

September, 2010 (No. 9)

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An affiliate of Post-Polio Health International (PHI)

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www.ventusers.org
info@ventusers.org

Greetings from International Ventilator Users Network in Saint Louis, Missouri.

IVUN's Home Ventilator Guide was updated September 27, 2010. Manufacturers are asked to check the specifications of their products listed in the guide.

IVUN's Resource Directory for Ventilator-Assisted Living is updated continually. *Note: We added two new sections: Respiratory Home Care Companies/DMEs and In-home Care Agencies.* To be included, send your information to info@ventusers.org.

Your next issue of *Ventilator-Assisted Living* (No. 5) will be sent via email in late October. A print copy is available on request. Click on the following to access all 2010 *Ventilator-Assisted Living* issues.

Ventilator-Assisted Living (**Vol. 24, No. 4**)

Ventilator-Assisted Living (**Vol. 24, No. 3**)

Ventilator-Assisted Living (**Vol. 24, No. 2**)

Ventilator-Assisted Living (**Vol. 24, No. 1**)

For Your Health

Flu Shot

It's time for the annual flu shot. The 2010-2011 inactivated influenza vaccine includes protection against the H1N1 influenza virus, in addition to the A/H3N2 and B influenza strains. For more information, contact a healthcare provider or visit www.cdc.gov/flu.

Breathing & Sleep Symposium II

Sunday, November 21, 2010, 9:00am – 2:30pm
Salk Institute for Biological Studies, La Jolla, California

Sponsored by Salk Institute and ResMed Corp.

Topics: Breathing and sleep basics for people with PPS, ALS, and muscular dystrophy, as well as pulmonary function tests (PFTs),

anesthesia and post-surgery respiratory support solutions, settings on noninvasive positive pressure ventilation (NPPV) equipment; and interfaces.

Presenters include several members of IVUN's Medical Advisory Committee:

Josh Benditt, MD, FCCP, and Louie Boitano, MS, RRT, RPFT, Northwest Assisted Breathing Center, University of Washington Medical Center, Seattle, Washington.

Selma Calmes, MD, (Retired), Chief Physician of Anesthesiology and Professor of Anesthesia, UCLA School of Medicine, Los Angeles.

Helen Kent, BS, RRT, Founder, Progressive Medical Respiratory Care Co., Carlsbad, California.

Angela King, BS, RPFT, RRT-NPS, ResMed Corp., Senior Director, Clinical Ventilation – Americas, San Diego, California.

Register for the **free** symposium online:

www.salk.edu/breathingandsleep. **Free** CEU credits for RTs are also available.

Advocacy

Competitive Bidding Update

The health subcommittee of the House Energy and Commerce Committee held a hearing on the competitive bidding program of the Centers for Medicare and Medicaid Services for durable medical equipment (DME) on September 15, 2010. The hearing examined the conception and implementation of the competitive bidding program, the implementation of the Round One Re-Bid, and its potential effects on patients, providers and physicians.

A DME provider testified on behalf of the American Association for Homecare. The competitive bidding program, as now conceived and without correction of its many flaws, may prove harmful to ventilator users. For the latest developments, go to www.aahomecare.org.

Community Living

\$68 million in grants which support President Obama's [Community Living Initiative](#) are going to states, territories, tribal and community-based organizations. The funds will help seniors and individuals with disabilities and their caregivers in several ways, including understanding their Medicare and Medicaid benefits and options for long-term care, and community-based services that can help them continue to live in their homes. Funding will also go to the [National Center for Benefits Outreach and Enrollment](#), which helps organizations enroll seniors and younger adults with disabilities into benefits programs, and to [Aging and Disability](#)

[Resource Centers.](#)

[Click here for more information.](#)

Networking

"My name is Michael and I have DMD and am Administrator of Kids with Vents Facebook page. My friends Patricia and Deborah have created a group for children and young adults who use invasive or noninvasive ventilation. If you are interested in joining this Group (Kids with Vents) and the Facebook page, please email me off group at mkeen@ntelos.net. We request that you explain why you would like to join us.

From our Supporters....



Philips Respironics announces the new **[Trilogy200](#)**. *(Allow time for PDF to load)*

Check out **Passy-Muir's** news, events and education newsletter [Talk Muir](#). You can sign up for the publication at www.passy-muir.com.

