It is estimated that about 1,000 persons in Finland receive mechanical ventilation because of hypoventilation. All neuromuscular disorders in Finland are considered rare disorders, with a prevalence of less than 1 in 10,000 people. People with neuromuscular disorders who receive home mechanical ventilation are a growing group.

Finland has legislation that dates back to the 1950s when polio was prevalent and there was interest in guaranteeing good care for people with polio using ventilators. Legislation includes the concept of respiratory paralysis and the according of “respiratory paralyzed person” status. It is used in administrative decision-making.

The interesting point about this concept is that people are registered as in-patients, even when living at home. Respiratory paralysis patients get all treatment and services from a hospital. They are entitled to five helpers for assistance 24 hours per day. All costs are paid by hospitals. In order to be accorded status as a “respiratory paralyzed person,” one must use invasive ventilation, and the need for ventilator support must be almost 24 hours per day.

All ventilator users do not meet the criteria and are not accorded this status. As a result, they have to organize to obtain helpers. The Act on Services for the Disabled was renewed this fall with the provision that people with disabilities have the right to get personal assistance, with salaries for that assistance paid by social services.

Since the 1950s, it seems that at least once a decade there has been interest in home mechanical ventilation, especially concerning services for ventilator users. During the last nine years there has been more interest, because mechanical ventilation saves lives and provides quality of life to many people, and also because of the high costs of the homecare.

There are 20 hospital districts, and people with hypoventilation are treated in both central and university hospitals. Hospitals are responsible for diagnostics, treatment, equipment and homecare plans whatever the ventilation interface. Ventilators are provided at no charge. Nobody can buy or change a ventilator without a doctor’s prescription.
Help Eliminate Competitive Bidding

What is competitive bidding? A competition among suppliers of certain durable medical equipment is held in areas around the country. Bids and contracts are awarded to the Medicare suppliers who offer the best price and meet applicable quality and financial standards. Contract suppliers must agree to accept assignment on all claims for bid items and will be paid the bid price amount. The amount is derived from the median of all winning bids for an item.

This process is an attempt by the Centers for Medicare and Medicaid Services (CMS) to control Medicare expenditures for durable medical equipment, including CPAP and bilevel units. It was halted by an act of Congress in 2008 after many flaws and problems were detected in Round 1 that had serious ramifications for ventilator users.

Reducing the number of homecare providers means less choice for consumers and forces many Medicare beneficiaries to obtain equipment and supplies from an unfamiliar, non-local provider that may be unlicensed and inexperienced in providing the equipment and services that people depend upon.

However, competitive bidding was only halted, not eliminated, and with the high cost projections for health care reform, it has been resurrected for Round 2. Congressperson Kendrick Meek (D-Fla) is co-sponsor of H.R. 3790 that would end this program.

The American Association for Homecare is advocating support for the bill, and IVUN has joined their advocacy efforts. Consumers may also advocate in favor of H.R. 3790 by writing their congresspersons.

Details and a sample letter are available by visiting www.aahomecare.org.

For background, visit www.ventusers.org/edu/valnews/VAL_22-2su08p9.pdf.

For more information, visit www.cms.hhs.gov/DMEPOSCompetitiveBid/.
Since 2000, central and university hospitals have opened service units for ventilator users, especially for those who have the status of respiratory paralysis. These clinics don’t have beds. Most of these clinics have only one head nurse working fulltime and a consulting doctor. Only three university hospitals have a doctor working halftime. Hospitals have also founded VENHO (Ventilation Treatment) working groups, consisting of a multi-professional team that serves all ventilator users with hypoventilation.

Officers from the Ministry of Social Affairs and Health found that in 2004 there were 135 people in Finland accorded respiratory paralysis status. The cost of the treatment of those 135 amounted to 27 million euros. Out of those 135, fewer than 10% had polio.

In 2006, the Ministry appointed a national expert working group on the treatment of patients with respiratory paralysis in order to examine their status as well as the legislation and care recommendations in the present social welfare and healthcare system.

Based on the report’s recommendations for further actions, one university hospital team started to develop guidelines and recommendations for quality care.

