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IVUN's Ninth Educational Conference Call

My Continuing Medical Education as a Post-Polio Patient/Physician

Bonnie Jo Grieve, MD, interviewed by Joan L. Headley, Executive Director, IVUN

Introduction:

Headley: As some of you know, there is a sense that there is no need to educate about post-polio conditions due to the lack of population – it is small and is getting smaller. However, if you are the one patient of a pulmonologist, his/her education *is* important. It is also a misconception that all polio people who have problems with sleep have obstructive sleep apnea (OSA), which is typically treated with CPAP. Some do.

But many have breathing muscle weakness, which makes it hard to inhale and exhale. New muscle weakness in the back muscles can cause more scoliosis and thus cramped lungs and less air entering the lungs. Both of these situations also make it more difficult to cough, which causes more lung infections that are treated, but the root cause is not acknowledged, and people have recurring infections and treatment when they need breathing assistance. In the later instance, the devices of choice are the bilevels, volume vents and iVAPS – volume assured pressure support. But, people may have other conditions, too – COPD, for example.

For years, we at IVUN have been writing about this topic to provide information to both health professionals and potential users or long-time users. We can make general statements, but ultimately each of us is different and we must seek solutions that work for ourselves. Dr. Grieve did just that, and she talked about her experience, which may help others. A person's late effects of polio or even post-polio syndrome problems are best understood when we know the acute poliomyelitis history.

Dr. Grieve: I contracted polio at age 4 in 1953. At first, I was totally paralyzed and set up in a small iron lung in Queens General Hospital in New York City. A week after admission, I broke out in chicken pox and was put in total isolation for three weeks to keep chicken pox away from the children's wards. I was generally ignored, but they put me on the floor and eventually I could shuffle around and pull myself up. After three weeks, I was taken by ambulance to the New York State Rehabilitation Hospital in West Haverstraw (www.polioplace.org/history/artifacts/haverstraw) and stayed there for several months. I was discharged

with a shoulder harness, back brace and special heavy shoes. I was brought back to Haverstraw every few months for scoliosis checks, but my mother did not want to deal with scoliosis surgery, so she threw away my back brace and never took me to any further appointments. www.polioplace.org/sites/default/files/files/BJ%20Grieve%20FINAL.pdf

Headley: In post-polio circles, physicians/researchers talk about a polio person's "personal best." That is the next benchmark in a post-polio person's history. What was yours?

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Product News

Philips Respironics' latest nasal pillows masks, the **Nuance** and **Nuance Pro**, bring the comfort and sealing power of gel to nasal pillows and offer a choice between fabric or gel frame. Gel padded frame (pictured) and non-slip headgear holds mask in place, reduces need for re-adjustment. The all-fabric frame and headgear provides soft fabric for better sleep and fewer red marks. Additional features include non-slip headgear and lightweight, flexible tubing. The gel pillows provide greater comfort and seal and conform to different size nostrils. www.theanswer.philips.com/nuance

ResMed's newest vented nasal mask is compact with two-point headgear allowing for an open line of sight for reading and viewing screens. The modified dual-wall cushion is ultra-soft and maintains a secure gentle seal. Ball-joint elbow rotates 360 degrees to accommodate various sleeping positions, assisted by the lightweight tubing that stretches. With three main parts, it easy to wear, clean and assemble. The **Swift™ FX Nano** is pictured. The Swift™ FX Nano for Her features stylish headgear and fit range specifically for women. See www.resmed.com/us/products/swift_fx_nano_for_her/swift-fx-nano-for-her.html?nc=patients



Nuance



Swift™ FX Nano

New Web Course on CareFusion LTV Series

CareFusion has announced the release of a new web-based course now available on the CareFusion Learning Portal for customers using the LTV Series ventilators. The LTV Series ventilators were originally launched in 1999, and this course is an interactive self-guided discovery featuring the most recent versions of the ventilator. Participants can choose between a course designed for healthcare professionals and one for non-clinical users. Enrolling in this course requires registration at <https://clp.carefusion.com>, then logging in and entering any part of the course title, CLP1210: LTV Series Ventilator Overview and Setup, into the search bar.

