Ventilator-Assisted Living

www.post-polio.org/ivun

How My Vent and I Underwent Radiation Therapy

Richard Daggett, Downey, California, richarddaggett@ca.rr.com

Just because we have one disabling condition doesn't make us immune to other health problems. I am a respiratory polio survivor who uses trach positive pressure ventilation fulltime. In February 2005, a biopsy of my prostate detected cancer. The initial prognosis was not good. I tried to keep a positive outlook, but it seemed that with every new test the prognosis got worse.

I researched treatment options. Surgery did not seem the best choice for me because of my particular polio complications; my urologist recommended androgen-deprivation therapy and radiation. But both treatments can cause fatigue and weakness. The fatigue I could probably handle, but I am already weak and any increased weakness would interfere with my diminishing independence.

A medical journal article I found indicated that a regimen of strenuous exercise could reduce the weakness associated with cancer treatments. Strenuous exercise? That wouldn't work for me. I get about as much exercise as I can tolerate just brushing my teeth, feeding myself, and standing to transfer.

Just in case I misunderstood the article, I asked Jacquelin Perry, MD, to review it. Although Dr. Perry is retired, she still serves as a consultant for the post-polio clinic of Rancho Los Amigos National Rehabilitation Center. She concluded that a similar exercise regimen might work for me, excluding the "strenuous" parts.

A physical therapist designed a program tailored to my concerns about losing the ability to transfer unaided. I was told to slowly work up to three sets of eight repetitions, three days a week of the following exercises:

- Extend my legs from the knee, focusing on my quadriceps.
- Lift my bottom off the bed, focusing on my gluteus muscles.
- Lift my head off the bed, focusing on my abdominal muscles.

I started these exercises about the same time I started androgendeprivation therapy.

Radiation treatments – Intensity Modulated Radiation Therapy (IMRT) – began about a month later. A major concern was using my ventilator while receiving radiation. I can breathe on my own for about an hour while sitting, but when lying down, I quickly feel breathless and my breathing is shallow. Would I be able to use my ventilator in the treatment area? Would the high radiation levels affect the electronics of the ventilator? The radiation facility staff assured me on both questions.

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Richard Daggett accepts his award at the Amistad Gala, April 2006, from Debbie Tomlinson, Director of Volunteer and Support Services, Rancho Los Amigos National Rehabilitation Center.

International Ventilator Users Network

An affiliate of Post-Polio Health International (PHI)

International Ventilator Users Network's mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.

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Special thanks ... Mark Boatman and Paul Kahn Judith R. Fischer, MSLS

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> To be sure you receive email updates from PHI, set your spam filters to allow messages from info@post-polio.org and news@post-polio.org.

Inside this Issue

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How My Vent and I Underwent Radiation Therapy

An experienced ventilator user reminds us that conditions can affect vent users other than the "diagnosis" for using a vent and that doing your homework and being proactive can pay off.

Pages 4-5 and 9

Judith R. Fischer, IVUN Information Specialist, and Diana Guth, RRT, explain the new rules for Medicare payment for bilevel ventilators with a backup rate that can initiate breaths. Fischer relates news bits from around the Network and keeps all of us up-to-date on where and when important meetings will be held.



Judith R. Fischer

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Interview with Mark Boatman

Paul Kahn, who uses a PLV[®] -100 24 hours a day, interviews a 31-year-old man with muscular dystrophy who describes the barriers and solutions to being institutionalized. Kahn's plays have been staged in California, Maine, New York and Rhode Island, and in many venues in his home state of Massachusetts. In addition to writing plays, he is an editor, feature writer and poet.

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NIV Conference: ICU & Beyond

IVUN has a 20-year history of promoting the international meetings focusing on noninvasive ventilation. IVUN founder Gini Laurie spoke to the gathering in 1988 about the "Utopia of pulmonary rehabilitation – the Polio Regional Respiratory and Rehabilitation Centers" that included "extensive preparation for going home with trial periods of a day, overnight, a weekend. At first the centers trained the attendants, but the turnover was so rapid that it was obvious the most effective method was to train the ventilator user to hire and train his/her own attendants. The home care programs resulted in financial savings and a greater degree of independence and self-sufficiency than were ever dreamed possible for people so severely disabled."

