

VENTILATOR-ASSISTED LIVING

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IVUN's mission is supported by its Membership.

PFROMMER AWARD HONORS HEADLEY AND FISCHER

Joan L. Headley, Executive Director of IVUN, and Judith Fischer, retired Executive Director and IVUN Information Specialist, received the Margaret Pfrommer Memorial Award in Long-term Mechanical Ventilation from the American College of Chest Physicians at CHEST 2014 at the annual meeting in Austin, Texas, on October 28.



Pfrommer Award recipients Judith Fischer, left, and Joan Headley with Curtis Sessler, MD, FCCP, President of the American College of Chest Physicians (ACCP). Photo credit: ACCP

The award is presented to a clinician or ventilator-assisted professional or advocate who has advanced the area of mechanical ventilation and fostered partnerships between physicians and users of home mechanical ventilation. Through their work for Post-Polio Health International and International

Ventilator Users Network, the two were cited for significant contributions to mechanical ventilation.

Headley and Fischer presented the honorary lecture at the annual meeting entitled, "Ventilator Users Can Survive the System with Your Help."

They explained the history of their organization and its parallels to the growth and technological development of ventilators. Founded by the late Gini Laurie in the 1950s, many polio survivors went home from the hospital with chest cuirasses, iron lungs and rocking beds. Believing in their need to network with each other and stay connected, Laurie's newsletters were the link that provided practical information on how to live at home in their communities.

Laurie was networking before it became a buzzword. "Networking links people who share common needs or common goals. Networking is a support system. It is a method of self-organizing. It is the structure of a social movement. Most of all it is method by which people get things done."

Vent users were solely polio survivors, and they lived at home cared for by families. With the success of the Salk and Sabin polio vaccines, the March of Dimes stopped funding the respiratory centers that had been set up during the 1950s' epidemics. Polio survivors needed to find an alternate source of funding for attendant care, although they were primarily children cared for by their parents at home.

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Health and Human Services (HHS) spurs innovation to develop next-generation portable ventilator

Acknowledging that low-cost, user-friendly, flexible ventilators are needed for pandemics and routine care, the U.S. Department of Health and Human Services announced it will sponsor the advanced development of a next-generation portable ventilator to help fill the need. The new ventilator will be developed under a three year, \$13.8 million contract with Philips Respironics of Murrysville, Pennsylvania.

In a severe influenza pandemic and potentially in other public health emergencies, a large number of severely ill patients would require mechanical ventilation. This number could overwhelm the capacity of the health care system to provide such care, both in the number of ventilators available and staff trained to operate them.

“An affordable portable ventilator will help us meet the needs of critically ill patients during a public health emergency, whether due to a naturally occurring pandemic or an act of bioterrorism,” states Robin Robinson, PhD, Director of Biomedical Advanced Research and Development Authority within the HHS Office of the Assistant Secretary for Preparedness and Response, the group responsible for overseeing the project.

The ventilator in development will be a reduced size and low-cost (currently cost from \$6,000 to \$30,000 per unit) and will be designed in a way that doctors, nurses and other health professionals can operate without special training. The ventilator will be required to meet the needs of everyone from infants to the elderly.

In addition to aiding in response to a public health emergency, the next-generation ventilator in development can have important implications for routine care. The modernized features, agility and ease of use can improve patient care for triage in the field or advanced treatment in the hospital.

“Ventilators Market to 2020 – Technical Advances and Hospital Expansion Serve as Distinct Regional Growth Drivers”

by Market Research Reports is now available. The report’s promotion states that the global ventilators market was valued at just over \$765 million in 2013 and will exceed \$1 billion by 2020. The report states that while the increasing prevalence of Chronic Obstructive Pulmonary Disease (COPD) will continue to be the primary driver of market growth, new technologies will also make a crucial contribution.

The senior analyst of this report says: “The already-high prevalence of COPD will be exacerbated by the aging population, leading to more critical care admissions, where the use of mechanical ventilation is common.”