ResMed Acquires Unimedis

ResMed announced that it had acquired Prague-based Unimedis, a distributor of equipment for the treatment of sleep-disordered breathing in the Czech Republic and Slovakia. The company said that the acquisition continues ResMed's emerging market strategy of growing its distribution to bring market-leading sleep-disordered breathing and respiratory care solutions to places where they're needed most. In October, ResMed acquired Warsaw-based Mediserv, now known as ResMed–Poland. ■

Send product news to
info@ventusers.org

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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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Biphasic Cuirass Ventilation and the United Hayek RTX Ventilator

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

IVUN's last educational conference call was conducted in late August. The series of 10 calls was supported by funds from the national office of the March of Dimes (New York). The goal was to expose users of home mechanical ventilation with neuromuscular conditions to the options of devices available to them and to answer questions, specifically related to new problems due to aging and to phasing out of certain ventilators and their maintenance, for example the PLV[®]-100, 102 and 102b.

Gary W. Mefford, RRT, Vice President, Clinical Operations, Hayek Medical Devices, the final guest speaker, explained the functions of the RTX Ventilator, but first he described the complications of respiratory muscle weakness: difficulty breathing and clearing secretions.

Weak muscles impair cough, resulting in poor clearance of airway secretions, and impair chest wall range of motion and lung expansion. Recurrent infections exacerbate muscle weakness. Hypoventilation or underventilation is a key problem.

The Hayek is a ventilator. It is composed of a power unit and a chest shell or cuirass and can effectively treat hypoventilation with support that is non-mask and noninvasive. (It can be used if a trach is present.) It also provides a means of improving chest wall range of motion, pulmonary muscle tone and strength, and lung volume expansion.

The power unit connects via a hose to the cuirass that has a flexible foam seal that creates an air chamber over the chest and abdomen. The unit alternately applies negative and positive pressure to the chest and abdomen through the cuirass to duplicate the two phases of natural breathing – inhalation and exhalation.

The negative pressure causes the lungs to expand producing inhalation; positive pressure in the cuirass assists with exhalation. The device can provide several modes. One is the continuous negative pressure mode that provides negative pressure in the cuirass, which holds the ribs up and the diaphragm

down, so that one breathes from a greater FRC or functional residual capacity – the amount of air left in the lungs after exhalation. This mode is not for everyone because it does not provide support but it does open up the smaller airways, counters atelectasis and improves gas exchange in the lungs.



Continuous negative pressure is typically not the answer for patients with neuromuscular conditions. But, other modes are. Controlled ventilation is when the inspiration and expiration rate and duration are set and controlled by the machine. It is used in acute care to get people off of a ventilator, at night only or for just a few times during the day.

Triggered or respiratory synchronized breathing means that the device senses a user is inhaling and augments the breath, and then helps with expiration by placing

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“I find putting on the BiPAP is very relaxing for either reading or watching TV when tired, or going to sleep. Without it, when I am tired or lying down, it takes effort to breathe; my chest feels like it has a weight on it.”

Dr. Grieve: This was during my college and medical school years, ages 16 to 24, when I was able to keep up with others for most sports, including skiing and backpacking at high altitudes out West. I became solidly competent to go down black diamond runs, but used to stop several times along the way to catch my breath. I did internship and residency, used all my energy to work 80 to 120 hours a week. I emerged from those overworked years significantly short of breath compared to my peers, with diminished strength, so never went out West to ski again. In retrospect, my strength was noticeably diminished by my mid- to late 20s, but I kept lifting small weights to counterbalance the deterioration. At 35, at the end of pregnancy, I was too weak to walk 100 feet, but kept working.

Headley: When did you begin to notice some significant problems? How did you deal with them initially?

Dr. Grieve: In my late 40s, I started getting weeks of bronchitis following every cold, and this worsened with the years. At age 52, I had pneumonia with rusty sputum, the classic sign of pneumococcal pneumonia. At age 60, I did not fit the demographic for the swine flu shot, and a few days into the flu developed pneumonia again. I became aware of awakening at night more often with shortness of breath. At age 61, while working, I had to climb multiple sets of stairs with equipment suitcases and went into atrial fibrillation. Knowing about overnight polio hypoventilation, I went into the ER saying that the atrial fib was probably the result of heart conduction damage from overnight hypoxia from polio/scoliosis hypoventilation. All evaluation supported this, but the doctors refused to get a pulmonary consult and said, “accept that you are aging.” That went on for six months.

Headley: So as a physician you did not find your colleagues up-to-date. How did you deal with that?

