

International Ventilator Users Network Doubles Research Fund Grant to \$50,000

William Stothers, Post-Polio Health International's (PHI) Board Chair announced that it will increase the yearly amount given from The Research Fund to \$50,000.

Established in 1995 with assets from the estate of Thomas Wallace Rogers, the dedicated fund grew from donations and wise investing. Rogers was a polio survivor who slept in an iron lung and sought the organization's help when his breathing problems worsened. He led an active life and ran his own securities business.

"I recall discussions he had with Gini Laurie about using positive pressure ventilation," said Joan L. Headley, executive director of IVUN. "With the help of Oscar B. Schwartz, MD, a St. Louis pulmonologist, he added the PLV-100

(Philips Respironics) to his breathing aids. I think he would appreciate the fact that additional donors and the market greatly expanded his initial contributions."

Longtime Board member and Chair of the Medical Advisory Committee, Fred Maynard, MD, said, "We are excited to double the amount of our research awards in order to accelerate the rate of investigation into useful solutions to the problems of our aging polio survivors who make up the majority of our membership."

IVUN's eighth Request for Proposals has changed from prior years. It is now a one-step process, rather than two, and the award will be given annually, with an option for \$100,000 over a two-year period.

The application deadline for the grant to be awarded in 2014 is February 3, 2014. The recipient, if one is warranted, will receive notice by April 15th. An application is available on www.ventusers.org for the Thomas Wallace Rogers Memorial Respiratory Research Grant to study the management of neuromuscular respiratory insufficiency and to explore historical, social, psychological and independent living aspects of long-term home mechanical ventilation.

"In future years we may narrow the focus of the request to particular medical or social problems affecting ventilator users," explains Daniel Wilson, PhD, Chair of the Research Committee. "We invite members of IVUN to suggest possible subjects for future research." ■

Past PHI/IVUN Research Fund Awardees

- 2001 – \$20,000
University of Toronto, Toronto Rehabilitation Institute, West Park Healthcare Centre. *Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life.*
- 2003 – \$25,000
University of Michigan-Ann Arbor. *Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress.*
- 2005 – \$25,000
Johns Hopkins University. *Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis.*
- 2007 – \$25,000
University of Arkansas for Medical Sciences–Little Rock. *Pilot Study to Identify PPS Biomarker.*
- 2009 – \$25,000
University of Insubria, Varese, Italy. *Persisting Noninfectious Fragments of Poliovirus in PPS Patients: Virus Detection and Susceptibility to Antiviral Drugs.*
- 2011 – \$25,000 each to:
University of Michigan-Ann Arbor. *Oral Glutathione and Health Outcomes among Persons with Post-Polio Syndrome.*
Hadassah Medical Center, Jerusalem, Israel. *Characteristics of Poliomyelitis and Post-Polio Patients among Jews and Arabs in Jerusalem.*
- 2013 – \$25,000
Texas Woman's University-Houston, and TIRR-Memorial Hermann Rehabilitation & Research. *Effects of Whole Body Vibration on People with Post-Polio Syndrome.*



Amara Gel

Product News, Masks

Amara Gel and **Amara Silicone** are two new options of a full face mask from Philips Respironics. The smaller, lighter mask with one “click” design is available in petite, small, medium and large to conform to the contours of the face, providing comfort and a seal. In addition to the gel option, a clear silicone option is available. It requires just a single “click” to disassemble and reassemble the cushion and mask frame for cleaning and replacement. <http://amara.respironics.com>



Amara Silicone

Vivo® 50 Approved by FAA

Roger Nyström, Product Manager, GE Healthcare – Respiratory & Sleep/Breas, reports that the Federal Aviation Administration (FAA) compliance letter for the New Vivo® 50 has been issued. (See copy at www.ventusers.org/adv/Vivo50FAAcomplianceLtr.pdf.) Note that this FAA certificate is valid for Vivo 50s produced from July 8, 2013. For older Vivo 50s, the company provides a service kit so Vivo 50s can, by service engineers, be updated to also fulfill the requirements, and those units will get individual FAA certificates.