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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 our newsletter.



- ▷ The increasing preference for noninvasive ventilation in the developed world will be another significant trend over the forecast period, with Europe currently leading the United States in the adoption of these systems. The research attributes the low penetration of noninvasive ventilation in the United States to the lack of efforts towards increasing respiratory therapy and nursing time. Furthermore, there is an inaccurate perception that additional time is required to implement this treatment method.

Labor Department Delays Minimum Wage and Overtime Protections for Home-Care Workers

The U.S. Department of Labor in October granted a six-month delay in enforcement of a new rule applying federal minimum wage and overtime provisions to home care workers employed by “self-directed” Medicaid consumers.

In October 2013, the Labor Department said that the wage protections would take effect on Jan. 1, 2015, but in its recent announcement the department said that it would not enforce the rule for six months through June 30, 2015. For the second six months of the year, it said it would exercise “prosecutorial” discretion in bringing enforcement actions against employers that decline to pay minimum wage or overtime.

Under the new rule, home-care workers would have to receive the federal minimum wage of \$7.25 per hour and time-and-a-half when they work more than 40 hours a week. When the new rule was announced in 2013, the Labor Secretary said, “Almost two million home-care workers are doing critical work, providing services to people with disabilities and senior citizens,” but are “lumped into the same category as babysitters.”

Several states, facing budget constraints, had complained to the Obama administration about the cost. Home-care industry officials warned that the increased costs of the new rule could make families unable to afford home care and could push disabled American and seniors older than 65 into nursing homes, increasing costs for governments.

But the president of an advocacy group for home-care workers, criticized the announcement, saying, “The decision to delay means that two million workers – largely low-income women, and disproportionately women of color – will have to wait as long as another 12 months to receive even the most basic labor protections ...”

HAMILTON-T1

Hamilton Medical now offers a new neonatal option* for the HAMILTON-T1 transport ventilator. During transport, it delivers the same performance as a fully featured NICU ventilator at the bedside.

The specially adapted hardware and software meet the needs of ventilated neonates. Supporting tidal volumes of just 2 ml, the HAMILTON-T1 allows for effective, safe and lung-protective ventilation for even the smallest preemies. The neonatal flow sensor accurately measures pressure, volume and flow proximal to the patient. This guarantees the required sensitivity and response time, and prevents dead space ventilation. The new neonatal expiratory valve can balance even the smallest differences in pressure and offers the neonate the possibility to breathe spontaneously in each phase of a controlled breathing cycle.

In addition to all modern neonatal ventilation modes, the HAMILTON-T1 offers a new generation of nCPAP. With the new nCPAP-PC (pressure control) mode, the ventilator automatically and continuously adapts to the desired CPAP target value accommodating for the patient’s condition and possible leaks.

The ventilator has approvals and certificates for most types of transport and situations and is reliable everywhere, both inside and outside the hospital, in the air as well as on the ground.



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Safe Straw Might Help You Swallow Through Thick and Thin

Mary Spremulli, MA, CCC-SLP

Aspiration, food or liquid getting misdirected into the airway can be a source of aspiration pneumonia, and result in a hospitalization and recommendation for altering the diet, which often includes thickening liquids.

Thickened liquids, no matter what formula to get there, are not often enjoyed by patients, and many individuals, once out of the hospital or rehab, do not adhere to the recommendation to drink thickened liquids, and resume thin liquids on their own.

The ability to resume thin liquids once recovered from an aspiration pneumonia may be a very doable goal for people who are mobile, have a strong and effective cough, and are generally in a good state of state of health, despite a diagnosis they might have of Parkinson's or other neurological disorder.

But for others, who are wheelchair- or bed-bound, need to be fed by someone else, and have a weak voice and weak cough, their risk for another aspiration pneumonia is greater. "But it's only water," the patient or caregiver might say. True, small amounts of water getting misdirected into the airway will probably be of minor consequence to the lungs, but bacteria that resides in the mouth gets carried along with the water, and it's often the oral bacteria that finds its way into the lungs that contributes to infection.