Meet Artist Kaija Pöytäkivi
Life changed for Kaija Pöytäkivi when she was a little girl in the 1950s. She contracted polio and became a ventilator user before her 10th birthday. Today she is living independently in her own household. She does not feel sick or disabled. “Maybe I am blind concerning my own disability,” laughs Kaija.

Kaija has had her own helpers since 1968 when she moved back home from the hospital, where she lived for 12 years. This year one of Kaija’s helpers retired after working for 40 years for her. Kaija has had seven different ventilators. Her current ventilator is the PLV®-100, which she considers to be the best. She also uses the smaller and lighter Elisée 150 when traveling.

Kaija is very active, and her days are full of different activities. She visits her elderly mother in the countryside and godchildren in a nearby city.

“Music is important to me and I like to go to concerts,” says Kaija. “My enthusiasm is also porcelain painting. I have been fascinated with painting ever since I was a young girl. I started to paint small gifts for my friends but for the past 10 years, people have given me orders to make gifts for them.”

Five years ago, Kaija won first prize in a porcelain painting contest. The jury members were surprised to hear that she paints everything by holding the paintbrush with her mouth.

Kaija’s motto is “Take care of each other!”

Jukka Sariola, chairman for Ventilator Users Association, is an active electric wheelchair hockey player.

Kaija Pöytäkivi was named “Artist of the Year” and awarded a €2000 scholarship at a recent art exhibition.
Breathing and Sleep Symposium
Joan L. Headley, Executive Director, Post-Polio Health International, Saint Louis, Missouri, director@post-polio.org

The setting was the Salk Institute for Biological Studies designed by architect Louis Kahn. The topics of the November 1 half-day symposium were breathing problems and sleep problems of individuals with neuromuscular conditions and solution options for them.

First to present was Geoffrey Sheean, MBBS, FRACP, Director, Neuromuscular Division, Clinical Professor of Neurosciences, University of California, San Diego. His task was to explain the breathing mechanism and how it is affected by neuromuscular diseases. People with ALS, muscular dystrophy and post-polio can have new weakness of the diaphragm, the major breathing muscle. For some, throat and tongue weakness can cause obstructive sleep apnea (OSA). For others, the brain fails to send the message to breathe, and central sleep apnea is diagnosed. Sheean’s presentation can be viewed at www.poliotoday.org, a new site created by the Salk Institute.

Noah Lechtzin, MD, MHS, FCCP, Pulmonary & Critical Care Medicine, Assistant Professor of Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland, focused on how pulmonologists determine the cause of breathing problems, i.e., what tests are used, and on the importance of coughing and other ways to get rid of secretions in the lungs.

Later in the day he teamed up with Louis J. Boitano, MS, RRT, RPFT, Northwest Assisted Breathing Center, University of Washington Medical Center, Seattle, Washington, to provide solutions to breathing problems, citing several case studies. Both presentations are available at www.poliotoday.org.

Lechtzin was challenged to explain in one sentence why using oxygen only is not recommended for people with neuromuscular conditions. It took more than one sentence and bears repeating:

“We all rely on the concentration of CO2 levels in the blood to stimulate breathing. If someone has weak breathing muscles, he or she may chronically underventilate, which results in a chronically high CO2. Over time the ability to sense elevated CO2 diminishes.

“We all rely to a lesser degree on low oxygen levels to stimulate breathing. However, someone with weak breathing muscles and chronically elevated CO2 may rely on low oxygen levels to stimulate breathing. If oxygen is given without close monitoring and ventilatory support, the breathing rate may slow, or even stop.

“Most patients with neuromuscular conditions, in the absence of underlying lung disease, don’t need supplemental oxygen. If someone has underlying lung disease, oxygen absorption may be hampered and oxygen may be needed but should be added to the bilevel device or ventilator.”
Boitano’s take-away message was the explanation of a protocol developed by John Bach, MD, and Yuka Ishikawa, MD, to reduce the potential for hospitalization due to respiratory infection. He and Josh Benditt, MD, Northwest Assisted Breathing Center, University of Washington Medical Center, use this protocol with all of their neuromuscular patients who have respiratory limitations.

