

It's Flu Season

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

Whether it is the seasonal flu or H1N1 (earlier referred to as the swine flu), people with disabilities and chronic health conditions, particularly ventilator users, need to be knowledgeable in order to protect themselves to avoid either contracting or spreading the viruses. The H1N1 virus can cause severe complications in people whose respiratory function is already compromised.

The symptoms and severity of new H1N1 infections are similar to seasonal flu. Although most cases of H1N1 have been mild, additional hospitalizations and deaths are anticipated during the fall.

Influenza-like illness is defined as fever ($>37.8^{\circ}\text{C}$ or 100°F) with either cough or sore throat. It is spread from person to person through coughing or sneezing by people who are infected. Other symptoms can include a runny or stuffy nose, body aches, headache, chills and fatigue. A number of people with H1N1 also have reported diarrhea and vomiting.

The highest-risk category for seasonal influenza is people over age 65. H1N1 appears to be different, because the high risk groups are under 25 years of age. Adults older than 64 do not yet appear to be at increased risk of new H1N1-related complications because they have immunity from a similar strain that appeared decades ago. The unknown is how much protection may be afforded against new H1N1 flu by any existing antibody.

Few cases and few deaths due to H1N1 have been reported in people older than 64, another difference

from seasonal flu. However, pregnancy and other previously recognized high risk medical conditions appear to be associated with increased risk of complications from H1N1, including asthma, diabetes, suppressed immune systems, heart disease, kidney disease, and neurocognitive and neuromuscular disorders.

Caregivers and respiratory health professionals are also at risk and need to take extra precautions such as cleaning hands with soap and water or using an alcohol-based hand rub after touching someone sick or handling used tissues or laundry. The use of gloves and masks can also help to avoid inadvertently transmitting the viruses. However, masks must fit properly in order to be effective.

The first doses of a vaccine for H1N1 are due in October, however, at this writing, it is unknown whether more than one dose will be needed, but there is speculation that it will be two.

The annual seasonal flu vaccine is recommended, because the seasonal influenza virus will still be around. "The real reason to get vaccinated for seasonal flu is because seasonal flu

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"The real reason to get vaccinated for seasonal flu is because seasonal flu kills people."

Dr. Aaron Glatt, Infectious Diseases Society of America

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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Editor: Joan L. Headley, MS
editor@post-polio.org

Designer: Sheryl R. Rudy
webmaster@ventusers.org

Special thanks ...

Judith R. Fischer, MSLS

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How to contact IVUN

International Ventilator Users Network (IVUN)

An affiliate of Post-Polio Health International (PHI)

4207 Lindell Blvd., #110

Saint Louis, MO 63108-2930 USA

314-534-0475, 314-534-5070 fax

info@ventusers.org

www.ventusers.org

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

Ave atque Vale!

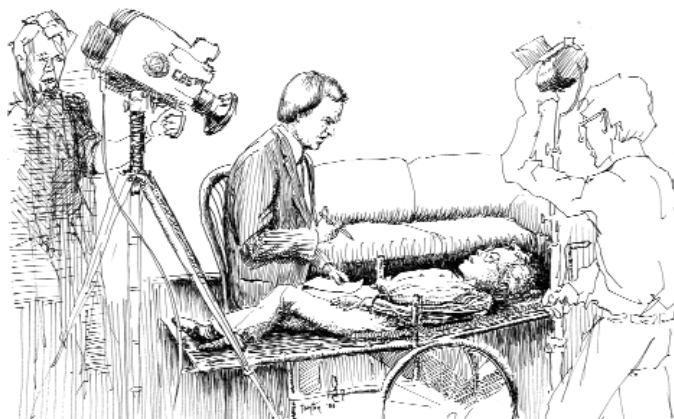
Remembering Susan Armbrecht, 1939-2009

Susan Armbrecht, one of our founder Gini Laurie's most fierce admirers, and supporters, died on August 19 at MetroHealth Hospital, Cleveland, Ohio, from a stubborn pneumonia.

