claustrophobic?
- ◆ Do you wear glasses?

The answers to these questions will help your RT better understand the severity of your breathing problems and help the RT make an informed choice on which mask would work best for you.

If you have questions about wearing a mask, please ask the RT to review the information and selection with you and your spouse/partner/care-giver. It is not uncommon to have anxieties about using a mask: be honest in expressing them to your RT.

The next step is determining what type of nose bridge you have and your nose length and width. Nose bridge analysis is critical in ensuring a leak-free seal without undue pressure on the nose bridge. (Historically, this small area has been the greatest cause of failure in fitting masks.) An effective seal is necessary to prevent air leakage into the eyes (which can cause eye irritation or damage) but the seal should not be so tight that it causes serious nose bridge ulcers and other skin irritation.

To determine nose length and thus the correct mask size, the RT should measure from the top of the nose bridge to under the nose. Nose width is mainly assessed by visual inspection. There are mask gauges and calipers available to help RTs determine mask size, but experience is the best aid.

In finding and fitting the best mask for you, the RT should offer a comprehensive selection of masks, in a variety of sizes, from various manufacturers.

In an ideal world, the fitting should be done at the home health care company's office in a private room that is designated for that purpose. To properly test the masks, the room should have a bed and pillows so that you can lie down in the position in which you are accustomed to sleeping.

Even the most skilled RT cannot predict the success of the fitting without following up after you have used the mask for a few nights. If the treatment is going well, you can report to the RT again in a week, then in a month, and periodically after that.

If you have a problem with the mask, you need to tell the RT so that he or she can review how the mask (and the PAP device) is working, make the necessary adjustment, or, if necessary, select and fit a different mask. ●

*Adapted from an article in Home Health Dealer/Provider, May 2005.*

**Part II will discuss the kinds of masks, headgear and chinstraps.**

## Equipment and Interfaces

**ComfortCurve™** is the latest in nasal masks from Respironics, Inc. (800-345-6443, [www.respironics.com](http://www.respironics.com)). A cross between nasal pillows and a nasal mask, the ComfortCurve™ features a curved cushion, supported by two ergonomic and adjustable cheek pads, which cradles the nose to provide a comfortable seal. This eliminates the nostril irritation and pulling sometimes caused by nasal pillows. Available in three sizes with exclusive tubing system. Check with your local home health care dealer.

**BiPAP® S/T**, the new model from Respironics, is smaller and lighter than the BiPAP® Synchrony. It features an optional heated humidifier, SmartCard® for use with Encore Pro® to track usage and compliance, Digital Auto-Trak Sensitivity™ and integrated alarms.



### READERS RECOMMEND:

**MK battery** – long-life, deep-cycle, gel cel 12V battery, model M22NF SLD G ([www.mkbattery.com/hmemobil/M22NFSLDG.html](http://www.mkbattery.com/hmemobil/M22NFSLDG.html)).

**Battery Charger** from Soneil, a Canadian company. Model 1212SR is an automatic switch-mode charger that transforms 115/230 VAC into 12 VDC at 100,000 Hz, much faster than a conventional charger. Small size and light weight. ([www.soneil.com/completesets/1212SR\(rev09\).14-Sep-04.pdf](http://www.soneil.com/completesets/1212SR(rev09).14-Sep-04.pdf))

### ACQUISITIONS

**Pulmonetic Systems, Inc.**, the manufacturer of the popular laptop-sized LTV® ventilator series, has been acquired by **VIASYS Healthcare Inc.**, in a merger that is expected to be final by the end of July 2005. ([www.pulmonetic.com](http://www.pulmonetic.com), [www.viasyshealthcare.com](http://www.viasyshealthcare.com))

**ResMed Inc.** acquired **Saime, S.A.**, a French manufacturer of a wide range of ventilators that are currently available only outside the USA. ([www.resmed.com](http://www.resmed.com), [www.saime.fr](http://www.saime.fr))



## Home Is Best

Liz Martin, Port of Monteith, Scotland (martin\_liz@tiscali.co.uk)

**M**y 40th birthday was a prolonged celebration lasting a week. Unbeknownst to me it was to be the last I spent as a nondisabled person. My life as a riding instructor and controller in the fire brigade ended in February 1991, when a lorry driving down a hill too fast collided with my stationary car and catapulted me into an electric junction box and a tree.

Not only did I have to come to terms with a complete C3/4 spinal cord lesion but also with facing a future totally dependent on other people. All aspects of my needs required input from someone else. I received a “mini-trachy” for suctioning only, not for ventilation.

As I looked out of the hospital window, I believed that when I escaped home, the problems would settle down. I concentrated my mind on survival.

My specialist care began in the neuro-surgical unit in Glasgow. Then I was transferred to the rehabilitation unit, and finally to a housing complex for people with physical disabilities nearer my home.