Under this protocol, individuals are encouraged to buy a finger oximeter to monitor their oxygen saturation level. Oximeters are available through Internet medical supply companies for about $60-100. Be sure to purchase one that is FDA approved for human use.

To assure a good reading if circulation is poor, either place hand in warm water or wrap hand in a towel soaked in warm water before attaching the device.

A normal oxygen saturation level is 96-98%. If symptoms of a respiratory infection develop and oxygen saturation falls below 95%, pulmonary congestion may be developing. Individuals should do the following:

1. Use either a manual hyper-inflator or CoughAssist® device to hyper-inflate the lungs and to increase cough support.
2. Increase the use of mechanical ventilation as needed.
3. Contact a physician and request a broad spectrum antibiotic for respiratory infections.

Helen Kent, BS, RRT, Progressive Medical, Carlsbad, California, and Diana Guth, BA, RRT, Home Respiratory Care, Los Angeles, California, displayed numerous nasal and face masks, which attendees could try. Several ventilator equipment exhibitors offered a close-up look at a range of assisted breathing devices.

For the meeting, Guth updated her article, “Masks, Part II: Noninvasive Interfaces,” first published in 2005. It is available at www.ventusers.org/edu/valnews/val19-3b.html.

More than 150 individuals attended the symposium, co-sponsored by ResMed Corp. and the Salk Institute for Biological Studies.
From Around the Network

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

New Products

**Forma™ Full Face Mask** from Fisher & Paykel Healthcare features the FlexiFoam™ Cushion that adjusts to a range of facial/nasal contours and an under-chin design to maintain a good seal. Available in four sizes. www.fphcare.com

**Sil. Flex™ Stoma Pad** from B & B Medical Technologies provides a silicone cushion between the flange of the tracheostomy tube and the stoma site. It can help reduce irritation of the skin around the stoma. Available in three sizes. Latex-free and easily cleaned. www.BandB-Medical.com

**Sleep Comfort Care Pad**, designed by CHI-SAN LLC, acts as a barrier between a facial/nasal mask and the skin. It helps prevent skin breakdown and facial sores. Made of a polymer gel, silicone and latex-free, it is available in two sizes. www.sleepcomfortcaresystem.com

Product Recall

The FDA issued a Class I recall in October of single-patient use manual pulmonary resuscitators (MPR) manufactured by ConvaTec (Unomedical, Inc.) between July 2002 through March 2008. The units with clear or transparent rings and those with no visible ring are recalled. Units with a blue retention ring are not affected by the recall. Class 1 recalls are the most serious type of recall and involve situations in which there is a reasonable probability that use of these products will cause serious injury or death.

The FDA maintains a list of medical device recalls and safety alerts, as well as information on 510(k) clearances. For 510(k) clearance, device manufacturers must register their intent to market a medical device at least 90 days in advance. This allows the FDA to determine whether the device is equivalent to a device already placed into one of the three classification categories. Thus, “new” devices (not in commercial distribution prior to May 28, 1976) that have not been classified can be properly identified. www.fda.gov/MedicalDevices/default.htm

Product Discontinuation

Philips Respironics announced that it is discontinuing the manufacture of the PLV®-100, PLV®-102b and PLV®-102, effective December 31, 2009. The company will provide rental units, service, replacement parts and technical support through December 31, 2014. However, repairs will be subject to the availability of parts from suppliers. Manufacturing and service warranties currently in effect will be honored.
**Business News**
Cardinal Health announced the spinoff of CareFusion (and its ventilatory product lines: Pulmonetic’s LTV\(^\text{®}\) series, TBird\(^\text{®}\) Legacy, Tiara Medical) as a separate company in July. www.carefusion.com

**Frogbreathing (glossopharyngeal breathing) Resources**
Gary McPherson, respiratory polio survivor and frogbreathing pro, demonstrates. www.garymcperson.com
The Ottawa Hospital Rehabilitation Centre, online education on lung volume recruitment and frogbreathing.
www.irrd.ca/education/slide.asp?RefName=e2r4&slideid=60

**Research Study on Quality of Life in ALS**
Researchers at Penn State College of Medicine are seeking people with ALS for a research study to better understand the quality of life and problem-solving skills of people with ALS who attend multidisciplinary clinics versus those who do not. Participants will complete a questionnaire that asks questions about physical health status, quality of life, social problem-solving skills, and use of medical services for care of ALS. Survey responses are confidential.

