



Sean with his mother.

Fun and Fast

Vent User Starts Powerchair Football Club

Sean Stamp, Auckland, New Zealand, lions.mouth@orcon.net.nz

I have Duchenne muscular dystrophy (DMD), which means that I lack a protein for building muscle called dystrophin. Because of this I had trouble walking because my muscles didn't develop properly, and as I grew, it got harder and harder to walk. I started using a manual wheelchair at age 11, and since age 12, I've used an electric wheelchair.

DMD is a progressive disability, and at 30 years old, I've gradually lost more of the use of my legs and arms but stay active as much as I can through sports.

In 2009 I had some respiratory problems and was put on a bilevel machine (ResMed VPAP™ III) overnight to control carbon dioxide because my breathing is very shallow. As time went by I had to start using it during the day too, because when I get tired, I have trouble breathing. It got to the point where I was only off the VPAP for two hours a day, which pretty much meant I was stuck in the house.

I had a feeding tube put in, as I wasn't eating well, and this helped with my



Sean and his friend, Jenny, play powerchair football.

breathing. A course of steroids also helped my chest muscles, and I was able to be off the VPAP up to about six hours a day.

A friend from Australia showed me his ResMed Elisée™ 150, and I knew it was something that would change my life. I arranged a trial and straight away it meant I could go out again and not have to worry about breathing as the Elisée was there waiting when I needed it. I use CoughAssist at night to keep my airways clear.

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Powerchair Football

A couple of years ago I saw a video of powerchair football and thought it looked like a lot of fun. I just had to have a go somehow. I decided to start a club in Auckland and applied for private funding for the equipment needed to play. The funding came through in February 2012 and in July we played our first game.

I had a great time as did the other players. The game is fun and very fast. I was worn out after the game so turned the Elisée on and had a rest.

From Around the Network

Judith R. Fischer, MSLS, IVUN Information Specialist, info@ventusers.org

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.

Ventilator-Assisted Living December 2012, Vol. 26, No. 6

ISSN 1066-534X

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Special thanks ...
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Product News

BiPAP A40 from Philips Respironics features AVAPS-AE, a new ventilation mode that monitors upper airway resistance to automatically adjust the EPAP, no matter what changes in body position, respiratory mechanics or sleep stages occur. The average volume assured pressure support (AVAPS) mode adjusts the pressure support (up to 40 cm H₂O) to maintain the target volume. It can be used both invasively and noninvasively. Small and lightweight (2.1 kg, 4.6 lbs), the BiPAP A40 also has a detachable external battery that can provide power for up to five hours. Currently, the BiPAP A40 is only available outside the United States. www.healthcare.philips.com/main/homehealth/respiratory_care/bipapa40/default.wpd

SleepWeaver® Élan™ soft cloth nasal mask from Circadiance inflates like a balloon to create a seal – no leaks, pressure points, sore spots or red marks. Hose rotates easily due to double swivel connection. No obstruction to vision. Sizes are regular and large. www.circadiance.com/sleepweaver-elan.php

AMBU®, the company that developed the first self-inflating resuscitator in 1956, is celebrating its 75th birthday. The “Ambu bag” revolutionized emergency medical care. Many vent users rely on Ambu bags to help them breathe during power outages, and for breathing exercises that help expand the lungs. Resuscitation bags are a vital safety accessory for vent users. www.ambuusa.com

Humidification

“**Humidification During Invasive and Noninvasive Mechanical Ventilation: 2012**” is the title of a Clinical Practice Guideline recently released by the American Association for Respiratory Care (AARC). It can be downloaded from www.rcjournal.com/cpgs/pdf/12.05.0782.pdf. Other guidelines from AARC are available: www.rcjournal.com/cpgs/index.cfm.

Illinois Waiver Extended

The Centers for Medicare and Medicaid Services (CMS) has granted Illinois a second 60-day extension of the Medically Fragile Technology Dependent (MFTD) Waiver. This money-saving program provides home- and community-based services to prevent costly institutionalization and permanent hospitalization of children with catastrophic medical conditions and expenses. The extension allows the program to continue as is until January 30, 2013. For full details, go to <http://savemftdwaiver.com>. ▲

Ventilator Users' Report and Manufacturers' Role

Joan L. Headley, Executive Director, International Ventilator Users Network, St. Louis, Missouri, director@post-polio.org

International Ventilator Users Network (IVUN) surveyed users of home mechanical ventilation (HMV) in late 2011. The survey was translated into Spanish, French and Dutch. IVUN also surveyed the manufacturers of portable breathing devices and the airlines regarding their policies pertaining to flying while using a ventilator. A poster was presented at the 13th International Conference on Home Mechanical Ventilation – 4th European Respiratory Care Association Congress in Barcelona in March 2012.

This is the first of a two-part series in which IVUN reports its conclusions and provides advice and links for users of HMV who choose to fly. Part II, "Role of the Airlines, Resources and Reporting Travel Problems," will be published in the February 2013 issue of *Ventilator-Assisted Living*.

The Vent Users' Survey

Who: Thirty-two users of home mechanical ventilation completed IVUN's "Flying While Using a Vent: A Survey of Ventilator Users." Seventeen individuals live in the United States (11 states), six in the Netherlands, three each in Canada and France, two in Spain and one in the United Kingdom.

Twenty-four hour use was reported by 40.6 percent; 59.4 percent use a ventilator only at night; and 34.4 percent use the ventilator for naps.

Flying Needs: Eleven need a vent each time they fly, while 12 can breathe on their own if the flight is less than three hours. Only six reported using oxygen during flight, and they experienced no major problems.

Almost half have never flown using a vent, while only five flew in 2011. Those who don't fly state they have no need to, it is too much hassle and it is expensive. If the hassle were eliminated, 75 percent said they would fly at least four times a year.