Pages 11 and 12

Our work is supported by your Memberships and the contributions of our sponsors and supporters. In the near future, we will be asking you for your preferences and opinions regarding *Ventilator-Assisted Living*.

–Joan L. Headley, Executive Director of IVUN

Unfortunately, my wheelchair with a PLV®-100 ventilator on the back could not get close enough to the treatment table. I felt it would be too time consuming to disconnect the hoses and battery cable from my PLV®-100 ventilator and take the ventilator off the chair every time I had a treatment. Fortunately Respironics allowed me to use a spare PLV®-100 that I placed on a small luggage carrier and kept at the radiation facility. It was stored safely and wheeled into place after I was lifted onto the table. My aide made the necessary adjustments and connected the hose to my trach.

Radiation treatments were five days a week for nine weeks. Fatigue set in about halfway through. Some days, especially in the early afternoon, I felt as if I would fall asleep in front of the computer. If I had not been using a ventilator, I'm sure this additional fatigue would have further compromised my breathing. Fortunately, these episodes of fatigue faded. About a month after the treatments ended the greatest part of the fatigue was gone.

I have continued my exercise regimen. I can move around in bed more easily, and I've lost an inch in waist measurement. It is too soon to know how effective the treatments will be long term, but my latest tests have been encouraging. I'm feeling good and I'm hopeful. ▲

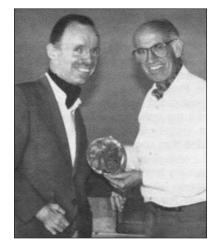
Richard Daggett was born in 1940 in Los Angeles, California, and contracted polio in the summer of 1953, just after his 13th birthday. He and his family had just returned from a camping trip that included swimming in a creek.

Richard was taken to the communicable disease ward of Los Angeles County General Hospital, trached and placed in an iron lung. Subsequently he was transferred to Rancho Los Amigos Hospital, a respiratory polio center funded by the March of Dimes, in Downey, California. After enduring hot packs, extensive physical therapy, body casts for scoliosis, and spinal fusion, Richard was able to stand upright and walk with braces.

Gradually he became able to breathe on his own, and his trach was closed in May 1954. Ten years later Richard began parttime use of positive pressure ventilation and a cuirass during the night. In 1984, after a cold pushed him into respiratory insufficiency, Richard received his second and permanent trach. He had tried non-invasive ventilation with a mouthseal but couldn't tolerate it.

Over the years, Richard has been active in the disability rights movement, his community church, and particularly in the Polio Survivors Association of which he has been president since 1980. In 1985, he presented Jonas Salk, MD, an honorary plaque from Post-Polio Health International (then Gazette International Networking Institute). A significant force in Rancho's Centennial Celebration in 1988, Richard has also been a tireless advocate to save the renowned rehabilitation hospital from closure. Richard has been featured in several television documentaries about polio and polio survivors.

To read more about Richard, go to www.downeydaggetts.com.



Daggett presenting GINI recognition to Dr. Jonas Salk in 1985.



UPDATE: Medicare Reimbursement Changes Affect Vent Users

Judith R. Fischer, IVUN Information Specialist, ventinfo@post-polio.org Diana Guth, RRT, Home Respiratory Care, Los Angeles, California, diana@hrcsleep.com

The changes

In January 2006, the Centers for Medicare and Medicaid Services (CMS) ruled that bilevel ventilators (renamed respiratory assist devices or RADs by CMS) with backup rates would no longer be classified as durable medical equipment (DME) requiring frequent and substantial servicing (FSS).

This ruling, along with a provision of the Deficit Reduction Act of 2005, meant that Medicare payments would end after 13 months, with the initial ruling start date of April 1, 2006. Ownership of the device would be transferred from the DME provider to the user.

If you used a bilevel device with backup rate before April 1, 2006, the clock started ticking April 1, 2006. You will be sent documentation transferring the ownership of the device to you on your anniversary date in May 2007.