To access the online questionnaire, go to the Penn State Hershey ALS Clinic website – www.pennstatehershey.org/als – and click on the link “ALS Patients: Click here to participate in a research survey.”

To request a paper copy of the questionnaire, contact the study coordinator, Beth Stephens, hstephens1@psu.edu. Zachary Simmons, MD, Department of Neurology, Penn State College of Medicine, is study director.

**Mouthpiece Ventilation Resources**
“My Experience with Setting up Day-time Ventilation” by Luke Melchior in Ventilator-Assisted Living (Fall 2009, Vol. 23, No. 3) should have included the following web resources:
Snap-Loc, the jointed tubing and connectors, www.cedarberg.com
Provincial Respiratory Outreach Program (PROP), www.bcits.org
Northwest Assisted Breathing Center, Josh Benditt, MD, and Louis Boitano, RRT, University of Washington, www.uwtv.org/programs. Click on Program Library, then click on Programs by Title, and scroll down to Noninvasive Assisted Breathing.

**Disaster Planning**
QUESTION: I am a vent user with a trach who has MRSA (methicillin-resistant *Staphylococcus aureus*) for the second time. I have been suctioning both fresh blood and blood plugs and clots for a week. I use the CoughAssist® intermittently and try not to suction too often, using the red rubber suction tubes to avoid irritation. Is it your experience that MRSA causes bleeding and, if so, what are options for resolving the problem? I am on Bactrim based on my sputum culture. The last time I had MRSA for four months. It wasn’t until Bactrim was combined with rifampin that it cleared up.

ANSWER: Bactrim would not be my choice for treating MRSA. Depending on your organism’s sensitivities, you might be able to treat it in combination with something like rifampin, or might require an IV drug like vancomycin. Zyvox™ is another possibility.

Bleeding would be unusual for MRSA. There are many other potential causes for bleeding. It is important that you get evaluated, with at least a chest x-ray (CXR), and maybe other imaging, and a bronchoscopy or airway evaluation, because you might have an area of granulation tissue (irritated area) that is bleeding. An evaluation also will determine if another antibiotic will help.

The underlying question for your physician to resolve would be whether this represents colonization (bacteria present but not making you sick), or true infection. Infection or pneumonia would require much more vigorous treatment.

I agree with minimal suctioning but see no benefit to red rubber vs. current plastics in terms of catheter irritation. But I recommend maximal CoughAssist use. You can often just suction the trach hub after CoughAssist use to clear secretions and not use a catheter at all.

*Brenda Jo Butka, MD, FCCP, Respiratory Care, Pulmonology, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee, brenda.butka@vanderbilt.edu*

ANSWER: It is difficult to tell here if this is colonization plus an airway problem, such as granulation tissue, or true bacterial bronchitis or pneumonia. If you do not have a fever and are not very ill, I would get an ENT to look at your airway.

You need to know what drugs your MRSA is sensitive to. One of the better MRSA drugs is linezolid (Zyvox™) @ 600 mg orally twice a day for a minimum of 14 days. I advise a re-culture 72 hours after stopping the medication if symptoms are under control to see if the “bugs” have been eradicated or a population has been changed. The trach tube must be changed (if not done already) and again on the last day of an effective antibiotic regimen so the infection does not stay colonized.

My recommendation for airways:

1) Use nebulized 2% lidocaine, which can be added to any bronchodilator every four hours (except when asleep) to reduce pain and bleeding. One dose with epinephrine (1 ml of a 1:10,000 mixture) may be enough to stop the bleeding. The bleeding is from a combination of the infection and the trauma from suctioning no matter what kind of catheter is used. Lidocaine has a small antibacterial action, so it can synergize with the antibiotics you are taking.

2) To reduce suction trauma, I suggest that you use an Ambu® Bag connected to the trach to gently suction, without a catheter, the secretions into the trach tube’s inner cannula.
Remove the inner cannula and clean it. Repeat this process until clear, with ventilator breaths in between until a comfort level is reached.