Joan L. Headley, Executive Director

July, 2010 (No. 8)

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Greetings from IVUN

Your next issue of Ventilator-Assisted Living (August, Vol. 24, No. 4) will be sent during the third week of August.

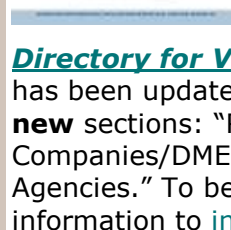
All 2010 issues are online.



[Ventilator-Assisted-Living \(June 2010, Vol. 24, No. 3\)](#)

[Ventilator-Assisted-Living \(April 2010, Vol. 24, No. 2\)](#)

[Ventilator-Assisted-Living \(February 2010, Vol. 24, No. 1\)](#)



IVUN's **Resource**

Directory for Ventilator-Assisted Living

has been updated. Note: We have added two **new** sections: "Respiratory Home Care Companies/DMEs" and "In-home Care Agencies." To be included, send your information to info@ventusers.org.



Do you have suggestions for articles?

Questions for the "Ask the Experts" column? If so, send them to info@ventusers.org. IVUN would also like to hear from users of the VS III (ResMed) or the BiPAP AVAPS (Philips Respirationics) or the Vivo 50 or iVent 201 (GE Healthcare).

Videos

Making Life Easier ([view videos en Español](#))

The "Making Life Easier" video series about home mechanical ventilation was created by the [Division of Pulmonology](#) at [Childrens Hospital Los Angeles](#) with support of a generous grant from the [Christopher and Dana Reeve Foundation](#).

Want to know about the Puritan Bennett™ 540 ventilator?

Lifetime Network's show called "The Balancing Act" featured the Puritan Bennett™ 540 ventilator in a recent segment. **[Check it out!](#)** (Allow time for the file to download.)

Help stop competitive bidding.

Competitive bidding, as it is structured now, has the potential to affect users of home mechanical ventilation. It is an attempt by the Centers for Medicare and Medicaid Services (CMS) to control Medicare expenditures for durable medical equipment, including bilevel units aka respiratory assist devices (RADs).

What is competitive bidding? CMS holds a competition among homecare providers of certain durable medical equipment in areas around the country. According to CMS, the Medicare providers who offer the best price, whom the agency decides can meet beneficiary demand and meet applicable quality and financial standards, is given a contract with CMS for a three-year period. The winning suppliers must agree to accept assignment on all claims for bid items and will be paid the bid price amount- the median of all winning bids for an item.

CMS [press releases](#) and fact sheets released this month (July) state that Medicare will pay for the 9 product categories* included in the first round of bids an average of 32 percent less than Medicare's previous payment amounts. Companies must bid low to win the bid, and according to the rules, all companies must accept that payment. The home care sector is concerned that many companies will not be able to stay in business or will have to cut services.

However, CMS stands by its processes and decisions at the moment and plans to implement the new payment system in these areas January 1, 2011. See www.cms.gov/dmeposcompetitivebid/

At the urging of the home care companies and many organizations who serve people with disabilities, Congressman Kendrick Meek (D-Fla.) introduced a budget-neutral bill (H.R. 3790) to repeal the controversial and deeply flawed program.

To learn more about the details and consequences of competitive bidding for people who use bilevel devices and their home health care suppliers, go to [AAHomecare's Competitive Bidding Page](#).

Call or email your Representative to advocate in favor of H.R. 3790. See if your Representative is one of the [current 254 co-sponsors](#). If not, please ask him or her to support H.R. 3790.

** Oxygen, Oxygen Equipment, and Supplies; Standard Power Wheelchairs, Scooters, and Related Accessories; Complex Rehabilitative Power Wheelchairs and Related Accessories (Group 2 only); Mail-Order Diabetic Supplies: Enteral Nutrients, Equipment and Supplies; Continuous Positive Airway Pressure (CPAP) Devices, Respiratory Assist Devices (RADs), and Related Supplies and Accessories; Hospital Beds and Related Accessories; Walkers and Related Accessories; Support Surfaces (Group 2 mattresses and overlays in Miami-Ft.-Lauderdale-Pompano Beach, FL only).*

The 20th Anniversary of the ADA

The Missouri History Museum (St. Louis) created a special exhibit

The Americans with Disabilities Act:

Twenty Years Later that will be open from June 26, 2010 to June 6, 2011. Check out the related website –

actionforaccess.mohistory.org. PHI's founder Gini Laurie is featured in the "Independent Living Movement" section. The site and the exhibit include photos from the PHI archives.