Medicare will pay for repairs, but routine periodic servicing of the equipment is the responsibility of the beneficiary, namely you. Replacement of the equipment is according to "the reasonable useful lifetime of durable medical equipment" determined through "program instructions." In the absence of such instructions, the lifetime cannot be less than five years.

The changes in reimbursement may also result in a loss of accompanying respiratory care services from the DME company – such as regular visits to assess your condition, inspect the ventilator, and adjust the ventilator settings – because the DMEs will not be able to absorb the costs. Depending on the results of the new competitive bidding program also recently proposed by CMS, several service issues may change and also result in wide regional variability.

Who is affected?

Medicare beneficiaries who use bilevel ventilatory equipment with backup rates, e.g. users of:

- BiPAP[®] S/T (Respironics, Inc.)
- BiPAP[®] Synchrony (Respironics, Inc.)
- VPAP[®] III ST (ResMed Corp.)
- VPAP[®] III ST-A (ResMed Corp.)
- KnightStar[®] 330 (Puritan Bennett)

Options for you

Pay privately for respiratory care services through your DME company. (The cost may range up to \$100 for an hourly visit.)

If not an emergency situation, call or go to your physician's office. However, some physicians may not be as familiar with adjusting the settings on the equipment as are the respiratory therapists from the DME companies.

If an emergency situation arises, go to an emergency room. However, you should always be prepared, through careful advance decision-making, to advise the ER personnel about your ventilatory wishes. Do you want to receive invasive ventilation through an endotracheal tube or a tracheostomy? Do you want to continue receiving noninvasive ventilation? You also need to be prepared with medical information to resist the provision of oxygen therapy instead of assisted ventilation, which may be harmful. Medicare states, "The overall clinical care of a beneficiary who receives DME is the responsibility of the beneficiary's treating physician." Discuss with your physician changing the ventilator prescription to a volume or pressure support ventilator. Volume and pressure support ventilators are in a DME category that calls for frequent and substantial servicing (FSS). Medicare's monthly reimbursement for this will enable the DME companies to provide the respiratory care services you need. CMS will no doubt keep a very close eye on sudden shifts to new equipment unless there is clear physician documentation and demonstration of a change in medical status and medical necessity.

What you can do NOW!

Contact your Senator or Congressperson to explain the situation and ask them to initiate legislation to change this potentially harmful ruling.

Under the leadership of Peter Gay, MD, pulmonary physicians with the National Association for the Medical Direction of Respiratory Care (NAMDRC) have already begun to advocate for legislative action to change this seemingly capricious and arbitrary ruling by CMS. ▲

For background ...

www.post-polio.org/ivun/VAL_20-1p2.pdf (Ventilator-Assisted Living, Spring 2006, Vol. 20, No. 1)

https://www.noridianmedicare.com/ dme/news/manual/chapter5.html#po

From Around the Network

EQUIPMENT AND INTERFACES

Puritan Bennett discontinued the LP10 ventilator in November 2006. In a statement, PB pledged to " ... use all reasonable efforts to continue to provide LP10 ventilator parts, technical support and factory service to our customers through October 31, 2011. However, certain key components may not be available for the durations of the service period." The KnightStar®330, PB's bilevel unit which was discontinued in February 2006, will continue to be supported until 2009 "... subject to parts availability." (www.puritanbennett.com)

Respironics, Inc. "continues to sell **PLV**[®]**-100** and **PLV**[®]**-102b** portable ventilators. Durability, ease of use and reliability are all hallmarks of these longstanding Respironics products. We are committed to servicing and supporting all existing and future **PLV**[®]**-100** and **PLV**[®]**-102b** ventilators sales. A firm release date for the **PLV**[®] **Continuum**[™] has not been established at this time." (www.respironics.com)

Nasal Pillow Interfaces. New from Respironics, Inc. (www.respironics.com), OptiLife[™] comes with four sizes of pillow cushions. New headgear has an integrated chin support. Opus[™], new from Fisher & Paykel Healthcare Inc. (www.fphcare.com), comes with three sizes of silicone nasal prongs. Tubing can be directed over the head or along the side of the face. Both allow unhindered vision for eyeglass wearers.