Looking Ahead to 2015 in Lyon, France

The JIVD 14th International Conference on Home Mechanical Ventilation and the ERCA 5th European Respiratory Care Association Congress will meet jointly March 26-28, 2015, in Lyon. Both associations are well known to health care professionals – JIVD in the field of home mechanical ventilation since 1989, and ERCA in the field of respiratory care since 2003. The common objectives of both associations are to promote the knowledge and understanding of disease, to educate and to share experience in order to ensure optimal patient respiratory care.



Don't Forget Your Flu Shot

The Centers for Disease Control and Prevention recommends a yearly flu vaccine for everyone 6 months of age and older as the first and most important step in protecting against this serious disease. While there are many different flu viruses, the flu vaccine is designed to protect against the three main flu strains that research indicates will cause the most illness during the flu season. Getting the flu vaccine as soon as it becomes available each year is always a good idea, and the protection you get from vaccination will last throughout the flu season.

In addition, you can take everyday preventive steps like staying away from sick people and washing your hands to reduce the spread of germs. If you are sick with flu, stay home from work or school to prevent spreading influenza to others. ■

Send product news to
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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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International Ventilator Users Network (IVUN)

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Notify IVUN before you move by calling 314-534-0475 or email info@ventusers.org, and tell us your old and new addresses.

Away temporarily?

Send us your second address and dates you will be there and we'll do our best to send you our newsletter.

New Rules for Pay of Home Health Care Workers

The U.S. Department of Labor issued new rules recently that mandate home health care agencies pay their workers the minimum wage and receive overtime pay starting in 2015. Although the new rules apply primarily to home health care agencies and other third party employers, individuals or families are subject to the requirements if they hire their own home health care aides to perform medically related tasks for which training is necessary or for domestic work that benefits other members of the household.

Currently, 15 states provide (www.dol.gov/whd/minwage/america.htm) minimum wage (currently at least \$7.25 an hour) and overtime protections to home care workers, and six more require minimum-wage pay.

Medicaid pays for a large share of these services. The long time period before the rule goes into effect is to accommodate states and families so they can plan for the additional costs.

The Department of Labor launched a new website to better inform people about the regulation – www.dol.gov/whd/homecare.

AAPD Response

The American Association of People with Disabilities (AAPD) supports this ruling, and issued a statement detailing the reasons for support. “Prior to the effective date of this rule, we urge HHS and DOL to develop and implement a plan to provide assistance to states, service providers and people with disabilities to minimize any disruption to the people who use consumer-directed programs. This should include a targeted technical assistance effort directed at those areas of the country where consumer-directed programs serve the greatest number of people.

“Managed care organizations have a particularly important role to play, leveraging their infrastructure and provider networks, as they are increasingly involved in contracting with states to manage their long-term services and supports systems. In addition, we call on organized labor to work with the disability and aging communities as these changes become effective. Further, consistent with the Administration’s priorities, this interagency effort must make certain that any unintended consequences

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Response from Carrie Ann Lucas, an attorney, founder and executive director of the Center for Rights of Parents with Disabilities. She has a form of muscular dystrophy and uses a ventilator and trach full time. She is a single adoptive parent to four children, all of whom have various disabilities.

The new rules are simply fair for our attendants. They are entitled to fair wages and working conditions. I understand that the rules create issues for some consumers, but it is simply not ethical to have our workers receive less than fair pay. It is possible to have around-the-clock care, and pay attendants not only minimum wage, but a living wage.

Under Colorado’s consumer-directed care model, I am able to pay a living wage and overtime to attendants and stay within my budget. I have 24 hours of care most days. It is not uncommon for attendants who work less than full-time hours to work for more than one consumer.

In states where it is not yet possible to pay fair wages, this rule change should be the impetus for immediate directed legislative and policy change to increase consumer-directed care budgets. The problem is not with this rule change, but with the oppressive and outdated medical model of providing care that favors agency and institutional care over consumer-directed community care.

These changes may result in service delivery changes for people with disabilities. Some people may need to start hiring more than one care provider to stay within their budget for care. To suggest that having to hire a care provider strips a person of dignity is an affront to the entire independent living movement. We rely on attendant care, and ventilator users tend to rely on many hours of care. It is not unreasonable to expect that someone requiring more than eight hours of paid care a day would have more than one attendant.