Susan first met Gini in the 1950s when Gini volunteered at Cleveland's respiratory polio ward. Susan slept every night in an iron lung. In the mid-1990s, she reported, "Last night at the restaurant, I had to choose between breathing and eating," and added mouthpiece ventilation during the day.

Susan lived in her own apartment with a team of attendants whom she hired, fired and trained. "It has never occurred to me not to be in charge of my life."

At the 1983 post-polio conference in St. Louis, Susan, interviewed on national television (see sketch below by Bob Tanton), said, "I am just a normal person who happens to be lying down. That is how I feel. Even though my physical form is a little different, my life doesn't have to be."



Gini Laurie died 20 years ago this past June 28, but never would have doubted Susan's capacity to live fully and independently for all those additional years.

Gini was the organizing force behind International Ventilator Users Network and Post-Polio Health International. We salute her vision and brilliance, knowing that she would be immensely proud that the organization has continued, that its reach has expanded and its influence has grown, and that it continues the mission of education, networking, advocacy and research that she envisioned.

Hail and farewell to two immeasurably intelligent, creative, joyful, and independent spirits.

– Judith R. Fischer and Joan L. Headley

kills people,” according to Dr. Aaron Glatt, spokesperson for the Infectious Diseases Society of America.

Serious complications, such as pneumonia, resulting in hospitalizations and deaths are linked to the seasonal flu virus. Because the body is in a weakened state, bacterial pneumonia, *S. pneumonia*, can invade the lungs. Therefore the pneumococcal vaccine (Pneumovax® 23) is suggested. It provides protection against pneumonia for up to ten years. One dose of the vaccine is usually sufficient, but sometimes physicians recommend a second dose of the vaccine.

Treatment of H1N1 is with the use of antiviral agents, such as Tamiflu® (oseltamivir) and Relenza® (zanamivir), which should be prescribed ideally within 48 hours after the first symptoms of H1N1 develop.

However, the widespread, inappropriate use of these medicines could increase the risk of the virus developing resistance to them. Otherwise healthy people with mild flu-like symptoms need not be given the drugs. British researchers recently concluded that children should not routinely be treated with flu drugs like Tamiflu since there is no clear evidence they prevent complications, and the medicines may do more harm than good.

Common Sense Precautions

- Cover your mouth and nose with a tissue when you cough or sneeze. Throw the tissue away after use.
- Wash hands often with soap and warm water for 15-20 seconds or use alcohol-based hand cleaners and sanitizers, especially after you cough or sneeze.

- Avoid touching your nose, mouth and eyes, and spreading germs.
- Avoid close contact with people who might be ill.
- Reduce the time spent in crowded settings.
- Stay HOME. Do not go to school or to work until you are without fever (afebrile) for at least 24 hours.

Other Important Actions

- Follow public health advice regarding school closures and avoiding crowds.
- Be prepared in case you get sick and need to stay home for a week or so. Stock up on alcohol-based hand rubs, tissues and other related items to avoid trips out in public.

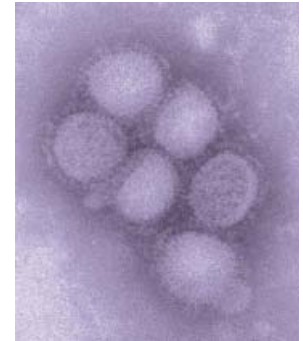
For the most current, accurate and reliable information, go to the following websites:

Centers for Disease Control and Prevention, www.cdc.gov/h1n1flu/#stay_healthy

The World Health Organization, www.who.int/csr/disease/swineflu
American Academy of Pediatrics, www.aap.org

Your local county government's public health department

Do not rely exclusively on television or radio newscasts for influenza information. ▲



H1N1 Virus
Photo by CDC Influenza Laboratory

INFORMATION FOR PEOPLE WITH DISABILITIES ABOUT H1N1

VIRUS is a two-page document, with related websites, by long-time disability educator and activist Lex Frieden (lex.frieden@uth.tmc.edu) with contributions by Kim Dunn, MD, and Gerard Francisco, MD, from the University of Texas Health Science Center, Houston, Texas.