TRAVEL WITH OXYGEN

The **Equalizer™** portable oxygen concentrator from **SeQual Technologies** (www.sequal.com/Travel_connection.asp) is now approved for inflight use by nine airlines, with pending approval by Delta and United. Portable oxygen concentrators also approved for inflight use are **Inogen's One** (www.inogen.net/faa) and **Airsep's LifeStyle™** (www.airsep.com/medical/ airline.html).

CHILDREN

"Daily Respiratory Care with an SMA Family" is a 25-minute DVD by Mary Schroth, MD, pediatric pulmonologist with the University of Wisconsin's Children's Hospital. A wealth of practical in-home respiratory care information for families of children with SMA, the DVD is available free through Families of SMA, www.fsma.org.

Tool Kit on Teaching and Assessing Students with Disabilities now has a **Parent Kit**, both available online: www.osepideasthatwork.org/parentkit. These documents were written specifically for parents and include information they need to work with schools to ensure that their children are receiving a quality education through their Individual Education Plan (IEP), mandated by the Individuals with Disability Education Act.

ALS

The Will Rogers Respiratory Symposium, sponsored by The ALS Association (ALSA) in January, drew a standing-room-only crowd of pulmonologists and neurologists, nurses, respiratory therapists, and patient services coordinators from ALSA chapters to learn the latest on respiratory management of people with ALS. A recurring theme was when to initiate noninvasive ventilation and what is the best test to predict and diagnose hypoventilation in ALS. The Will Rogers Institute is sponsoring ALS respiratory research grants for the next five years with grants of \$50,000 each year. For applications, contact Sharon Matland, RN, MBA, Vice-President, Patient Services, ALSA, smatland@alsa-national.org.

Independence with a Ventilator: An Interview with Mark Boatman

Paul Kahn, Newton, Massachusetts, cairokahn@aol.com

Kahn: Will you start by telling me about your family and where you were born?

Boatman: I was born and raised in Jamestown, North Dakota. I'm the only one in my family with a disability. I was diagnosed with Duchenne muscular dystrophy in 1980 when I was five.

Kahn: What were your parents told about your condition?

Boatman: My parents were told by my doctor that I would be lucky to live to 16. They were told to take me home and give me whatever life they could. I attended regular school. In high school I had an aide, and the school had an elevator. After I graduated in 1993, the big thing was what to do and where to go next.

Kahn: Where did you end up going?

Boatman: I found out that a company called Accessible Space Inc. was putting up a building in Jamestown that was going to have 18 apartment units for people with mobility impairments.

What is a Medicaid waiver?

Under Section 1915(c) of the Social Security Act, Medicaid law authorizes the Secretary of the US Department of Health and Human Services to waive certain Medicaid statutory requirements. These waivers enable States to cover a broad array of home and community-based services (HCBS) for targeted populations as an alternative to institutionalization.

To be a waiver participant, an individual must be medically qualified, certified for the waiver's institutional level of care, choose to enroll in the waiver as an alternative to institutionalization, cost Medicaid no more in the community under the waiver than he or she would have cost Medicaid in an institution, and be financially eligible based on their income and assets. They were going to provide attendant care using a Medicaid waiver. In North Dakota, someone with a disability can qualify for four to five hours of attendant care per day. By combining everyone's hours together, the residents could have an attendant 24 hours a day. So I moved there.

Kahn: How was it living away from your family home?

Boatman: It was hard at first, because my parents were my caregivers until that point. They were nervous at first. But once I got used to the setup, I really, really liked being independent.

Kahn: What did you enjoy most about it?

Boatman: Being in control of my own life. I could go to the movies when I wanted to, or I could cook whatever I wanted to for supper. I didn't have to go to bed at a certain time. It was the freedom to run my own life with the proper support.

Kahn: When did you start having respiratory problems?