Ed Roberts, advocate for disabled, gets own day

Ed Roberts, a Berkeley quadriplegic who began the disability rights movement 40 years ago, now has his own California day. [Read more.](#)

International Disability Rights

Follow the success of the adoption of [Convention on the Rights of Persons with Disabilities](#).

Joan L. Headley, Executive Director

May, 2010 (No. 7)

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Reminders from IVUN

- 2010 issues of *Ventilator-Assisted Living* are online - ([Vol. 24, No. 1](#)) and ([Vol. 24, No. 2](#)).
- Issue 3 of *Ventilator-Assisted Living* will be distributed later this month via email.
- [Home Ventilator Guide](#) and [Resource Directory for Ventilator-Assisted Living](#) were updated May 6, 2010.

Two New Articles From IVUN

International Ventilator Users Network (IVUN) releases "[Breathing and Sleep Problems in Polio Survivors](#)" and "[Tests for Breathing Problems If You Have a Neuromuscular Condition.](#)" Be sure to review these articles, particularly if your healthcare professionals only mention obstructive sleep apnea and CPAP. They might be right, but they might not be right. You may be underventilated and in need of a different breathing device. The second article, "Tests for Breathing Problems..." describes a routine evaluation for respiratory function which is good for the first evaluation and for later periodic check-ups. The document also includes a select bibliography for ALS, cough, Duchenne muscular dystrophy and the late effects of polio.

New Book Due in Late August

IVUN's Consumer Advisory Committee member Linda L. Bieniek has co-authored a chapter, "Psychological issues for the mechanically-ventilated patient," with physicians Daniel F. Dilling and Bernd Schönhofer, in a new book, *Non-Invasive Ventilation and Weaning*.

In the section on "Medical Emergencies," the authors encourage providers to discuss their patients' wishes in case of a respiratory crisis and refer to Bieniek's companion article on "[Exploring the Option of a Trach.](#)" She explains, "Planning for changes in your breathing condition takes courage. It is natural to avoid thinking about a possible breathing crisis. Yet, making informed decisions about your treatment options before a health crisis occurs has several benefits. As a result, you can make a decision that brings you peace of mind."

The book is edited by Mark Elliot, Stefano Nava and Bernd

Schönhofer and will be published by Hodder Arnold, London, in late August 2010.

JIVD DVD Available

Copies of the proceedings of the 12th International Conference on Home Mechanical Ventilation held March 27-28, 2009, in Barcelona, can be purchased [here](#).

Question from IVUN Member

"I am exploring alarm/response companies after a bout with congestion and trouble coughing, which frightened me because I live alone and was choking. I am looking for recommendations of companies that vent users have used and liked." Contact awmailhot@aol.com.

Old Devices Available

Several Thompson Zephyrs, and at least one Thompson Bantam, were donated to [Polio Survivors Association](#) (Downey, California). All appear to be in working order. If anyone is interested in these positive pressure machines, please contact Richard Daggett at richarddaggett@ca.rr.com or Richard@polioassociation.org.

Men's Health Center

The [HealthyWomen](#) website now has a section for men's health at www.healthywomen.org/healthcenter/mens-health. Check out info on cholesterol, colon cancer and diabetes screening.

New Ultra-Accessible Family Fun Park

Morgan's Wonderland is a 25-acre attraction in San Antonio, Texas, designed specifically for children and adults with special needs, their family members, caregivers, friends and the entire community. Reservations are required. For details, visit www.morganswonderland.com/ or call tollfree 877-495-5888.

New Report on Accessible Air Travel

The UK Civil Aviation Authority has just published a report on how the European Union regulations on accessible air travel have been implemented in the country. It can be downloaded from: www.caa.co.uk/docs/33/Accessible-Air-Travel.pdf. The extensive document covers oxygen use, but does not mention use of ventilators, or any breathing machine.

Keeping up with Medicare in the US

The [Medicare Rights Center](#) is a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs and public policy initiatives.