IVUN has posted it on its website at:
www.ventusers.org/H1N1BulletinLF0809.pdf

No Way Out But In: Responding Positively to Chaos with Forgiveness and Grief

Deshae E. Lott, Bossier City, Louisiana, deshaelott@hotmail.com



Deshae E. Lott

The rapidity and volume of chaos for individuals using life-support devices can lead to lifestyles in which “crisis mode” becomes the norm. Our lifestyles often entail extremely ritualized self-care routines, highly limited mobility, occasional intense infections, steep medical bills, serious equipment malfunctions, voluminous healthcare paperwork, and the need for a reliable caregiver present at all times. Accordingly, most of us who are ventilator users or part of vent users’ teams become keenly interwoven with people, systems and machines.

Some matters, in time, grow predictable enough that plans can be established for responding to needs as swiftly and safely as possible. Certainly much can be done logistically to mitigate crises, and *Ventilator-Assisted Living* and other resources help us with that. However, I am happiest when I do more than prepare for or tend my body’s needs. Whether much is going awry or right, I restore my inner serenity and well-being each day by using prayer and meditation, by processing grief, and forgiving.

No day seems to pass without me using these mental resources. For example, with caregivers there can be an unending source of unpredictable inconsistency. In a four-week period recently, five caregivers (one fulltime, three parttime and one backup) experienced surgeries, both minor and major, intense abdominal pain, car problems, sick children, infections and viruses, food poisoning and a family funeral. One stole valuable items from my home. Another fractured her spine when thrown from her horse. This convergence of mishaps among my caregiving team left me with only my husband, who has a full-time job, to tend to me.

Those providing my care soon realize how very quickly a vent user’s health can deteriorate when their own health, transportation or communication problems, or even the needs of others who depend upon them, interfere with their ability to perform routine tasks. Even when caregivers care deeply, their problems become a vent user’s issue, too.

One of the most strenuous challenges accompanying chronic long-term disease is navigating human interconnections in healthful ways. It would be inappropriate for me to lash out at an employee for personal problems, even if those problems create grave situations for me.

Similarly, there is no solace in remaining riled when insurance companies and healthcare agencies or providers cannot resolve my problems as swiftly as I like or when their errors introduce hours of time I must spend calling, writing and re-addressing matters. Nor would it help me to harbor resentment toward God, nature, my parents or any factor I might blame for the genetic code that created me a body with limb girdle muscular dystrophy (LGMD).

However, having a debilitating disease and a need for life support from human and mechanical interfaces

present unending situations in which my life depends on how quickly I hone my coping skills and how well I can govern my own responses to unwelcome chaos.

Prayer, meditation, grief-processing and forgiveness are the best way I've found to counter the stress that emerges when my body has setbacks, machines malfunction, or unsettling events emerge in the lives of those upon whom I depend. I sustain myself with a reservoir of abiding peace by opening my day with prayers for my team and for the resources I need to do all that is mine to do. To keep myself fueled, I make time for mental relaxation exercises akin to those Adolf Ratzka describes in the Winter 2008, Vol. 22, No. 4, *Ventilator-Assisted Living*.

When disturbances arise, I use other forms of meditation, problem solving, deep rhythmic breaths, and self-reflection so my feelings align with my values of resilience, compassion and authentic cheer. The latter is where grief and forgiveness fit in.

The grief process begins automatically for any of us facing loss: we experience shock, anger, searching (most often to pinpoint a culpable source even if a scapegoat) and depression (whether mild or severe). Whether we recycle through those negotiations, thereby keeping ourselves incensed, or move ourselves forward into more empowering attitudes depends upon our willingness to try.