Controlling the amount of liquid that is swallowed can sometimes make a big difference in swallowing safety, and the difference between thin or thick liquids.

The "small sip" that might be recommended by the swallowing therapist, can be hard to judge by the patient. So, enter, the Bionix Safe Straw.TM

The Safe StrawTM is a clever little invention that controls the amount of liquid that can be taken at a time. A regular straw is placed in a chamber of liquid. One teaspoon of liquid is drawn up the straw, and the float in the host chamber floats back to the bottom, creating a nice little "pause," as you prepare for your next sip.

"... a sip through a Safe Straw might be a great solution for 'getting started' with the swallow."

Straws have often been on the list of things not to use when drinking, but, with the volume controlled, the Safe StrawTM might be the perfect way for many people to keep drinking liquids safely. For people who tend to "hold" food or liquid in their mouth or can't quite coordinate the tongue to give the push it needs to the liquid, a sip through a Safe StrawTM might be a great solution for "getting started" with the swallow.

The Safe StrawTM chamber is available for thin or nectar thick liquids, and is reusable for a single person. Having used it recently with a few patients, I would judge this a worthwhile investment. Ask your speech/swallowing therapist for more information, or visit the company website: www.bionixmed.com/MED_Pages/SafeStraw.html ■



Safe Straw

Mary Spremulli, MA, CCC-SLP, a medical speech pathologist and licensed nurse, with more than 25 years of health care experience, frequently posts articles at <http://voiceaerobicsdvd.blogspot.com>. She is also president of Voice Aerobics, LLC, a speech-language pathology private practice located in Southwest Florida.

Hans Rudolph is serious about making NIV Masks

Kelly Rudolph, President, Hans Rudolph, Inc., Shawnee, Kansas

Hans Rudolph, the inventor, started making respiratory valves in the early 1930s at Indiana University, and the Rudolph family continues to design and manufacture respiratory valves, masks, flow measurement devices, lung simulators and many other respiratory products for lung therapy, testing and research.

Our company is about designing and making high quality, functional and effective masks for NIV (noninvasive ventilation) and CPAP (continuous positive airway pressure) for use in the home and hospital.

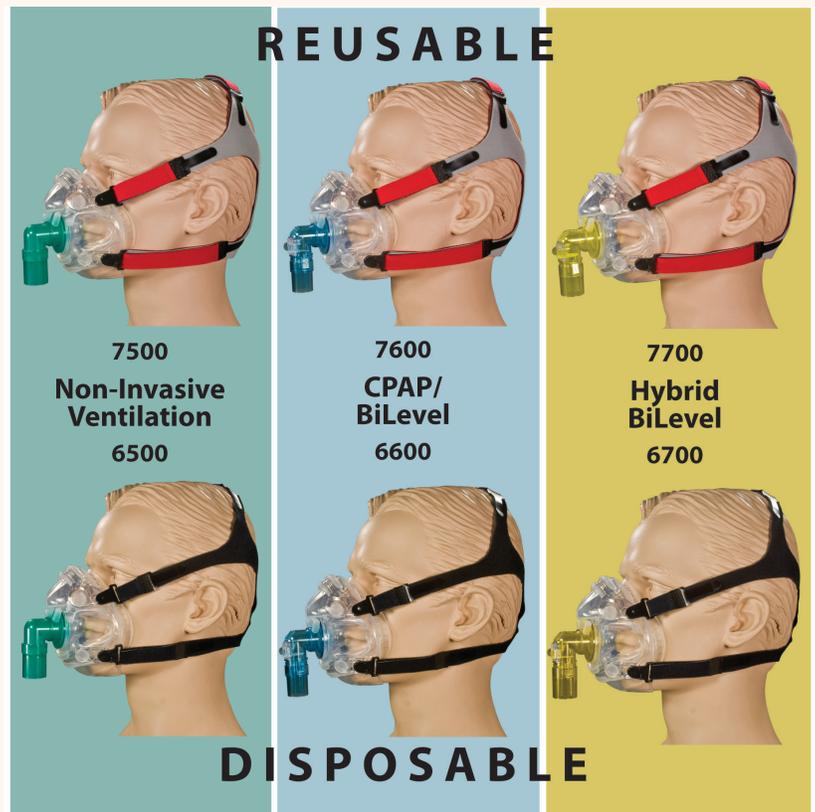
We make the widest range of face mask sizes in the world with our five sizes of the V2 Masks that are available in both reusable multi-patient use and disposable single-patient use versions.