Boatman: In 2001 I started having some headaches, felt sluggish and short on energy. After a sleep study, the solution was a BiPAP[®] (Respironics, Inc.) machine to use during the night. I made an incredible turnaround. But after a while my symptoms came back again. I started losing weight, losing all my energy and retaining CO₂. By December of 2002 I had lost so much weight that I had to have a stomach tube put in. It went well, but in the recovery process my body just got stressed out too much. That was when the decision to trach me was made. I got the trach at the very end of January 2003. I switched from the BiPAP® to an LP10 (Puritan Bennett).

Kahn: What happened after that?

Boatman: I couldn't return to where I had been living. Under North Dakota's Medicaid rules and regulations for attendant care services, you do not qualify if you require skilled nursing care. Having the ventilator and trach automatically put me into that category. The only option for me was a nursing home.

Kahn: What was it like for you to go from living independently in the community to living in a nursing home?

Boatman: It was kind of hell. The nursing home told me when I could shower, when lunch was going to be, and when I had to be in bed. To go from being an independent young guy and then have the nursing home control my life! They'd chart where I was going or if I had company. And I had to share a little room. There was just no privacy. I got very depressed.

Kahn: Did you think it was unfair that you couldn't live in the community?

Boatman: Yes. I was very capable of living in the community. I could direct everything that I needed. I knew my care. I just couldn't believe the State was not going to make any accommodations for me.

Kahn: What did you do to try to get out of the nursing home?

Boatman: I contacted my State Protection and Advocacy office, and they assigned me advocates. We put together a plan of care. Our goal was for North Dakota Medicaid to cover the cost of my care in the community. But the State was going to make me go through an agency and use nurses and nursing aides. That made it too expensive, and they said that there was no way to do it.

Kahn: What happened next?

Boatman: It was taking forever. I had talked to everyone in the Department of Human Services, but they kept saying no. That's when I met Theresa and Dustin through a muscular dystrophy Internet support group. Theresa was Dustin's caregiver. He has a disability and uses noninvasive ventilation.

Theresa wanted to help me find a way to get out of the nursing home when the State was kicking its feet, and we had the idea of me coming to Missoula, Montana.

Kahn: Is that where you're living now?

Boatman: Yes. I can get funding for nine hours of nursing a day in Montana. I moved out here in September 2006.

Kahn: Had you met Theresa and Dustin in person before you moved?

Boatman: I had met Theresa. She stopped in North Dakota at the beginning of July. I just packed up, came 850 miles away, and made things work.

Kahn: What is your life like now?

Boatman: It's awesome! I have control. Little things like grocery shopping or errands in town are a big deal for me. I can go out to dinner with friends, stay up late, sleep until noon. Theresa and Dustin are very active

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Mark Boatman

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Excerpt from Boatman's Blog ...

"Last Friday (February 2), I experienced a burning pain on the left side of my chest ... my heart checked out fine but my lungs were inflamed. I was given steroids and sent me home ... but the pain didn't subside ... and he got me in right away for a CT scan.

"The Radiology Department placed me on a HoverMat (www.hovermatt.com), which they inflate and glide me ... with a couple fingers. ... it made things much easier on me.

"... they couldn't find a good vein. We discussed our options and ... put a central line into my femoral vein ... which was pretty uncomfortable.

"To make a long story short, they found three small blood clots in my left lung. The doctor started me on blood thinners and put me in ICU for overnight observation. Tuesday afternoon they removed my central line and discharged me. I was sent home on Coumadin and there will be pretty frequent blood draws until my levels become stable."

Mark Boatman (Nodakwheeler) Disability Blog http://nodakwheeler.blogspot.com

in Montana with disability advocacy. They bought a van last summer. We're going to Helena for the legislative session, lobbying and testifying.

Kahn: Is Theresa the sole caregiver for both of you?

Boatman: We have a nurse come in three days a week, but Theresa's the primary live-in caregiver. It really has turned out to be a good setup. The only drawback is that the State pays her for attendant care, but nothing for the vent care. That really offends me, because she is the most skilled attendant I've ever had.

Kahn: What else do you enjoy doing with your time now?

Boatman: I run an online ventilator support group called the Vent Support Network (http://health.groups.yahoo. com/group/npventsupport) that I started while I was in the nursing home. I spend a lot of time on that. There are more than 100 members. We talk about various issues, and it's a great way to meet other people.