Its latest update notified those on Medicare that "Starting June 1,

two new Medicare supplemental plan options—M and N—will be available, and four plans—E, H, I and J—will no longer be sold, although Medicare consumers who have these four plans will be able to keep them. Further, all Medicare supplemental plans sold on or after June 1 will also include a hospice benefit to cover drugs and respite care. Two benefits—at-home recovery and preventive medical care—will no longer be included in plans sold after June 1.” For details on this topic go to [MedicareInteractive.org](https://www.MedicareInteractive.org).

Visit www.medicarerights.org/ to sign up for emails that keep you informed about Medicare changes.

Joan L. Headley, Executive Director

March, 2010 (No. 6)

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Updated and Uploaded

International Ventilator Users Network's [2010 Resource Directory of Ventilator-Assisted Living](#) is now online. IVUN Members (Contributor and above) may request a print copy by emailing info@ventusers.org. The *Resource Directory of Ventilator-Assisted Living* is continually updated. Send IVUN your changes and additions.

Visit our updated [Home Ventilator Guide](#). Additions and changes are welcomed.

Reminder: *Ventilator-Assisted Living* is now published bi-monthly and sent electronically. (Last issue: [Volume 24, No. 1](#)) The next issue will be sent in late April. Do you have a question for the "Ask the Experts" column? If so, please send it to info@ventusers.org.

Update on Flying

Vent user Marie Latta contacted American and Delta Airlines for IVUN. Please see [Airlines and Links to Accessibility/Medical Policies](#) for what she learned and for updates on all airlines. Also, check out the site of the [Department of Transportation](#) for general information.

Larry Becker reports that he will be flying United from the East to the West Coast using his bi-level device next week. United booked him in a seat with an electrical outlet and required him to purchase an "RP-DC Power Adapter Kit, reference number 1012975. It comes with a power cord that attaches to the BiPAP at one end, and a variety of things at the other -- notably an automobile's cigarette lighter or, with another apparatus included (part number 687-2445) directly to an automobile battery."

In Case You Missed It

Health Care Reform Bill and Debate Available on Government Printing Office's Federal Digital System.*
(These are very large files.)

Direct links to [H.R. 3590, Patient Protection and Affordable Care Act](#) and [H.R. 4872, Health Care and Education Reconciliation Act of 2010](#) and to the to the Congressional Record [containing the vote](#).

* The authentic, electronic versions are available on GPO's Federal Digital System (FDsys). GPO authenticated the document by digital signature. This signature assures the public that the document has not been changed or altered. A digital signature, viewed through the GPO Seal of Authenticity, verifies the document's integrity and authenticity.

H1N1 has affected children and teens with neuromuscular (NM) disorders more severely than other children, both in terms of mortality and of complications, according to statistics released in January by the [Centers for Disease Control and Prevention \(CDC\)](#). During a typical flu season, it is estimated that one out of every five childhood flu deaths occurs in children with a neuromuscular disorder. "This year, it's almost one in two," says CDC's Lyn Finelli. No one knows why. Physicians at Children's Hospital of Philadelphia report that children with NM disorders are six times more likely than other children to develop severe complications from the flu.

Requests of IVUN

IVUN has been contacted by Russell Jackson (Russell.Jackson@yahoo.com; Voice: 310-289-8742). He explains, "I'm the freelance reporter for 'Respiratory & Sleep Management.' We're putting together patient care case studies for the magazine. Can you connect me with ventilator users who would be willing to communicate with me about their story and equipment?" Please contact him directly if you are interested in participating.

The Department on Disability Services in Washington, DC, would like to communicate with professionals who have worked with ventilator users with intellectual disabilities. Contact Emma Hambright at emma.hambright@dc.gov.

On the Internet

The American Veteran, a series of short video features, includes a profile of Sandy Stuban, RN, ventilator user and Army veteran. Click on [The American Veteran](#) and then go to the February 2010 video "**Living With ALS.**"

[Starbright World](#), created by Starlight Children's Foundation, is an online social network exclusively for teens with disabilities and chronic conditions, 13-20, and their teenaged siblings.

[DMD Pioneers](#) has updated its website. The new key feature is the DMD Pioneers Blog that discusses the extension of life, quality of life, and anecdotal information gleaned from the experiences of the Pioneers. The chat room will hold weekly group chats but will also remain open for use at any time.