It is not automatic to remake one's self in a way that reasonably accounts for a past we cannot change and, thereafter, to invest in that new identity. It is a matter of choice. And mak-

ing that choice, for me, rests at the heart of forgiveness.

I prefer to integrate the final grief steps, or forgiveness, into each of my days because I think it best reflects my compassion for myself and others. I aim to abide by personal ideals of harmless, authentic, resourceful, cheerful and thankful thoughts, speech and behaviors.

Some days I am more consistent with this than others. At times I feel overwhelmed, and the process goes more slowly. But regardless of outer crises or discomforts and no matter the emotional anguish, I've not indefinitely lost my inner harmony and joy. Self-reflection, creative expression, meditation and prayer allow me to infuse my life with hope, purpose and vibrancy once again.

It becomes a self-sustaining cycle, because processing my grief and forgiving fully brings me solace and the clarity to see all the goodness and blessings in my life. Seeking and finding solace and optimism shore me up when the wearisome phases appear.

Sometimes there is no way out but in. That is, I turn inward when the going gets tough, and I dig down to find my own resilience, to make choices that maximize what's feasible in a given moment. No matter how impoverished my body, I feel rich because my mind, technology and other human beings continue working together to keep me going. At this I marvel. That fact is omnipresent, and for it I am grateful. ▲

Deshae E. Lott earned her PhD in English and Religious Studies from Texas A&M University more than a decade ago. Her publications and presentations deal primarily with disability or spirituality in America, and sometimes with both topics simultaneously.

Deshae currently teaches online English courses for Louisiana State University in Shreveport. She leads a non-profit organization whose participants weekly engage in spiritual studies including meditation, prayer, and inner purification techniques. You can learn more about Deshae at www.deshae.net.

Improving Long-term Respiratory Care in Ontario, Canada

Audrey J. King, MA, Toronto, Ontario, Canada, king.aj@rogers.com

In 2006, the Ontario Ministry of Health and Long-Term Care designated a \$6 million Ventilation Strategy. Driven by the need to free up ICU beds by moving medically stable ventilator-assisted individuals elsewhere, the Ministry established a hospital-based ventilator weaning program and funded additional chronic care beds at Westpark Healthcare Centre. The Ventilation Strategy acknowledged that community living was preferable to hospitalization and institutionalization, and far less costly and essential to quality of life, yet neither money nor Ministry commitment was allocated to support community living.

The Canadian Paraplegic Association Ontario (CPAO) and the Ontario SCI Solutions Alliance intend to change that by pushing the focus of effort where it belongs – in the community – where people such as Khadijah (*See box on page 7*), who require long-term ventilator support have the right to live safely and fully.

These advocates know there are comprehensive programs in other countries and even in Canada.

Contact Peter Athanasopoulos (petera@cpaont.org) for a copy of the CPAO's revised position paper, "Living Fully in Ontario Communities: People with Spinal Cord Injuries and Disease Who Use Respiratory Supports."

British Columbia's Provincial Outreach Respiratory Program (PROP) is an excellent model for providing long-term respiratory care and support that enables ventilator users to remain in their homes and in their communities.

Through PROP, solutions and expertise are available in areas relating to equipment, new equipment trials, individualized respiratory solutions, specific disability-related expertise, innovations in mobility and portability, peer-inspired services, and developing home ventilation standards.

Respiratory therapists visit clients in their homes at least once a year and more frequently as needed. In the year 2007-2008, for example, 856

home visits were made and 700 phone calls received.

An education program provides workshops to clients, families and caregivers as well as healthcare professionals working with PROP clients. Biomechanical technicians maintain and repair all respiratory equipment, including mounting ventilators on wheelchairs. The team also works with acute care units in transitioning ventilator-assisted clients into the community.