Kahn: And you have a blog. Tell me about it?

Boatman: The blog was a way to keep all the people who were supporting me in the loop with what was going on with my fight with North Dakota to get out of the nursing home. But it really blossomed when I moved out here, because I could share with friends, family and perfect strangers my experiences being out of the nursing home. Being out has given me a lot of confidence. What troubles me is that other folks are still in nursing homes.

Kahn: What do you think are the key changes that have to happen for ventilator users to live independently?

Boatman: The Nurse Practice Act needs to be amended to let caregivers who aren't nurses care for vent users. The board of nursing in each state has guidelines for what medical procedures need to be done by a nurse. If States free up some of these laws to allow non-nurses to do some of these procedures, it would lower the cost. I've had a lot of good nurses, but nonnurses can be excellent. Vent and trach stuff is pretty routine.

It still comes down to more money being put into attendant care throughout the country to allow people options. A nursing home is not the place for anybody to be stuck in, especially people who still have a life to live. I'm 31 years old, and according to the doctors shouldn't even be here. But I've never listened to the medical establishment too much.

2007 Camps for Ventilator-Assisted Children

MARCH 31-APRIL 6. VACC (Ventilator-Assisted Children's Center) Camp. Miami, Florida. Contact Bela Florentin, VACC, Miami Children's Hospital, 305-662-8222, bela.florentin@mch.com, www.vacccamp.com.



JUNE 3-8. Trail's Edge Camp. Mayville, Michigan. Contact Mary Buschell, RRT, Camp Director, 231-228-3371, mdekeon@med.umich.edu, www.umich.edu/~tecamp

JUNE 3-9. Camp Pelican. Lion's Camp, Leesville, Louisiana. Contact Cathy Allain, 985-764-0343, cathyallain@cox.net, www.camppelican.org.

JUNE 10-15. Fresh Air Camp. Camp Cheerful, Strongsville, Ohio. Contact Kathy Whitford, MSN, PNP; Cleveland Clinic Foundation, 216-721-7159, whitfok@ccf.org, www.freshaircamp.org.

JUNE 13-17. Camp Inspiration at Double H Hole in the Woods Ranch. Contact Tara Bogucki, Admissions Coordinator, 518-696-5676 ext. 222, theranch@doublehranch.org, www.doublehranch.org. *Application deadline: April* 15.

JUNE 18-22. CHAMP Camp. Recreation Unlimited, Ashley, Ohio. Contact Camp Administration, 317-679-1860, admin@champcamp.org, www.champcamp.org.

JUNE 24-28. Pennsylvania Vent Camp. Camp Victory, Millville, Pennsylvania. Contact Lois Marshall, Pediatric Critical Care Department, Penn State Children's Hospital, 717-531-5337, Imarshall@psu.edu.

JULY 5-8. Light the Way Camp. Children's Harbor, Alex City, Alabama. Contact Kara Bishop, 205-370-9605, karabishop@ventkidsofalabama.com, www.ventkidsofalabama.com.

JULY 29-AUGUST 3. Camp Inspiration. Rocky Mountain Village, Empire, Colorado. Contact Monte Leidholm, RRT, The Children's Hospital, 303-837-2502, leidholm.monte@tchden.org.

2007 Conferences

APRIL 19-21. Seventh Annual Focus on Respiratory Care and Sleep Medicine Conference. Opryland Hotel & Convention Center, Nashville, Tennessee. www.foocus.com

APRIL 26-27. 9th Annual Conference in Mechanical Ventilation: New Trends. Marriott Boston Newton, Newton, Massachusetts. http://ventilationtrends.com

MAY 18-23. American Thoracic Society International Conference. San Francisco, California. www.thoracic.org

JUNE 21-23. FSMA Families and Professionals Conference. Hyatt Regency Woodfield, Schaumburg, Illinois. www.fsma.org

JUNE 22-24. Noninvasive and Home Mechanical Ventilation: ICU and Beyond. Le Centre Sheraton, Montreal, Quebec, Canada. www.chestnet.org/education/courses/NMHV07/registration.php. See *details on page 10.*

