

IVUN's mission is supported by its Membership.

\$100,000 Grant Announced at 11th International Conference

On behalf of his team, Antonio Toniolo, MD, FAMH, University of Insubria, Varese, Italy, accepted the two-year grant award of \$100,000 (\$50,000 per year) from Post-Polio Health International/International Ventilator Users Network at the organization's 11th International Conference on May 31, 2014.



Antonio Toniolo, MD, FAMH

Dr. Toniolo's proposal, "Poliovirus genome in patients with post-polio syndrome (PPS): Defining virus mutations by novel genome sequencing methods and investigating possible treatments with antiviral antibodies and drugs," was selected from 11 proposals reviewed by the expert Review Panel and approved by PHI/IVUN's Board of Directors. Proposals were submitted from researchers representing seven different countries. Of the 11, six were

investigating issues related to ventilator use throughout the world. This represents an increase from past years.

The Research Fund Legacy

The Research Fund was started in 1995 with a bequest from the estate of Thomas Rogers, a quadriplegic polio survivor who spent about a year and a half in

three hospitals. He had been successfully weaned from the iron lung to a rocking bed and with a "great proficiency in frog breathing." In later years, he used the portable Bantam Positive Pressure Respirator and the PLV-100.

Rogers had completed one year of college when he contracted polio. He pursued an education with a friend who taught at the local community college, and he started selling mutual funds and insurance. In 1966, with the help of an uncle and a friend he started his own firm, employing one full-time person and one half-time person. Rogers was proud of the fact that the company allowed him to be self-supporting.

He did better than that. Rogers died in 1994 leaving a percentage of his assets to initiate The Research Fund of our organization.

The announcement at the opening dinner of the conference by Research Committee Chair Daniel J. Wilson, PhD, represents the eighth award year. PHI/IVUN has given nine awards between 2001-2014 totaling \$295,000. (Two awards were granted in 2011.) To review past awards and final reports, go to www.ventusers.org/res/index.html#pri

Contributions to the fund may be made online at <http://shop.post-polio.org/> or by check to 4207 Lindell Boulevard, #110, St. Louis, Missouri 63108. ■

ResMed Launches New Platform of Portable and Lightweight Ventilators

ResMed has introduced a new platform of portable, lightweight and user-friendly life support ventilators in select European and Asia-Pacific markets with the launch of the Astral™ 100 and Astral™ 150. Already a leading player with its Elisée™ and VS III™ devices, ResMed's new generation of Astral life support ventilators offer even greater mobility and ease of use for patients suffering from neuromuscular disease, chronic obstructive pulmonary disease (COPD) and other adult and childhood breathing disorders.



Astral™ 150

Astral 100 and Astral 150 life support ventilators offer excellent battery-to-weight ratios with an eight-hour internal battery and a weight of only 3.2 kilograms (about 7 pounds). Two optional eight-hour external batteries provide a total run-time of 24 hours. With this expanded mobility, chronically ill adult and pediatric patients who would otherwise be hospitalized may be safely treated away from the hospital for a more enriched life. Less time in the hospital can also mean a reduction in the cost of care.

Astral life support ventilators make setting up a patient and entering adjustments simple and straightforward with a large touchscreen display and easy-to-navigate graphic user interface. The touchscreen functionality can be accessed without removing the device from its travel bag for patients taking advantage of the ventilator's enhanced mobility.

Astral life support ventilators feature eight customizable breathing modes to ensure that patients receive optimal treatment to manage their specific respiratory requirements. Therapies can be adjusted depending on patient need, so patients can gradually be weaned off the ventilator after a period of time, if appropriate.

Astral life support ventilators are scheduled to be available in the U.S. later this year, pending FDA clearance.

NIH Grant Aims to Improve Critical Patient Care

Intubating and placing patients on ventilators saves lives, but also comes with risks for people who are critically ill. According to several studies, use of ventilators is associated with complications, such as pneumonia. Pneumonia in these patients occurs from many factors, including leakage of saliva and other fluids from the mouth into the lungs around the breathing tube, called aspiration.

