

VENTILATOR-ASSISTED LIVING

October 2014

Volume 28

Number 5

www.ventusers.org

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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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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