In fact, it is safer for the consumer to have multiple attendants in the event of an emergency with a care provider or a natural disaster that disrupts care. This prevents unnecessary institutionalization in the face of crisis.

As in any other industry paying low wages, the care provider may work more than one job. The solution to this is to pay a living wage. Even with a living wage, some care providers will choose to work more than one job.

Protecting Every Breath and Improving Patient Comfort

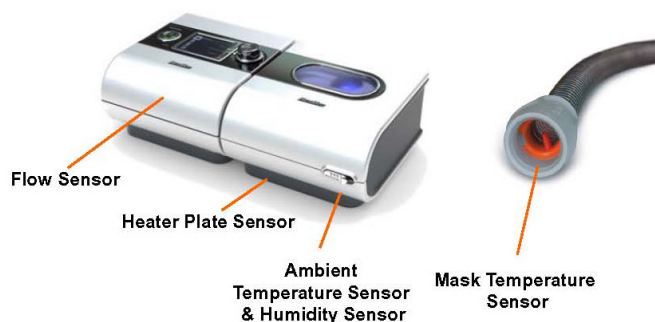
S9™, VPAP™, Stellar™ and ResMed Interfaces

Joan L. Headley, Executive Director, International Ventilator Users Network, St. Louis, Missouri

The first segment of a presentation by Michael Madison, RRT, a representative from ResMed's Respiratory Care unit, on June 26, 2013, described three major features of the S9™, the base platform for many ResMed products.

Climate control system: Lungs work best if the air taken in is warm, moist and filtered. It is important to control absolute humidity, mask temperature and relative humidity.

The S9 measures the room air using the ambient temperature sensor and the humidity sensor and also the air that is delivered to a patient with the mask temperature sensor. (See below.) In between, the machine compensates to produce the most comfortable air for a user based on the settings dialed in.



The default settings are 80°F and 80% humidity. The ability to continually adjust to keep the humidity at the desired level eliminates rainout (moisture) that can appear in tubing, improving patient comfort.

Noise reduction: The S9 is reportedly 78% quieter than the S8, because conducted noise, i.e., noise such as in a stethoscope, has been reduced. The Enhanced Easy-Breathe motor reduces the conducted noise that could be transmitted to the cheekbones and noise at the mask in the form of vibration.

Display capabilities: The S9 has a display (See below.) that lets ventilator users track sleep quality by usage in hours, observe their apnea/hypopnea index (AHI) and mask fit. The system indicates a good mask fit by displaying a green smiley face (good), or if there is too large a leak, a red unhappy face (adjust).



The S9 VPAP ST-A

Building on the platform described above, the letters of the S9 VPAP ST-A device stand for variable positive airway pressure with spontaneous timed mode and with apnea mode. Other possible modes include CPAP, S, T, PAC (pressure-assisted control) and iVAPS (intelligent volume-assured pressure support).

The breathing device is intended for respiratory insufficiency and obstructive sleep apnea. It is FDA approved for pediatric patients (greater than 30 pounds) and adults. It has user-settable alarms, climate control, a possible IPAP of 30 cm of H₂O and 50 bpm backup rate. It also has TiControl™ for customization of breath length, an adjustable rise time and Vsync leak compensation to



customize breath delivery. For details, see the PowerPoint presentation at www.ventusers.org/edu/call-Madisonnw.pdf.

The iVAPS feature – intelligent volume-assured pressure support allows for automated adjustment of pressure created by the machine to achieve a target volume. Pressure is measured as delivered out of the machine and at patient interface and then iVAPS adjusts the pressure based on the patient's measured activity. If the target volume is 20 L/min and the patient respiratory effort only achieves 14 L/min, then iVAPS, within preset limits, ramps up delivery pressures until the patient returns to the target 20 L/min. The iVAPS targets alveolar ventilation – ventilation in that part of the lung that actively participates in gas exchange, thus compensating for the dead space in the lung anatomy that does not participate in gas exchange.