Many educational materials have been developed, including a newsletter published three times a year, a website, booklets, program and service brochures as well as manuals. PROP maintains a detailed client database to ensure accurate information such as equipment settings, service records and inventory.

In an external review of the PROP program in 2008, Douglas McKim, MD, an Ottawa-based respiratory specialist, concluded, "*The advent of smaller, user friendly ventilators and the sheer cost of a life-supported patient in a critical care hospital bed has fueled the process of home mechanical ventilation. A very emphatic position has been taken on proper preparation and education of clients with recognition of their free-*

dom to evaluate their personal needs and values and maintain their own choices. The PROP program enables ventilator-assisted individuals to live outside of institutions and in the community where health-related costs are far less, and the quality of life and independence is recognized to be much greater. Home mechanical ventilation therefore provides a win-win situation for clients and ministerial budgets.”

In Ontario, ventilator equipment and support is provided by the Ventilator Equipment Pool (VEP) under the auspices of the Ministry of Health and Long-Term Care’s Assistive Devices Program. However, VEP does not provide clinical support, training, education or peer support. These services must be individually sought.

Ventilator-assisted individuals desiring to live in the community and able to direct their own care can spend up to 18 months living at Toronto’s Gage Transition to Independent Living where they learn how to manage their disability needs, direct their attendant care, and acquire daily life skills in order to live safely and successfully in the community.

Transitioning to “what” then becomes the dilemma. Community resources are scarce indeed. Vacancies in 24/7 attendant-supported apartments are few, and the waiting lists long. Most projects lack adequate staff or are reluctant to accept “heavy care” individuals with specialized needs and equipment. Ontario’s Direct Individualized Funding Program allows six hours per day with additional hours for 24/7 ventilator users, but the provincial waiting list is more than 400, with no increased provincial funding on the horizon. Discouraged,

Khadijah, a 24/7 ventilator-assisted mother of two, is grateful for life and quick to acknowledge the support she receives. But she is frustrated. Before she became a 24/7 vent user, her physicians would not approve her to fly with a BiPAP®. When she became more vent-dependent, she was institutionalized. While there and worried about her children at home, she was told that The Children’s Aid would look after her children.

“The biggest challenge to going home was to find five people with ventilator training to be with me 24/7. With help from others I escaped long-term care. If our healthcare system improved its provisions for people like me to live in the community, it would not have to bear the cost of keeping us in long-term care.”

“Attendant care and the CCAC (Community Care Access Center) in total only provide six hours of the day – so you live in fear – the slightest thing gone wrong with your ventilator can risk your life.”

“Ontario’s Ventilator Equipment Pool (VEP) provides my ventilator, but I know there are smaller portable ventilators.”

many ventilator-assisted individuals do not even apply.

The Canadian Paraplegic Association Ontario and the Ontario SCI Solutions Alliance have identified the critical prohibitive issues as:

- Insufficient attendant care hours;
- Lack of direct funding and supportive housing opportunities;
- Insufficient education for consumers, attendants and health care providers;
- Need for more appropriate ventilator equipment and evaluation (through the VEP);
- Nonexistent clinical support in the home (no access to RTs);
- Lack of community hotline for ventilator emergencies; and
- Lack of emergency preparedness planning.

Over the summer, the groups have met with Ontario ventilator users, agency staff and healthcare professionals involved in various hospital-based specialized facilities and community programs such as the Gage Transition to Independent Living Program. Their 2008 Position Paper, “Living Fully in Ontario Communities: People with Spinal Cord injuries and Disease who use Respiratory Supports,” has been updated to incorporate their recommendations and advice. ▲

References for this article are online at www.ventusers.org/edu/valnews/VAL23-3ref.html

My Experience with Setting Up Day-time Ventilation

Luke Melchior, Victoria, British Columbia, Canada, decaf@shaw.ca



Luke is 36 years old and uses a ventilator due to DMD. He and his wife live in a condominium in Victoria, BC. He receives 16 hours of attendant care per day from the British Columbia provincial health authority.