Dr. Grieve: I switched doctors, was diagnosed with both restrictive lung disease (from severe kyphoscoliosis) and neuromuscular respiratory failure (from polio weakness). I had an ablation for the atrial fib, and post op, I had much atelectasis, was put on CPAP, but then could not breathe out against the pressure, and no one knew why. After a month of problems, I contacted PHI/IVUN and you gave me links to BiPAP which I then requested. (The pulmonologist told me that if only I started playing the clarinet, I would be totally cured.) She put me on low-span BiPAP, but I kept awakening every night with my heart pounding for the next 12 months.

Contacting IVUN led to your connecting me to internationally recognized polio pulmonologist Dr. Norma Braun, who explained that polio and severe kyphoscoliosis hypoventilation problems required high span BiPAP. So I upped my settings to high span in July 2012 and starting that same night, have been sleeping through the night ever since. Dr. Braun gave me the name of Lisa Wolfe, MD, a pulmonologist in Chicago who is familiar with polio/scoliosis ventilation problems. I saw her in December 2012. She confirmed the high span settings, set me up with a CoughAssist machine, and a stacked-breathing setup.

Headley: Briefly tell us about your setup. What breathing device do you use now? What are your settings?

Dr. Grieve: I use a Philips Respironics BiPAP AVAPS. My settings are PC mode, IPAP 20, EPAP 5, Ti (inspiration time) 1.3 seconds, volume 750, backup rate 16. I find putting on the BiPAP is very relaxing for either reading or watching TV when tired, or going to sleep. Without it, when I am tired or lying down, it takes effort to breathe; my chest feels like it has a weight on it.

I have been concerned that my insurance provider in 2011 supplied me with a much older BiPAP model. So I purchased a new Philips Respironics BiPAP AVAPS as a backup, and I use it without a humidifier in the daytime, when I get tired of breathing, to keep my pulse ox above 95. Around the house, I keep it in a smaller plastic open box along with its tubing and a mask that fits over my TV glasses, so I can easily carry it around from room to room. Without the humidifier, it is only half the size, and it can be carried around without risk of getting water into it and ruining it.

The new ResMed Quattro Air is my favorite mask. It's softer at the edges, much less eye pressure. I use it with a double thickness nasal gel pad. Second favorite mask is the ResMed Mirage Quattro, also with a double thickness nasal gel pad. Backup mask for eye pressure pain or nasal bridge irritation is the Respironics FitLife. It is a very comfortable soft-edged total face mask, even the eyes are inside. But it is noisy. And I have discovered that to keep up my pulse ox, I have to up my volume to 850 with the FitLife mask.

Headley: Earlier you said you had pneumonia many times. Is that still the case?

Dr. Grieve: I have been remarkably healthy since upping the BiPAP AVAPS settings to high span a year ago. Two mild colds resolved quickly with no bronchitis. In January 2013, despite all of us having flu shots, my granddaughter brought home the flu from day care. It was days after receiving the CoughAssist,

so I was using it per protocol. I thought I was staying healthy, but discovered that I developed considerable sputum for several days, so I upped the number of times used. Then it all cleared without an actual illness. Since then, I have had the same experience several more times. Whenever my family brings home a new cold, I noticed that the CoughAssist brings up sputum, so I use it more, and my lungs clear without any illness developing.

Headley: Do you have any other tricks you use to stay well?

Dr. Grieve: On the IVUN educational conference call a few months ago, Dr. John Bach recommended checking pulse ox readings and keeping it above 95. He stated that a dropping pulse ox may signal the start of new problems, such as an infection, heart failure or machine problems. Realizing a low pulse ox – even prior to feeling ill – alerts vent users to use their vents and the CoughAssist.

I bought a pulse ox on my own last year, and have been using it as I go about my day, both off and on BiPAP, to get an idea of what is “normal” for me. My pulse ox without a ventilator varies from 78 to 96 and varies with how hard I'm breathing, what I am doing, whether I am standing, sitting or lying down and how tired I am. It bottoms out sitting and lying down, so that is when I put on the BiPAP AVAPS. When I use BiPAP AVAPS it goes up to 96-98 no matter what I am doing. ■



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The detailed program will be available soon.
Watch www.ventusers.org, *IVUN Membership Memo*
or [IVUN's Facebook page](#).

positive pressure in the cuirass. The breaths are based on (synchronized with) the patient's own natural breathing.

The RTX is more than a ventilator because it can clear airways. The RTX provides high frequency chest wall oscillation that loosens secretions in the lower airways and brings them up and then provides a means of coughing.