Joan L. Headley, Executive Director

January, 2010 (No. 5)

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The Research Fund

International Ventilator Users Network's deadline for Phase 1 of proposals for the 2011 \$25,000 [research award](#) is Friday, March 5, 2010. Details are available at [Call for Proposals for the Research Fund](#). If you have questions, call Joan L. Headley at 314-534-0475 or email director@post-polio.org.

Update on Using a Ventilator in Flight

In order to use a ventilator in flight more and more airlines are insisting that the breathing device be on their "approved" list or have a label (sticker). Just this week IVUN heard that the LP6+ was not accepted on a Frontier flight. Covidien/Puritan Bennett reports that since the "LP6 was discontinued quite some time back so we will not be pursuing the stickers for air travel. We are expediting the process for the Puritan Bennett 540."

Ventilator user Larry Becker reports that United Airlines accepted his Respironics' BiPAP S/T (model number 332203) and Respironics' BiPAP ST with Smartcard and Heated Humidifier (model number 1014248) for a future flight. He also was told that he needed the Respironics approved "cigarette lighter connection." Respironics states the "shielded DC cord PN 1001956 can be used to operate Philips Respironics CPAP as well as BiPAP systems and plugs into the Universal battery pack or a standard cigarette lighter socket." The cord can be purchased through a home care provider or an internet company. (Respironics assures IVUN that their new Trilogy100 is approved for in-flight use.)

Asking for your help: Have you flown lately while using your ventilator? If so, please report your experiences to IVUN. IVUN is also looking for volunteers to call the [airlines](#) (numbers are listed on this link) to obtain their approved list. All information gathered will be posted on www.ventusers.org. If you want to help, email info@ventusers.org.

More from Larry: "You might tell people to be persistent. They will probably have to get past an automated system to get to the airline's 'medical desk.' FYI: I used the number for United Airlines that was given in the previous IVUN newsletter. It was their main toll-free number, and nowhere in its automated options was there an obvious choice to get to the medical desk. Similarly, the

medical desk is nowhere listed on the United.com website. In order to get to it, I found out by trial and error that I had to pick one of the 'reservations' options and get past the automated answers to a human being. I was then transferred to the medical desk. The first time I tried this, they asked for the model number of the ventilator I travel with. I wasn't prepared with that information, but they gave me their unique number. Several days later, I tried again, model numbers in hand. This time, I was also asked for my confirmation number. I had that at hand, and the person at the medical desk put in an order for me for my flight. She also asked how I got their number! I'm not sure whether they would have dealt with me if I had not had a reservation, or at least been in the process of making one. I guess we are going to find out from our readers!"

IVUN is updating its *Resource Directory for Ventilator-Assisted Living for 2010*

Health professionals: If you haven't responded to our individual request to each of you, please respond ASAP. Can't find the email? Click on [Resource Directory for Ventilator-Assisted Living](#) and check your entry. To assist you, note that the Health Professional listings start on page 2. *Organizations, Associations and Foundations* start on page 23. Please check your listing and send any changes to info@ventusers.org.

Group in Ventilator-Assisted Living featured in Documentary

Among the Giants tells the story of the [Adaptive Design Association](#), a nonprofit organization located in New York City and builds customized equipment for kids and adults with disabilities, mainly using cardboard. The film portrays the organization's mission through the compelling stories of two fascinating individuals. *Among The Giants* causes viewers to question what it means to solve problems, be creative and impact the community all while working with cheap and easily accessible materials. The film is on the home page of the [Adaptive Design Association](#).

Quit Smoking Ads are Everywhere

Last week the Food and Drug Administration unveiled information "about how smoking cessation products work and what side effects they may cause." Check out [FDA 101: Smoking Cessation Products](#).

Home Heating Help

The U.S. Department of Health and Human Services (HHS) has announced the release of an additional \$490 million in funding to help eligible low-income homeowners and renters meet home energy costs. These [Low-Income Home Energy Assistance Program](#) (LIHEAP) contingency funds will provide states, territories, tribes and the District of Columbia with additional

assistance to pay heating and electricity costs. Contact the [LIHEAP program in your state](#) to find out if you are eligible for help.

WHO Responds

Amid rumblings that the H1N1 epidemic was “fake,” the World Health Organization issued an [official statement](#) defending its processes and conclusions.

The *Disability and Health Journal* special issue features "[A Disability Perspective on the Issue of Physician Assisted Suicide](#)." This issue is open to the public for free.