In the summer of 2005, I received a Legendair™ ventilator from the Provincial Respiratory Outreach Program (PROP), a government-funded program in Vancouver, British Columbia. This amazingly portable machine not only boasts an 11-hour internal battery (long enough so that I don't have to wire it into my wheelchair battery), but it also weighs less than 10 pounds and fits into a convenient backpack that attaches to my wheelchair.

The Legendair came at a time when I had been using my night-time ventilator (ResMed's VPAP® III ST) for an additional four hours during the day while I was in my wheelchair. The VPAP needed to be plugged into a wall outlet in order for it to operate, and this greatly impeded my mobility. Another drawback of using my night-time ventilator during the day was having to wear a nasal interface. The interface irritated my skin and also made it awkward for me to talk on the phone, see my computer screen and eat without aspirating.

Needless to say, when my Legendair arrived, I was determined to find a better interface to use with it. Luckily for me, my respiratory technician heeded my wish and set me up with an angled mouthpiece for mouthpiece ventilation. While this system managed to solve the issues I described earlier, the bracket used to hold the mouthpiece in front of my mouth created its own set of challenges. The bracket, which clamped onto the side

of my wheelchair, was bulky and difficult to adjust. Because it was affixed to my wheelchair, I would only be able to use the Legendair when I was sitting in the wheelchair.

Despite its limitations, that particular interface the technician could offer me at the time. I was not happy with this state of affairs so I decided to invent a new bracket. With the help of a different technician, I created a chestplate fitted with Snap-Loc bendable tubing to hold my ventilator hose and mouthpiece in place. Now the mouthpiece and hose were attached to me instead of to my wheelchair, and the hose could be easily readjusted with little to no effort.

The incredible battery life and light weight of the Legendair combined with a chestplate interface and mouthpiece allowed me to achieve complete portability for my daytime ventilation. Now I can breathe with ease whenever I have to travel by airplane or in a manual wheelchair. ▲

More about PROP

The PROP (Provincial Outreach Respiratory Program) began in 1998 in response to a crisis when the Ventilator Outreach program at Vancouver's Pearson Hospital closed. Coalescing around the idea of a provincial respiratory community outreach program, the Technology for Independent Living (TIL) program – housed on the same premises – and necessary clinical and administrative staff came together as a team consisting of client services, respiratory therapists, biomedical engineering technicians, peer supporters, and the ongoing clinical expertise of a respiratory specialist. Around the clock "on-call" services provide a centralized service to clients throughout British Columbia, giving individualized information and advice.

New Products

FitLife Face Mask is new from Philips Respironics. The total face mask provides a good seal around the outer face, from above the eyebrows to below the lower lip, and a mask alternative for people who are hard-to-fit. It does not restrict vision. Available in two sizes: large and small. Available globally in late 2009. <http://fitlife.respironics.com>

Monnal T30 is a new bilevel ventilator from Air Liquide Medical Systems, S.A. (the company recently acquired the French ventilator manufacturer Taema). The Monnal T30 offers four inspiratory and three expiratory sensitivity triggers and up to 30 cm H₂O inspiratory pressure. It is not available in the U.S. www.airliquidemedicalsystems.com

Venise Nasal Pillows, also from Air Liquide Medical Systems, S.A., is available in small, medium and large sizes. The headgear enables three different configurations for comfortable use. www.airliquidemedicalsystems.com

Freedom Vent Systems provides carrying and mounting accessories for ventilators and battery packs, as well as rain, shower and circuit covers. The products were developed by Dan and Kay Wilson to enable mobility and independence for their son Adam. Contact info: 910-947-3806; freedomventsystem@yahoo.com; www.freedomvent.com/products.htm

Disability Rights

U.S. Signs U.N. Convention on Disabilities

On July 30, 2009, President Obama marked the 19th anniversary of the Americans With Disabilities Act with the announcement that the U.S. would become a signatory to the U.N. Convention on the Rights of Persons with Disabilities.