JULY 12-15. Parent Project for Muscular Dystrophy. Lowe's Hotel, Philadelphia, Pennsylvania. www.parentprojectmd.org

SEPTEMBER 15-19. European Respiratory Society Annual Congress. Stockholm, Sweden. www.ersnet.org

OCTOBER 4-6. ALS/MND Nursing Symposium. Radisson Hotel, Chicago, Illinois. www.lesturnerals.org/educationalactivities.htm#nursing

OCTOBER 20-25. CHEST 2007. American College of Chest Physicians, Chicago, Illinois. www.chestnet.org

DECEMBER 1-4. 53rd International Respiratory Congress of the American Association for Respiratory Care. Orlando, Florida. www.aarc.org



Networking

Noninvasive and Home Mechanical Ventilation: ICU and Beyond

WHEN:	June 22-24, 2007		
WHERE:	Le Centre Sheraton, Montreal, Quebec, Canada		
WHAT:	An important conference (alternates every two years between Lyon, France, and North America) devoted to all aspects of assisted ventilation.		
Conference topics include noninvasive ventilation in acute care, manage- ment of acute crises in individuals using long-term assisted ventilation, interfaces and ventilators, assisted ventilation beyond the ICU – where and when, European experiences with long-term ventilation, pediatric applica- tions, the role of noninvasive ventilation in people with COPD and obesity hypoventilation syndrome, caregiver burnout, sex and the ventilator user, long-term ventilatory management in neuromuscular diseases, reimburse- ment issues, cough/secretion management, telemedicine and its use for ventilator users and MORE.			

Plus exhibits of the latest in ventilatory equipment and masks.

SPEAKERS: Experts in noninvasive ventilation, including: Nicholas Hill, Barry Make, Josh Benditt, David Birnkrant, Peter Gay, Allen Goldberg, Roger Goldstein, Dean Hess, Sean Keenan, Angela King, Noah Lechtzin, Douglas McKim, Stefano Nava, Barbara Rogers, Dominique Robert, Anita Simonds, Alexander White.

REGISTRATION: Ventilator users (\$175.00), as well as respiratory health professionals, are invited to attend. (Early registration closes May 22.) For registration information and the complete conference program, go to www.chestnet.org/education/courses/NMHV07/registration.php

Looking for ventilator users living at home in Massachusetts

Miguel Divo, MD, Pulmonary, Critical Care and Sleep Medicine, Caritas St. Elizabeth's Medical Center of Boston, is currently conducting a census of mechanically ventilated patients living at home in Massachusetts. To complete his brief survey, email him at mdivo@copdnet.org or contact IVUN for a copy.

Ventilator Users' Medical Emergency (VUME)

Project Leader Virginia Brickley reports that a cadre of health professionals and ventilator users are putting the final touches on the packet of materials to help ventilator users, their caregivers and their health professionals improve the outcome of a medical emergency. The project is funded by a grant from the Christopher Reeve Foundation.



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Membership Application

Institution/Support Group _____

(area/country code)

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

Membership Level

□ Subscriber, \$25 □ Ventilator-Assisted Living OR □ Post-Polio Health

Subscriber Plus, \$45

Contributor, \$75

 Sustainer, \$125 | am designating this person for the additional Subscriber Membership. Please send:
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Address		
City, State/Province		
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Or, donate this complimentary Subscriber Membership

to person selected by International Ventilator Users Network.

Payment Options

Signature

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Name _

Address

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email

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Enclosed is my check made payable to	
Post-Polio Health International. (US dollars only)	
OR, charge my: UISA UMasterCard U	Discover

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_ Fax_

(area/country code)

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DST-P@IIO|HFAITH

Send to:

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ResMed Corporation (800-424-0737, www.resmed.com) ResMed is a leading developer, manufacturer and marketer of products for the screening, treatment and long-term management of sleep-disordered breathing (SDB) and other respiratory disorders. ResMed operates in over 65 countries via 16 direct offices and a network of distributors with extensive knowledge and experience of local markets.

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Post-Polio Health International Including International Ventilator Users Network

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