The masks have three different colored swivel choices that allow the masks to work effectively with all the ventilators and CPAP/bilevel devices made throughout the world, and we are selling them very successfully throughout the world.

The **Green swivel** on the **7500 & 6500 Series Masks** is non-vented for use with critical care ventilators that typically have a Y- or T-piece connected to the mask. The **Blue swivel** on the **7600 & 6600 Series** has venting and an anti-asphyxia valve for use with all CPAP and bilevel bedside blower devices. The **Yellow swivel** on the **7700 & 6700 Series** is non-vented but has an anti-asphyxia valve for use with the very popular BiPAP Visions and subsequent V60 sub-acute care vents where there is vent port downstream in the breathing circuit.

Getting a good comfortable seal and fitting a wide range of faces is paramount to us along with making masks durable yet eliminating any issues to the vent user's face when worn for a long period of time regardless if it is a reusable mask or a disposable mask. Clients around the world tell us that our disposable mask is higher quality than the reusable masks that they have used.

RT's, nurses, patients and the dealers throughout the world continue to compliment the masks for their great seal and wide range of sizes that fit the largest patients in bariatric wards down to smaller clients at home. Because the masks are so soft and don't have a hard frame, they have no skin breakdown issues at all.



We plan to continue designing and making masks for a very long time. Clients can contact Kelly or Kevin Rudolph at www.rudolphkc.com anytime for help, feedback or to learn about the masks and accessories. ■

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The polio survivors who had graduated from their early respiratory devices were used to being involved in life, were married, were educated, had jobs, traveled. When they found that they were underventilated, they were not interested in revisiting the old equipment and its often horrific memories. They were ready to try something new and welcomed bilevel devices or nighttime assistance, as did others with a neuromuscular disease. Full-time vent users were thrilled when the LTV appeared – lightweight, much more portable and modern looking.

International Ventilator Users Network was established in 1986 to share the knowledge of polio survivors with the newer users from the MD, ALS, CCHS, SMA and SCI communities. The network purposefully included health professionals and manufacturers.

IVUN has witnessed the dovetailing of historical events and social movements, but its mission remains what Gini

Laurie envisioned: enhancing the lives and independence

The Pfrommer Award was established in 1999 by Dr. Eveline Faure and Dr. Allen I. Goldberg in honor of their lifelong colleague and friend, Margaret Pfrommer, a polio survivor and patient advocate.

of users of home mechanical ventilation through education, advocacy, research and networking.

The change in ventilator equipment mirrors the rise of the home health care industry and the increasing use of assisted ventilation, particularly the use of bilevel devices. Reimbursement for the older equipment was adequate through March of Dimes, but then money got tight, and the reimbursement changed for polio survivors.

In 1993, there was a scare when HCFA (now CMS) and some physicians and vendors met to discuss a national policy for reimbursement for multiple ventilators. The national policy never happened, but people were grandfathered in. Also in 1993, the Social Security Act was amended to exclude CPAPs and bilevel devices with a backup rate from the “frequent and substantial servicing” payment category, and they are now (since 2001) reassigned to the “capped

rental” category and called “respiratory assist devices.”