When used for airway clearance the Hayek provides two sequential cycles that are set for duration and a number of total cycle repeats.

The first is oscillation. The device cycles negative and positive pressures in and out of the cuirass at high frequencies to provide a thinning effect on the mucus.

The second is the assisted cough caused by the RTX delivering a breath cycle that helps produce a good cough. This series of sequential cycles can be repeated as often as needed.

Mefford pointed out that when many physicians first hear about the biphasic cuirass ventilation they immediately think that it is old news, remembering the machines from the past.

Today, the Hayek RTX can be used in the home and in the various levels of the ICU. It can be used with a range of patients from small babies to people who weigh 350 pounds. In fact, currently more devices are placed in the home than in the hospital. The majority of patients who use it at home have a neuromuscular

condition such as post-polio syndrome, amyotrophic lateral sclerosis or muscular dystrophy. Finessing the settings can take some time, but once the RTX is set up, the system is relatively easy for vent users and caregivers to manage.

During his presentation, Mefford clarified that the Hayek RTX is manufactured by United Hayek, London, England, and

is distributed in the US by Hayek Medical Devices (Philadelphia, San Diego). A sister company, Personal Support Medical Supplies, supplies the device in the home.

Mefford's PowerPoint presentation can be viewed at www.ventusers.org/edu/Call-Hayektakealook.pdf



For more information, contact him at gary.mefford@hayekmedical.com or 855-243-8228.

Q & A:

Q: Has anyone put this device on a wheelchair?

A: It is possible but the current design does not have a battery backup, so to be mobile, one would need a power source.

Q: Is it possible to use the RTX 24 hours a day?

A: Yes, but with this qualification: There will be times, such as bathing and transfers when the cuirass will be off and there needs to be a predetermined strategy, such as nasal BiPAP or bag and mask. ■

MORE on www.ventusers.org

Presentations from all Educational Conference Calls are posted at www.ventusers.org/edu/confcalls.html#pas

Fourteenth Pfrommer Award Presented

Suhail Raoof, MBBS, FCCP, (left) past president of the American College of Chest Physicians (2012), presented the Margaret Pfrommer Memorial Award in Long-term Mechanical Ventilation to Roger Goldstein, MBChB, FCCP, Professor of Medicine and Physical Therapy, University of Toronto, and Director Respiratory Medicine and Senior Scientist, West Park Healthcare Centre, Toronto, Canada, at CHEST 2013. The award is given each year at the annual meeting of the American College of Chest Physicians held in October. Dr. Goldstein chose “Ventilator-Assisted Individuals: Integrating Across the Spectrum of Care” as the title of his honorary lecture.

This award, established in 1999 by Dr. Eveline Faure and Dr. Allen I. Goldberg, honors their lifelong colleague and friend, Margaret Pfrommer, a polio survivor and patient advocate. It is awarded to a clinician or ventilator-assisted professional or advocate who has advanced mechanical ventilation and fostered partnerships between physicians and users of home mechanical ventilation. ■



Past Recipients of the Margaret Pfrommer Memorial Awards in Long-Term Mechanical Ventilation

1999 Dominique Robert, MD
2000 Colin Sullivan, BScMed, MB, BS, PhD, FRA PhD, FRACP, FAA
2001 Augusta Alba, MD
2002 Joseph Ramsdell, MD, FCCP
2003 Anita Simonds, MD, FRCP
2004 John Downes, MD, FCCP
2005 Barry Make, MD, FCCP
2006 Allen Goldberg, MD, FCCP
2007 Dudley Childress, MD
2008 Joshua Benditt, MD, FCCP
2009 Nicholas Hill, MD, FCCP
2010 Barbara Rogers
2011 Not awarded.
2012 Norma Braun, MD, FCCP
2013 Roger Goldstein, MD, FCCP

Deadline for Research Proposals: February 3, 2014

International Ventilator Users Network (IVUN), an affiliate of Post-Polio Health International, is accepting proposals for a \$50,000 grant to be awarded by April 15, 2014. The Request for Proposals guidelines and application information is available at www.ventusers.org under the Research section. Changes, in addition to doubling the award, include an option for \$100,000 given over a two-year period.

The request for 2014 funds is generally described “to study the management of neuromuscular respiratory insufficiency and to explore historical, social, psychological and independent living aspects of long-term home mechanical ventilation.” If you have any questions about the process, email Joan L. Headley at info@ventusers.org or call 314-534-0475. ■

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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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