Save old inner cannulas to have a supply on hand for the switch without having to wait to clean one before re-applying. These can be cleaned with soap and water, rinsed in a 10% vinegar solution (ten minutes and re-rinsed with clear water. The cleaned ones can be placed in sealed plastic bags after they are dry and are ready for the next need.

**Norma M.T. Braun, MD, FACP, FCCP**, (Retired) New York, New York, nbraun@chpnet.org

### Travel by Air

**Update on Stickers**

Mike Luber reported in the Summer Ventilator-Assisted Living (Vol. 23, No. 2) that he and his brother, who use their vents during take-off and landing, were not allowed to fly earlier this year because their PLV®-100 (Philips Respironics) ventilators didn’t have the appropriate stickers as mandated by the Air Carriers Access Act amendments that became effective in May 2009.

Since then, IVUN has learned that the Federal Aviation Administration (FAA) has still not amended any operating rules to address labeling on Medical Portable Electronic Devices (M-PEDs), i.e, bilevel devices and ventilators. Nancy Clausen, a representative of the FAA, reports that they are awaiting the Department of Transportation’s (DOT) final notice that “will address a lot of the issues.”

Undaunted, the Lubers booked a flight to Las Vegas recently and report, “Our last trip to Vegas was very uneventful. They just asked the usual questions. Is the battery dry cell? Does the ventilator use oxygen? They did not even ask for a letter from the doctor.”

Philips Respironics reports that the Trilogy100 ventilator meets RTCA/DO-160 testing standard and is certified for use aboard all commercial airlines landing or taking off within the United States. The certificate can be found on the Philips Respironics Trilogy100 webpage http://trilogy100.respironics.com. There are no plans to test the PLV®-100.

**Air Carriers with Medical Policies**

Compiled by Tim Buckley, RRT, and Brian Tiburzi

This list, with direct links to the respective airline’s policies, is posted at www.ventusers.org in the “Networking” section.

**Airline** | **Phone #** | **Airline** | **Phone #**
---|---|---|---
Air Tran | 800-247-8726 | Lufthansa | 866-846-4283
Alaska | 800-654-5669 | Midwest | 800-452-2022
Allegiant | 702-505-8888 | Qantas | 800 227 4500
American | 800-433-7300 | SAS | 800-221-2350
Delta | 404-715-2600 | Singapore | 800-742-3333
Continental | 800-523-3273 | Southwest | 800-435-9792
Air France | 800-992-3932 | Sun Country | 800-359-6786
Frontier | 800-432-1359 | United | 800-864-8331
Hawaiian | 800-367-5320 | USAir/America West | 800-892-3624
Jet Blue | 800-538-2583

**Travel Insurance**

Barbara Rogers, vent user and frequent flier as President of the National Emphysema/COPD Association, recommends that all vent users consider travel insurance to cover medical/evacuation costs. There are more than 15 companies in the travel insurance business, and each one sells a variety of plans. To check out the options, visit Travel Insurance Review at www.travelinsurancereview.net.

**Ask The Experts, continued from page 8**

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**Norma M.T. Braun, MD, FACP, FCCP** (Retired) New York, New York, nbraun@chpnet.org
2010 CALENDAR

MARCH 5
10th Anniversary Conference
UK Respiratory Information for Spinal Cord Injury (RISCI), Southport, England. +44 (0)1704 704024. Check www.risci.org.uk for the call for abstracts.

MARCH 27-APRIL 2
Ventilator-Assisted Children’s Center (VACC) Camp
Miami, Florida. Contact Bela Florentin, VACC, Miami Children’s Hospital, 305-662-8222. bela.florentin@mch.com, www.vacccamp.com

APRIL 29–MAY 1
“A Breath of Fresh Air,” Canadian Respiratory Conference

MAY 13-15
FOCUS on Respiratory Care and Sleep Medicine, 10th Annual Conference
Disney’s Coronado Springs Resort, Orlando, Florida. www.foocus.com

MAY 14-19
American Thoracic Society International Conference
New Orleans, Louisiana. www.thoracic.org

JUNE 24-27
FSMA Family and Professionals Annual Conference
Santa Clara Marriott, Santa Clara, California. www.fsma.org