In 2005, the Deficit Reduction Act eliminated the capped rental category, and vent users can now own their bilevels after 13 months. Next came competitive bidding, which often forces the really good mom-and-pop home health care companies who are the experts for NM people out of business. The complaint is that the larger companies are not qualified to provide this equipment. Major efforts have been made to half competitive bidding, and it is hoped that the market pricing program act introduced last year (which has a 5% chance of being enacted) will be the solution.

A major topic of concern for long-time vent users is the phasing out of ventilators and the problems some people have in transitioning to newer ones. In 2012/13, IVUN coordinated a series of presentations/conference calls to assist long-time vent users during the transition.

Throughout the lecture, Headley and Fischer recounted some of the thousands of calls from vent users and their family members received by IVUN over the past 40 years about problems/issues. IVUN has advocated for vent users and developed a wealth of educational resources for vent users, their families and caregivers and medical professionals on a broad range of issues including:

- ◆ The refusal of nursing homes to accept vent users, even those who use noninvasive ventilation.
- ◆ The stigma and fear connected with using a ventilator.
- ◆ The problem of lack of common definitions of vent and vent user.
- ◆ The difficulty of finding a comfortable face mask and the trouble longtime vent users have in finding health professionals with the expertise to set up a mouth intermittent positive pressure system.
- ◆ Difficulty vent users have in dealing with airlines and the lack of consistent requirements and interpretation by airline personnel.

◆ The rise of sleep medicine and the difficulty in getting sleep labs to distinguish between sleep apnea and hypoventilation, the main cause of respiratory insufficiency for people with NM conditions.

◆ Increase in vent use by people with COPD, Obesity Hypoventilation Syndrome.

◆ How to decide if and when to have a tracheotomy.

◆ How to communicate unique needs to medical professionals, particularly when surgery and anesthesia are discussed.

Headley and Fischer urged helping ventilator users survive the system by:

◆ Utilizing IVUN's extensive resources.

◆ Listening to what patients say.

◆ Advocating with and for patients.

◆ Taking a team approach that considers emotional and psychological as well as medical needs. ■

From Around the Network continued from page 3

The built-in high-performance turbine makes it completely independent of compressed air, gas cylinders or compressors.

This saves weight and space and even noninvasively ventilated neonates can be transported over long distances. The combination of a built-in and an optional hot-swappable battery provides a battery operation of more than 9 hours. This can be extended indefinitely with additional hot-swappable batteries.

For details see: www.hamilton-medical.com/products/hamilton-t1.html

*Currently available in EU and EFTA member states and other countries that recognize CE marking. Regarding availability in other markets, contact HAMILTON MEDICAL. Not yet available in the USA.

November is COPD Awareness Month

Chronic Obstructive Pulmonary Disease (COPD), an umbrella term used to describe progressive lung diseases, encompassing emphysema, chronic bronchitis, refractory asthma and severe bronchiectasis, is the only disease in the United States to have increased in frequency over the past three decades – killing women at almost double the rate in some states.

While there is no cure for COPD, the COPD Foundation (www.COPDFoundation.org) aims to promote change and awareness in how individuals with COPD are treated – and ultimately how to save lives. ■

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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Ebola is Scary, But Flu Kills More People

As reports of the Ebola virus dominated the headlines recently, the fact is that only four people in the United States have been diagnosed with it.

On the other hand, influenza is a serious disease that can lead to hospitalization and sometimes death. Even healthy people can get very sick from the flu and spread it to others. Over a period of 31 seasons between 1976 and 2007, estimates of flu-associated deaths in the United States range from a low of about 3,000 to a high of about 49,000 people. During a regular flu season, about 90 percent of deaths occur in people 65 years and older. "Flu season" in the United States can begin as early as October and last as late as May.

An annual seasonal flu vaccine is the best way to reduce the chances that you will get seasonal flu and spread it to others. When more people get vaccinated against the flu, less flu can spread through that community.

Get your flu shot today!



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