My sister and brother-in-law came from Holland and supported me in a successful civil litigation. This enabled me to commission an accessible, disability-friendly house of my choice – in a field – in the Trossachs National Park, north of Glasgow near Stirling.

Six years passed from the time of my accident until I moved into my new home. After only three weeks there, I developed a chest infection and was readmitted to hospital. Although I quickly recovered and felt well enough to return home, the local community health services felt unable to take responsibility for my safe care now that I needed to use a ventilator with my trach. (I do receive nursing support for my daily routine.) Again my sister and brother-in-law came from Holland to rescue me, and we formed my own care team. Since returning

The UK does not have a Spinal Cord Injury National Database, and being one of the few people with a spinal cord injury using a ventilator at home in Scotland is a bit lonely. Last January one of the UK daily papers ran a Eurostar/SNCF (French railway) promotion with a first class “dis-



Liz boarding the train.

abled” roundtrip fare to Lyon, France, for £50. That prompted me to submit a poster to the Tenth International JIVD Congress on Home Mechanical Ventilation. I reserved wheelchair space on the trains, but my journey did not necessitate any other special arrangements, apart from the need for careful and clear communications. Five of my caregiving team accompanied me. The ramp system for traveling on SNCF and trolley buses in Lyon are excellent.

The Lyon congress was an exciting opportunity to meet other ventilator users – with similar needs and aims – in Europe.



home I have had only one brief hospital admission to adjust medication for pain control.

My care staff of six works singly with overlap at changeover, either 12-hour shifts or sometimes they share shifts. I recruit them locally, train them in my home, and pay them from the proceeds of my legal settlement. My daily routine is simple and followed diligently.

The maintenance of and training in the use of my medical equipment is from the clinical physics department of the Southern General Hospital in Glasgow. They introduced me to the Dragon Dictate Mark 7 for my voice-activated computer.

My ventilatory equipment is multinational in origin: two Swedish BREAS PV 501 volume ventilators – one at my bedside and one under my wheelchair; Nonin pulse oximeter (USA); Norwegian laerdal suction and resuscitator; and a Fisher & Paykel humidifier (New Zealand). I use an uncuffed Tracoe tube (USA) and Swedish Spiro speaking valve. The only Scottish component is me!

Currently, I use the ventilator overnight and during the day only when confined to bed with a chest infection, but I've only had three of those in 6½ years.

It probably took me about 18 months from the time I returned home before I felt confident that I would remain there. Thereafter, I began to “belong” to the community. ●

## Potpourri

**Paws With a Cause** is an assistance dog program in Wayland, Michigan. The program has worked with adult ventilator users who can vocalize commands and can ambulate. For more information, contact Paws With a Cause, 4646 S. Division, Wayland MI 49348, (800-253-7297, [www.pawswithacause.org](http://www.pawswithacause.org)).

**ADVANCE for Respiratory Care Practitioners**, a monthly publication, featured two articles about ventilator users in the February 2005 issue. Jake Etchart, 23, and Dan Monk, 34, detail their lives in one article, and Barbara Rogers discusses sex and the ventilator use in another. (<http://respiratory-care.advanceweb.com>; search by last names of people to find articles)

**Study and Work Abroad for All** is a three-year project of the Independent Living Institute (ILI), financed by the Swedish government, to increase participation of people with disabilities in international study, traineeships, and volunteer work opportunities in Europe, North America, and other parts of the world. Organizations, companies, and universities can register their training and volunteer opportunities online. ([www.independentliving.org/studyworkabroad](http://www.independentliving.org/studyworkabroad))

For NGOs, corporations, and governmental agencies with traineeship programs, ILI provides a resource kit for assessing accessibility of premises and operations for employees and clients with disabilities, and guidelines for formulating and displaying a corporate disability policy.

**Eric Obermann**, whose article “The Ventilator Boat: Will It Float?” was featured on the cover of *Ventilator-Assisted Living* (Vol. 18. No. 4, Winter 2004), testified before a US Senate subcommittee overseeing the budget of the National Institutes of Health. Obermann, 23, was the youngest of seven people who pleaded for more money for ALS research.

**Everyday Life With ALS: A Practical Guide** is a revision of the out-of-print *ALS: Maintaining Mobility* from The Muscular Dystrophy Association (MDA).

Copious photos of real people with ALS (amyotrophic lateral sclerosis, also known as Lou Gehrig's disease) and helpful graphics on glossy paper illustrate the wide variety of equipment and aids that are available to help people with ALS maintain a good quality of life. Chapters include assistive equipment, home modification, mobility, exercise and energy conservation, speech and communication, respiratory problems and resources.