The S9 VPAP ST-A with the iVAPS feature is suitable for neuromuscular disease and restrictive conditions, obesity hypoventilation and COPD.

ResMed offers a device specifically for people with COPD discharged to the home, a number estimated to be more than 1 million patients in 2012. The VPAP™ COPD has pressure capability up to 30 cm H₂O, and a ClimateLine^{MAX}™ Oxy tubing which accommodates the addition of oxygen to the air delivered to the patient and controls humidity. The machine provides for a longer exhalation period to match the slower exhalation flows of individuals with COPD.

The Stellar™

Madison next described the Stellar 150, which is another option for the survivors of polio, the target audience of the IVUN Educational Conference Calls.

The Stellar 150 is a pressure support device with the iVAPS feature. (The iVAPS is not on the Stellar 100.) It is small enough to be easily carried and a padded mobility bag is available. The device produces higher pressures and flows, so it can be used in the hospital and as a bridge to the home. It has a

two-hour internal battery and the capability to add two external batteries for another 16 hours.

It can be programmed for two different groups of settings for different patient activities, e.g., when someone is awake and alert and when someone is relaxing or asleep.

To assist clinicians, the device has preset options or “quick starts” for the following disease states: obstructive lung disease, restrictive lung disease, obesity hypoventilation and for normal lung mechanics, which then can be fine tuned.

The screen displays flow and pressure curves simultaneously, and these parameters: I:E ratio, minute ventilation, respiratory rate, leak, tidal volume and FiO₂ (oxygen being supplemented) when connected. There is also an option for measuring oxygen saturation (SpO₂).

Lastly, at the request of ventilator users, Madison briefly outlined the mask options available from ResMed.

Full-face masks are ideal for those who experience mouth leak, those with a deviated septum or with seasonal allergies. An improvement in full-face mask technology (Quattro™ FX) is the dual-wall cushion. The thick inner cushion provides stability and a thin outer membrane enhances the seal. Ventilator users don't have to tighten the headgear as much resulting in less pressure on the skin, fewer problems with skin issues and greater comfort.

Various nasal masks have been around for many years. The mask was first used for treating obstructive sleep apnea and seals around the nose. ResMed offers a variety of nasal masks in their Mirage™ line. Nasal pillows design is minimal with small “pillows” inserted into the nares (nostrils). ResMed's Swift line of products has a dual wall, a thin outer membrane that conforms to the nares and a thicker inner membrane that provides structure.

To view the PowerPoint for this presentation, go to www.ventusers.org/edu/call-Madisonnw.pdf ■



stemming from these changes do not result in institutionalization.” To read AAPD’s complete statement about the rule, please visit www.aapd.com/resources/press-room/aapd-supports-new-rule-to.html.

ADAPT Response

The national disability rights group, ADAPT, decried the release of federal rules finalizing changes to the Fair Labor Standards Act companionship exemption because the changes will result in the unwanted institutionalization of people with disabilities.

“No matter what kind of propaganda the Obama administration manufactures to promote these rules as a victory for attendants and people with disabilities, the reality is that these rules will be devastating for citizens with disabilities who rely on Medicaid-funded home and

community-based services for more than 40 hours of assistance per week.”

National Associations Respond

The national associations for state Medicaid, Aging and Disability and Developmental Disability directors issued the following statement on the Department of Labor’s changes to the Fair Labor Standards Act:

“Implementation of this rule will require additional funding and may result in the cost of supporting people in their own homes becoming prohibitive. We are deeply disappointed that the Administration ultimately failed to adopt a rule that balances fair compensation for home care workers with the equally critical goal of assuring the ability of older adults and people with disabilities to maintain their independence at home and in their communities.” ■

Response from Jeffrey Sadow, an associate professor of political science at Louisiana State University Shreveport. He has been his wife Deshae Lott’s primary caregiver for more than 13 years, 12 of which she has used a ventilator full time.

This is a recipe for reduced service provision for clients and fewer jobs for workers.