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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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Moving? Change of address?

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 your newsletter.

Ventilator Users Speak

IVUN receives numerous questions from individuals with differing backgrounds and for different reasons. Some are authors, columnists, students. Others are ventilator users, family members, health professionals, personal attendants, home health care companies and manufacturers.

A health professional reader of *Ventilator-Assisted Living* reports that he likes the newsletter because it lets him know what his patients are thinking. Here is a question we recently posed to our members:

Do you consider the machine that you use to assist with breathing as life support? If not, what would be the connotation if it was called life support?

“That is an interesting question. I really don’t know, and I don’t want to take myself off the high span BiPAP to find out. What I do know is that I do not breathe adequately when asleep to support basic health needs without it. The real question is whether sleeping without it would cause more hypoxic heart damage, which has already happened, or progress to hypoxic brain damage, or would I simply progress to not waking up. Life support is usually considered to be what is needed fulltime, whether awake or asleep. I breathe adequately when fully awake, but not when tired or asleep. So when awake, it is not required for life support. But asleep, for me I do consider my BiPAP to be life support.”

“The LTV950 ventilator I am using now is certainly life support. If I was without it I would first suffer by not getting adequate ventilation and soon would be in respiratory arrest. Brain damage and heart stoppage would follow.”

“I hadn’t thought about my BiPAP in this way before, but it really is life support. I doubt that I could get a night’s sleep without it, and without sleep, one can’t operate as normal.”

“Life support, as I use the term, in its primary sense, refers to things that are needed continuously – without which life ceases more or less immediately. Effective access to oxygen is an example. So for some people, the machine I use to assist with breathing could be life support in this primary sense. But since I don’t need it continuously, for me it is not, because I could survive for 24 or 48 or 72 hours without it. In a secondary sense, however, the machine I use is ‘life support’ for me in the same sense that insulin is life support for a diabetic. You can throw me in jail for a day or two without it, and I would probably survive. But eventually I would die, and it wouldn’t be too long before that happened. In a tertiary sense, the machine I use, as I use it, is ‘life support’ for me in the same sense that water is life support.”

“Life support? This gets complicated the more I think about it. I can still breathe on my own for short periods so, if my vent failed, I would still live ... at least for a while. I would be tired, but I would live.”

“If I’m speaking to a general audience, I say that I’m ‘breathing with mechanical assistance.’ But I also use a power chair for mobility, so my mobility is enhanced, ‘with mechanical assistance.’ In news stories about people who have sustained a very severe head injury, the family is often asked to make a decision to remove the person from ‘life support.’ This could mean several interventions: hydration, nutrition, etc. But this usually means the removal of a ventilator. I guess my answer depends on the person I am addressing. To a physician I might use the term ‘life support.’ To a stranger, or a lay person who is asking out of curiosity, I’m sure I would use a less medical term. ‘Life support’ carries too many negative connotations. This is probably a more long-winded answer than you wanted. It gave me something to think about. I would not ordinarily use ‘life support’ to describe my vent.”

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“No, I don’t consider it life support. If I could not breathe on my own, I would consider my vent life support. On most days, I only use my vent at night. Though, thinking the question through, if I couldn’t use the vent for a night, I would consider it life support. I could probably make it through one night without it, but would probably be very uncomfortable.”

“The Stellar 150 and its backup Synchrony are life support. I would be dead otherwise ... as simple as that.”

“Life support to me means the person cannot stay alive without it – period! I consider my Pulmonetics as an assist (meaning, with it I can rest my own breathing muscles at night, in the car, on the computer, etc.). Hopefully this ‘rest time’ helps me stay strong enough to breathe on my own when I want to and/or need to. So far, this definition has worked fairly well for me. I do require some vent time daily as well as all night. When I’ve had a very tiring day, I usually spend a big part of the next day resting with the vent. So is mine truly life support? Hmmm. Not by my definition above. Perhaps my Pulmonetics is ‘normal life enabling.’ Whatever that means!”