Center for Personal Assistance Services Bulletin January 2010--Volume 7, Issue 1

features 1) [The Centers For Medicare & Medicaid Services In Final Stages Of Developing A Checklist Called "Planning For Your Discharge."](#) The checklist re-emphasizes the importance of talking to healthcare providers about where one is to go following care in a particular healthcare setting, as well as the need to consider how, and by whom, care will be provided after such transitions. In conjunction with the discharge planning rights outlined in the article, it gives beneficiaries and their advocates more tools to use in assuring that beneficiaries receive the healthcare services they need as they move from care setting to care setting. 2) [Article Finds Improved Systems Of Care For Children With Special Health Care Needs \(CSHCN\) May Have The Potential To Optimize Work Productivity For Families.](#) Parents of CSHCN are at risk of work loss as a result of the complex health needs of their children. A new article by Megumi Okumura, Jeanne Van Cleave, Sangeeth Gnanasekaran and Amy Houtrow of the PAS Center looks at determining how child- and family-level factors and the medical home are associated with work loss for these families. The results of these studies showed that approximately 24% of families with CSHCN have experienced work loss to meet the medical needs of their child.

Joan L. Headley, Executive Director

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Ventilator-Assisted Living now online

IVUN has posted *Ventilator-Assisted Living* (Vol. 23, No. 3) for its Members at www.ventusers.org/edu/valnews/mem/val23-3fall09pAll.pdf.

IVUN has also added three new links to video demonstrations:

- [Frog Breathing \(glossopharyngeal breathing\)](#)
- [Lung Volume Recruitment \(LVG\) and glossopharyngeal breathing \(GPB\)](#)
- [Mouthpiece ventilation](#) – Click on Program Library/Programs by Titles/Non-invasive Assisted Breathing

IVUN Issues Call for Proposals for Sixth Grant Award

PHI 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 of the survivors of polio.

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 funds inception in 1995, PHI has given \$120,000 to support studies related to post-poliomyelitis and neuromuscular insufficiency. ([See Prior Awards.](#))

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 grants will be asked to complete Phase II.

Deadlines

Receipt of Phase I

Friday, March 5, 2010

Invitation for Phase II
Receipt of Phase II
Award Announcement

Friday, May 21, 2010
Friday, September 24, 2010
Friday, December 17, 2010

Do you need?

Gale (gmccourier@yahoo.com) in western New York has the back brace pictured below and would like to give it to someone who needs it. She requests postage.



Equipment requests. Can you help?

"I use the iron lung and am looking for foam rubber collars. Some people use the spiral collars, but my equipment isn't designed for them. If you know of any in stock somewhere, please contact info@ventusers.org. They will connect with me."

"I am looking for an Emerson rocking bed for my brother, who has Pompe Disease. He has one at his home, but we would like one in Florida so he can visit in the winter to get out of the cold. Please contact Russ Galati at russga@msn.com."

"We have a chest shell we would like to put in a display in our museum, but we need the machine that attaches to it. If you have a Monaghan 170C, Huxley or Thompson Maxi-Vent, please email me at sharons@mohistory.org. (It doesn't need to be in working order.)"

Reminders

CHEST, American College of Chest Physicians Annual Conference, meets **October 31-November 5, 2009**, in San Diego, California, www.chestnet.org

"Breathing and Sleep: Solutions for People with Neuromuscular Disorders" will be held **November 1, 2009** (Noon-5:00 pm) at the Salk Institute, La Jolla, California. [Registration \(available online\)](#) is requested for the complimentary half-day program designed for individuals with a neuromuscular condition and their families.

Keeping up with Medicare in the US

The [Medicare Rights Center](#) is a national, nonprofit consumer service organization that works to ensure access to affordable

health care for older adults and people with disabilities through counseling and advocacy, educational programs and public policy initiatives. Its latest update notified those on Medicare that “Starting June 1, two new Medicare supplemental plan options—M and N—will be available, and four plans—E, H, I and J—will no longer be sold, although Medicare consumers who have these four plans will be able to keep them. Further, all Medicare supplemental plans sold on or after June 1 will also include a hospice benefit. Two benefits—at-home recovery and preventive medical care—will no longer be included in plans sold after June 1.” For details on this topic go to MedicareInteractive.org. Visit www.medicarerights.org/ to sign up for emails that keep you informed about Medicare changes.