The 32-page Convention is a blueprint for ending discrimination against people with disabilities in education, jobs and everyday life. It requires countries to guarantee freedom from exploitation and abuse, while protecting rights already secured, such as voting procedures for those who are blind and wheelchair accessibility to buildings. It also advocates keeping people with disabilities within their communities, instead of institutionalizing them or educating them separately.

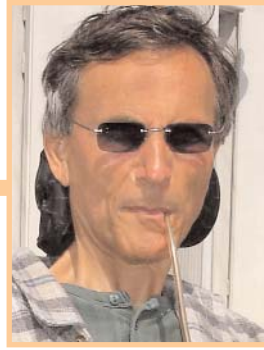
The second session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities will take place in New York, September 2-4, 2009. www.un.org/disabilities ▲



FitLife Face Mask



Freedom Vent System



Adolf Ratzka Receives European Citizen Award

The European Anti-Discrimination Council (EAC) of the European Union presented its annual European Citizen Award to ventilator user and disability rights activist Adolf Ratzka, PhD, in July 2009. The EAC honored Dr. Ratzka for his decades as a major force behind many successful initiatives promoting self-determined lives by persons with disabilities.

Known as the father of the Swedish independent living movement, Dr. Ratzka initiated and led the pilot project on personal assistance that became the model for the Swedish Personal Assistance Act of 1994. In 1989, he was the founding chair of the European Network on Independent Living, which works for disabled citizens' personal and political power, for self-determination and against discrimination.

Congratulations to Dr. Ratzka! He and his ventilator travel worldwide to lecture, to conduct workshops and to cooperate in projects focusing on the requirements for de-institutionalization of persons with disabilities. ▲

Did you know that IVUN's Resource Directory for Ventilator-Assisted Living is downloaded 1,800 times a month? Are you or your facility experts in home mechanical ventilation?

For details on how to be added to one of the subdivisions below, contact info@ventusers.org.

The online version is updated continually.

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

Did you know that IVUN's Home Ventilator Guide is downloaded 800 times a month?

Check it out at www.ventusers.org/edu/HomeVentGuide.pdf. Send additions or changes to info@ventusers.org. ▲

Conference Calendar

September — December 2009

To be listed in future issues of *Ventilator-Assisted Living* and on IVUN's online calendar at www.ventusers.org/net/calendar.html, send your conference details to info@ventusers.org

September 12-16. European Respiratory Society (ERS) Annual Congress. Vienna, Austria. www.ersnet.org

October 31-November 5. CHEST, American College of Chest Physicians (ACCP) Annual Conference. San Diego, California. www.chestnet.org

November 1. "Breathing and Sleep: Solutions for People with Neuromuscular Disorders." Southern California Polio Survivor Groups, the local MDA, ALSA and MS Society Groups, and IVUN. The Salk Institute, La Jolla, California. Contact Gladys Swensrud (swensrud@pacbell.net), and watch www.ventusers.org

December 5-8. 55th International Respiratory Congress, American Association for Respiratory Care (AARC). San Antonio, Texas. www.aarc.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 neuro-muscular 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-poliomyelitis 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!**

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\$10,000 **Gini Laurie Advocate**

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www.respironics.com



TrilogY100

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.

Ventilator-Assisted Living (Vol. 23, No. 3, Fall 2009)

It's Flu Season ... p. 1 & 3 ■ No Way Out But In ... p. 4 & 5 ■ Improving Long-term Respiratory Care in Ontario ... p. 6 & 7 ■ and more.

Moving? Change of address? Please notify IVUN before you move by calling 314-534-0475 or email info@ventusers.org. It is helpful if you tell us your old and new addresses. Will you be temporarily away? If you send us your "second" address and the date you will be at which address, we will do our best to send the newsletter.

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