While a minority of states already mandates minimum wage or higher payments and/or overtime to these workers, most do not require pay of at least \$7.25 an hour or time-and-a-half for any work over 40 hours. A good deal of the market involves families paying from their own resources or from insurance to a person or organization, meaning with the new rules the same individuals soon can afford fewer hours. Others receive aid in this form from states that pay agencies to supply services. These individuals will suffer the same difficulty but perhaps multiplied.

For states this could cause legal problems because states have an obligation to provide these services to a certain level and could run afoul of legal standards that mandate the state to provide care in the least restrictive setting. To prevent that from happening, this puts pressure on the state to raise reimbursement rates, which then either impairs other parts of the budget or taxpayers by taking more out of their hides in the future.

Thus, this new rule creates greater fiscal strains on the states. About the only salutary aspect of this government interference in the proper pricing of labor is that it could accelerate reform to curtail the preferential treatment that nursing homes receive in funding. Money currently going to subsidize the inefficient overutilization of them at the expense of home care could be shifted to stabilize those reimbursement rates thereby reducing nursing home populations in favor of greater home and community placements. Whether this necessity will attract sufficient political support remains questionable.

Lost in all of this is that the workers themselves suffer a greater level of unemployment if there is not beggaring of other government spending and/or taxpayers. The same amount of funds would have to be spread among fewer of them, replicating that familiar flaw from an imposed minimum wage.

All in all, the change creates an unpalatable future of more worker unemployment, reduced state services to the needy and/or increased taxes. Unless pressure comes to make Labor backtrack, clients likely will be made worse off.

St. Louis 2014 – May 31-June 3, Hyatt Regency St. Louis at The Arch

PHI's 11th International Conference, "Promoting Healthy Ideas," will feature three days of presentations and interactive discussions, demonstrations of the latest in respiratory assist devices, multi-mode ventilators and interfaces, and the opportunity for conference participants to gather facts and exchange experiences on attendant care, accessible homes and design, aging solo, staying active in mind and body, and tips on assess your abilities.

Included in "Promoting Healthy Ideas" will be topics such as weight management, sleep, managing medications, attention-getting pain, updates on research and future needs of ventilator users. You will be able to explore Qigong, yoga, music therapy, ideas for maintaining posture and dealing with worry.

On Saturday May 31, PHI will welcome first-time conference attendees at a special session from 3:00 pm–4:15 pm. All will be welcomed at a special dinner Saturday evening at 6:00 pm. (The final session will end at 3:00 pm on Tuesday, June 3.)

The other evenings will be a time for rest and reflection on the day's activities; spending time with old friends and making new ones. At nearby Busch Stadium, the St. Louis Cardinals will play the San Francisco Giants on Saturday and Sunday and the Kansas City Royals on Monday and Tuesday. The hotel is located in downtown St. Louis, and to find other evening activities in the area, see <http://explorestlouis.com>.

A block of rooms has been reserved at the conference headquarters hotel, the Hyatt Regency St. Louis at The Arch, 315 Chestnut Street. Additionally, we have contacted hotels close by and have accessible rooms available in an overflow hotel should the need arise. Individuals registered for the conference may register for a room online www.post-polio.org/net/11thConfHotelInfo.pdf or by phone 314-655-1234. As you all know, there are many people in our group who have mobility problems. PHI will make every effort to meet accessibility needs. Please understand these rooms will be assigned based on essential need, not solely on first-come, first-served.

Registration materials and updated program details will be posted on www.post-polio.org in early November. Individuals who do not have access to the internet may request a print registration packet by calling 314-534-0475 or mailing the request to PHI, 4207 Lindell Blvd., #110, St. Louis, MO 63108. ■



PHI's 11th International Conference

Not yet a Member?

Join IVUN for just \$30 a year (Subscriber Membership) and receive your own copy of *Ventilator-Assisted Living* via email six times a year (February, April, June, August, October and December), plus six *IVUN Membership Memos* via email. For \$55 (Subscriber Plus Membership), join IVUN and PHI and also receive *Post-Polio Health* in print four times a year (February, May, August, November) and eight *PHI Membership Memos*.

You can join online at <http://shop.post-polio.org> or send or fax (314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. Questions? 314-534-0475 .

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