“I definitely consider it life support because without it, I would eventually die. And I don’t think it would take long for my heart to give out. There have been times when I was using the vent and thought I would soon die (e.g., when I have pneumonia, an infection or am very anemic). However, I think for many, ‘life support’ means being full time on a vent and being kept alive, often in a comatose state.”

“My first reaction is that it isn’t ‘life support’ ventilation as I will not immediately die without it ... I can breathe on my own for a period of time. However, I would gradually die as I got more and more exhausted struggling to breathe. My sense of it changes depending on circumstance. In a power outage it is clearly ‘life support’ to me and I present it as such. If a hospital or service refuses me (e.g., airlines), the ventilator is not ‘life support’ because it scares them off.”

“In the non-medical mind, we all know that magazines and TV usually portray ‘life support’ as a ventilator for a newly comatose person who has no ability to breathe without the ventilator and no ability to recover. Turning off the ventilator is often an option being considered by outsiders and is equated with death.

“But the polio/ALS/SCI/neuromuscular community is not comatose. We are very much alive and aware. Our conditions vary in severity, but many of us need ventilators.

“I see my ventilator need as one end of a continuum. Everyone uses machines. We all use cars and smart phones, live in a home heated with a furnace, rely on water pumps, etc. Even our most distant ancestors used rocks and spears, both simple machines. In sealed modern buildings and airplanes, artificial ventilation systems keep everyone alive. So I see human life as enhanced by machines to facilitate living. In my particular circumstance I now require my closest machine to be a personal ventilator.

“The major problem with using the term ‘life support’ is that some segment of the population may see those needing ‘life support’ to be less than fully alive, and therefore think that they have the right to remove the ‘life support.’” ■

University of Central Florida College of Nursing Interim Dean and Orlando Health Distinguished Professor Mary Lou Sole seeks to improve the way nurses manage their patients' care when they need a ventilator.

In more than 20 years as a researcher and a practicing nurse, Sole found that many critically-ill patients have a lot of saliva and other fluids in the mouth increasing the risk of pneumonia, and she has developed a protocol to remove these fluids. The National Institutes of Health has awarded her a \$2.3 million grant to determine if regular removal of fluids that accumulate in the mouth and back of the throat can also help prevent aspiration.

Breas Acquired by PBM Capital

Breas Medical AB has been acquired from GE Healthcare by PBM Capital Group, a healthcare-focused private investment firm. Breas, headquartered in Sweden, is a leading manufacturer of home respiratory ventilators and sleep apnea products for the global healthcare market sold in more than 40 countries.

PBM Capital will integrate Breas into its Human Design Medical, a lifestyle medical device company focusing on the treatment of sleep apnea. Breas said that it “looks forward to leveraging our core efficient operation, our strong customer relationships and significant global breadth with an entrepreneurial owner that is focused on changing the respiratory industry.”

FSMA Care Series

The FSMA (Families of Spinal Muscular Atrophy) publishes a Care Series of booklets on a variety of specific topics including Breathing Basics: Respiratory Care for Children with Spinal Muscular Atrophy. All of the Care Series booklets are available in Spanish. Email info@fsma.org or call 800-886-1762.

Iron Lung Experiences Sought

Sherie Denham, CRT, Northwest Mississippi Regional Medical Center, Clarksdale, Mississippi, had an opportunity to purchase an iron lung for \$10 that was in storage at the facility where she works. With 25 years of experience, Denham cared for a woman who slept in an iron lung and was intrigued by the iron lung made by Fabrikators Inc. of Mass, Iron Lung Company of America, 19 Walnut Street, West Roxbury 32, Massachusetts. Denham would like to know more about this brand of iron lung and invites readers of *Ventilator-Assisted Living* to share their experiences, both as a health professional and as a patient. Send your comments to info@ventusers.org. ■





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