JUNE 24-27
Parent Project Muscular Dystrophy Annual Conference
Denver, Colorado. www.parentprojectmd.org

SEPTEMBER 18-22
European Respiratory Society 20th Annual Congress
Barcelona, Spain. www.ersnet.org

OCTOBER 30-NOVEMBER 4
CHEST, American College of Chest Physicians Annual Conference
Vancouver, British Columbia, Canada. www.chestnet.org

DECEMBER 6-9
AARC International Respiratory Congress
Las Vegas, Nevada. www.aarc.org

IVUN invites you to promote your meeting in future issues of Ventilator-Assisted Living and on www.ventusers.org. Send the details to info@ventusers.org.
Call for Proposals

IVUN is seeking proposals from researchers affiliated with an institution who are interested in studying an aspect of the cause(s) and treatment of neuromuscular respiratory insufficiency and the effects of long-term home mechanical ventilation.

The Research Fund of Post-Polio Health International and International Ventilator Users Network will award $25,000 in the fall of 2010 to a recipient selected by a panel of experts, including representation by users of home mechanical ventilation.

The grant’s funds can be used to initiate new research, to continue notable projects, or to combine with other resources to complete relevant research.

Issuing its sixth call since the fund’s inception in 1995, PHI has given $120,000 to support studies related to post-polio myelitis and neuromuscular insufficiency. Two of the five studies focused on ventilator use. The final reports of “Ventilator Users’ Perspectives on the Important Elements of Health-Related Quality of Life” (2001) and “Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis” (2005) are online in the “Research” area of www.ventusers.org.

The criteria for applying are online at www.post-polio.org/res/rfcall.html. The process is conducted in two phases. Applicants from Phase I will be screened and select applications will be asked to complete Phase II.

Deadlines:

Receipt of Phase I
Friday, March 5, 2010

Invitation for Phase II
Friday, May 21, 2010

Receipt of Phase II
Friday, September 24, 2010

Award Announcement
Friday, December 17, 2010

IVUN thanks its Members for their support. If you are not yet a Member, Join IVUN!

Support International Ventilator Users Network’s educational, research, advocacy and networking mission.

Rates Effective July 2007

IVUN membership levels make it easy to start taking advantage of timely and important news and activities relating to home mechanical ventilation. Select your level below and return it with your check or credit card information. Or join IVUN online at www.ventusers.org. Memberships are 100 percent tax-deductible.

☑ $30 Subscriber
Quarterly newsletter of your choice:
☐ Ventilator-Assisted Living OR ☐ Post-Polio Health

☐ $55 Subscriber Plus
Both quarterly newsletters: Ventilator-Assisted Living AND Post-Polio Health

☐ $100 Contributor
ALL the benefits of Subscriber Plus AND Resource Directory for Ventilator-Assisted Living and Post-Polio Directory; discounts on special publications and IVUN’s sponsored meetings

☐ $150 Sustainer
ALL the benefits of Contributor AND One additional complimentary gift membership to:
☐ Person of your choice (include name and address) or ☐ Person who has expressed financial need to IVUN

Membership at the following levels includes ALL benefits PLUS special recognition in IVUN publications:

☑ $250 Bronze Level Sustainer
☑ $500 Silver Level Sustainer
☑ $1,000 Gold Level Sustainer
☑ $5,000 Platinum Level Sustainer
☑ $10,000 Gini Laurie Advocate

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314-534-0475 314-534-5070 fax
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ResMed is a leading developer and manufacturer of products for the treatment and management of acute and chronic respiratory conditions for both adults and children. ResMed is committed to developing innovative and effective ventilation solutions, including masks and accessories, to offer assistance to health personnel and improve the quality of life of patients around the world.

Meet Our Supporters …

**Dale**  Dale Medical Products, Inc.  800-343-3980, www.dalemed.com

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**Philips Respironics**  800-345-6443, www.respironics.com

Philips Respironics is expanding the company’s solutions for patients who suffer from chronic respiratory diseases with the introduction of the new Trilogy100 ventilator. Trilogy100 is easy to use, versatile and remarkably portable. For more information, an interactive demonstration, or free resources, go to www.Philips.com/Trilogy100.