Joan L. Headley, Executive Director

September, 2009 (No. 3)

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International Ventilator Users Network
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Post-Polio Health International including **International Ventilator Users Network**
4207 Lindell Blvd., #110
St. Louis, MO 63108-2930
314-534-0475 phone
314-534-5070 fax
www.ventusers.org
info@ventusers.org

Breathing & Sleep Meeting at the Salk Institute

People living in the Southern California area who have breathing and sleep problems as a result of a neuromuscular condition are invited to a complimentary half-day meeting at the Salk Institute in La Jolla, California, on **November 1, 2009** (Sunday). Please go to www.ventusers.org to view the brochure under "This week at..." or review and pass along the attached flyer.

Presenters are:

Louis J. Boitano, MS, RRT, RPFT

Northwest Assisted Breathing Center
University of Washington Medical Center
Seattle, Washington

Diana Guth, BA, RRT

Founder, Home Respiratory Care
Los Angeles, California

Helen Kent, BS, RRT

Founder, Progressive Medical
Carlsbad, California

Noah Lechtzin, MD, MHS, FCCP

Pulmonary and Critical Care Medicine
Assistant Professor of Medicine
Johns Hopkins University School of Medicine
Baltimore, Maryland

Geoffrey Sheean, MBBS, FRACP

Clinical Professor of Neurosciences
University of California, San Diego
Director, Neuromuscular Division
San Diego, California

The meeting is sponsored by ResMed Corporation and the Salk Institute for Biological Studies.

Joan L. Headley, Executive Director

July, 2009 (No. 2)



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Resource Directory for Ventilator-Assisted Living, located in the "Networking" section of www.ventusers.org, is updated continually. Categories include the following.

- Health Professionals
- Ventilator Users, Networking
- Ventilator Equipment and Aids
- Manufacturers' Addresses
- Organizations, Associations and Foundations
- Facilities with Long-Term Ventilator Units
- Congregate Homes for Long-Term Ventilator Users

Should you be listed? Your product? Is your information correct? If there are additions or corrections, please email info@ventusers.org. We invite you to forward this message to other health professionals, organizations, and businesses involved in providing equipment and services to users of home mechanical ventilation.

Home Ventilation Guide, located in the "Education" section of www.ventusers.org, is a resource displays technical information about the world's home ventilators in charts that are easy to read and makes comparing home ventilators more convenient. It features bilevel positive airway pressure ventilators, volume-cycled ventilators, pressure support ventilators, and combination or multi-mode ventilators.

You are invited...to send contributions to IVUN's website feature, "This week at IVUN ..." on www.ventusers.org. What do we feature? Click to **View Prior Weeks at IVUN ...**

*You received this email because you are listed in **IVUN's Resource Directory for Ventilator-Assisted**. If you would prefer not to receive ventilator-related information from IVUN, please send an email to info@ventuser.org with "No IVUN Memo" in the memo line. Thanks.*

Joan L. Headley, Executive Director

July, 2009 (No. 1)

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Ventilator-Assisted Living now online

IVUN has posted Ventilator-Assisted Living (Vol. 23, No. 2) on its website – www.ventusers.org. IVUN Members can access the summer issue at www.ventusers.org/edu/valnews/mem/VAL_23-2sum09pAll.pdf

Do you have an item for “From Around the World”? Do you have a suggestion for an article? Are you a ventilator-user who wants to write about your experience with home mechanical ventilation? Do you have advice for new users? If so, please contact info@ventusers.org.

Request from IVUN Member: As a survivor of polio, I have used a volume ventilator at night with a nasal mask for years. I am now facing breast cancer and would like to communicate with other ventilator users who have been through therapy. Please send a message to info@ventusers.org.

Want to tell your story?

Do you use an iron lung? StoryCorps (www.storycorps.org), the oral history and public radio project, has a mission to record the stories of everyday Americans across the country and to archive them in the Library of Congress for future generations. StoryCorps would like to invite you to record your story with them. Contact Joan L. Headley at info@ventusers.org for details.

Resource Directory for Ventilator-Assisted Living

, located in the “Networking” section of www.ventusers.org, is updated continually. Categories include the following.

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Are you listed? Your product? Is your information correct? If there are additions or corrections, please email info@ventusers.org.

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Joan L. Headley, Executive Director