The respiratory section could have benefited from a more helpful and better organized explanation of noninvasive and invasive ventilation and the decision-making process. Fortunately, the importance of coughing and secretion removal was emphasized.

The 144-page spiral-bound book is free to people with ALS who are registered with MDA; \$15 to others; CD-ROM for \$10. Order from MDA's Publications Department: 520-529-2000, ext. 6299, or [publications@mdausa.org](mailto:publications@mdausa.org), [www.mdausa.org](http://www.mdausa.org).



## **Board Presents International Ventilator Users Network Legacy Awards at Ninth Conference**

More than 340 ventilator users, polio survivors, their families and friends, and the health professionals who treat them attended the Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: Strategies for Living Well in Saint Louis, Missouri, June 2-4, 2005.

Honored by the IVUN's Board of Directors and Staff, the following received recognition during the Friday evening program.



**Judith Raymond Fischer, MSLS**, has been the volunteer editor of *Ventilator-Assisted Living* (formerly *IVUN News*) since 1987. Fischer was honored for her exemplary contributions to health education and service to IVUN.



**David Jayne**, who was diagnosed with ALS at age 27, is the founder of the National Coalition to Amend the Medicare Homebound Restriction for Americans with Significant Illness (NCAHB) and RespiteMatch.com. Jayne was honored for his exemplary advocacy in policy and legislative reform.



**Japanese Ventilator Users Network (JVUN)** was founded in 1990 by Kimiyo Sato, a ventilator user who left the hospital to live independently. JVUN was honored for its exemplary networking and advocacy in promoting independent living.



**The following ventilator-related sessions are available on audio tapes or audio CDs from Network Communications**

**Order from Network Communications**

PO Box 219  
High Ridge MO 63049, USA  
800-747-1426  
636-677-1912 fax  
www.swiftsite.com/  
nettapes/PostPolio2005.html.

Audio tapes are \$8 each, plus shipping, and audio CDs are \$10 each, plus shipping.

- #PP-P02 – Anesthesia Precautions for People with Neurological Conditions, S. Calmes, MD
- #PP-P04 – Travel Tips: Taking Cruises/ And If You Use a Vent, L. Priest and A. King, RRT
- #PP-P20 – Clarifying Choices: The Right Ventilation at the Right Time, D. Guth, RRT; B. Thomason, RRT, A. King, RRT  
Noninvasive Ventilation for a Tracheostomized Polio-Patient without Intubation Tube, G. Nyholm, RNP, B. Lassen, RN, Lotte Mortensen, RN
- #PP-P29 – Analyzing Your Sleep: Is It Apnea, Hypoventilation ... Or Both ... Or Something Else? A. Alba, MD, O. Schwartz, MD  
Sleep Hygiene, William DeMayo, MD
- #PP-P37 – Maintaining Pulmonary Health: Monitoring and Preventing – What You Can Do, D. Guth, RRT, B. Thomason, RRT. The Importance of Cough, A. Alba. MD
- #PP-P39 – The Tracheostomy Option: Management of Neuromuscular Breathing Problems, The Danish Way, J. Qvist, MD  
What, Why and When, A. Alba, MD, D. Guth, RRT, B. Thomason, RRT, A. King, RRT
- #PP-P47 – Ventilator Users: Getting Your Act Together and Taking It on the Road, A. King, B. Rogers
- #PP-P52 – Interfaces: New, Tried and True, and Custom, D. Guth, RRT, B. Rogers



Jesper Qvist, MD, Copenhagen, and Augusta Alba, MD, New York, discussing management of neuromuscular breathing problems.

Larry Kohout, ventilator user, Edina, Minnesota.



PHI Board Member and ventilator user, Lawrence Becker, PhD, Roanoke, Virginia.



Selma Calmes, MD, Sylmar, California, providing anesthesia precautions for people with neurological conditions.



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Send this order to:  
**International Ventilator Users Network,**  
4207 Lindell Blvd., #110, Saint Louis, MO  
63108-2915 USA, 314-534-0475,  
314-534-5070 fax, or ventinfo@post-polio.org.

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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

### AUGUST 4-6

**ALS Nursing ... For the Americas.**  
Radisson Hotel and Suites, Chicago, Illinois.  
Contact Jennifer L. Armstrong, RN, BSN,  
Les Turner ALS Foundation, 888-ALS-1107,  
jarmstrong@nmff.org.

### SEPTEMBER 17-21

**European Respiratory Society Annual Congress.**  
Copenhagen, Denmark. Contact European Respiratory  
Society, info@ersnet.org, www.ersnet.org.

### OCTOBER 29-NOVEMBER 3

**CHEST 2005.** Montreal, Canada. Contact  
American College of Chest Physicians, 800-343-2227,  
www.chestnet.org.

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