The good news is that 72 percent of those who flew have never been denied a flight because they wanted to use their vent.

The five who reported problems flew on five different airlines (American, Air Canada, KLM, Air France and Frontier) between the years of 2001-2010. Three were using an LTV Series, one a Breas 501 and one a PLV-100 in 2010. (The PLV-100 has never been certified for flight, a requirement that began in 2009.) Reasons given to deny the flights were battery not allowed, ventilator too heavy, noisy, so big that another seat needed to be purchased and every reason "in the book." One user reported that the model of LTV "did not have an FAA certificate, so I couldn't use it on take-off and landing, but I did use it during the flight."

More than half reported a positive experience using a vent in flight and contributed the success (in decreasing order of mention) to preplanning, their flying companion or personal attendant, physician input, airline flight attendant, airline gate staff and the manufacturer certification letter. Two attributed it to their own knowledge and positive attitude.

Four of the 21 individuals who carried their vent aboard but did not use it experienced problems. Most were

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due to airline personnel being unfamiliar with the breathing device and “inspecting it by ‘twisting the dials.’”

IVUN also asked those who do not use a vent during flight if they experienced any physical problems while flying. Nine reported none; eight shortness of breath; two had a headache; two reported feeling unsafe; one each reported light-headedness, unusual coughing and the inability to stay alert.

When asked about priorities related to flying with a vent, the group chose “More and more planes have outlets for computers. It should be automatic: if there is an outlet we should be able to use it.”

Vent users expressed concern about the European Union rules that allow airlines to refuse transport justified on the grounds of safety, with “safety” not defined. In 2010, the Flying with Ventilation Working Group was established to address the increasing problems people needing ventilation experience when traveling by plane in Europe.

In response, the European Union Commission, with full support of the EU parliament, released guidelines regarding Regulation (EC) No. 1107/2006 prior to the 2012 London Paralympics. (See http://ec.europa.eu/transport/themes/passengers/air/doc/prm/2012-06-11-swd-2012-171_en.pdf) Although many problems were addressed, the EU did not choose to define the word “safety,” stating that issue should be addressed by the designated airline safety authorities.

Sixty-six percent of those responding to the survey felt that airlines should be required to provide a hook-up for a ventilator on all flights. About an equal number expressed that the airlines could do a much better job

of educating their staff about the various breathing machines that may be carried on or used during flight. Lastly, a few felt more emphasis should be put on proper handling of expensive wheelchairs that are just as important for many ventilator users’ independence.

Surprisingly, in 2011, 19 of the 32 vent users did not know that the ventilators they used needed to be certified before use in flight. Four of the users had copies of their ventilator’s certificate, which they had obtained online or from the manufacturer. Only 10 percent carried documentation about batteries – both internal and external.

Role of the Manufacturers

It is the manufacturer’s responsibility to test and certify their equipment as safe for flying. Below is a summary of their responses. More information and direct links are posted at www.ventusers.org/adv/flymfcltrs.html.

CareFusion confirms that LTV® 800, LTV® 900, LTV® 950, LTV® 1000, LTV® 1100, LTV® 1150, LTV® 1200 and SprintPack Lithium-Ion Power System are all certified to fly. To obtain copies of the certification letters, call Tech Support at 1-800-754-1914, Option 2, and request a copy.

Covidien (Puritan Bennett)– The Puritan Bennett™ 520 and Puritan Bennett™ 560 ventilators meet the requirements. Email Jean Le Roux at Jean.LeRoux@covidien.com to obtain the document if needed. However, these two ventilators are not currently registered in the United States.

Covidien (Newport)– Newport HT50® Ventilator & HT70® Series of ventilators (all models, including HT70®, HT70S® and HT70® Plus) are certified. ▶

Vent User Starts Powerchair Football Club

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(The VPAP Sean uses only has pressure support modes and no internal battery so was not designed for mobile use. He uses it at night with a full face mask. The Elisée has both an internal and external battery, which gives him the freedom and flexibility to leave his home, using “sip” ventilation.)

Now that I have my own Elisée I’ve been able to go back to playing sports and racing remote control cars again. I have recently started sailing too.

The Elisée also has enabled me to go to more family functions as well because with the long battery life of the Elisée, I can go out at night. A highlight was being able to attend my sister’s 21st birthday party. ▲



Sean prepares to set sail.

► Copies are available at <http://newportnmi.com/HT50.asp> and <http://newportnmi.com/HT70.asp>. Click on “Airline Info.”

GE Healthcare/Breas reports that there have been delays in re-testing the Vivo® 50 so certification has not been completed.

Impact Instrumentation’s home vent is the Uni-Vent® Eagle™, Model 754. It is tested to military specification for fixed and rotary airplanes, which is the highest standard.

Philips Respironics states that Trilogy100, Trilogy200, BiPAP AVAPS, BiPAP S/T (c series) are all cleared for flying. A certificate can be downloaded from the product website for each, e.g., <http://trilogy100.respironics.com>. The company’s newest version of CoughAssist T70, soon to be released, also complies with the requirements. The PLV series of ventilators are all discontinued and will not be tested. All BiPAPs that are not “c series” will not be tested, either.

ResMed’s S8s, S9s, VPAPs all have been tested and letters can be downloaded at www.resmed.com/us/patients_and_families/living_with_sleep_apnea/travel.html?nc=patients. Other hints on flying appear on the same page. The letter for the Stellar is located at www.resmed.com/assets/documents/service_support/air_travel_compliance/faa_letter_rtca_do_160g_germany_signed_eng2.pdf

SIARE Engineering International group s.r.l. does not have an official certification for its line of home care ventilators (Falco 101, Falco 202).

Letters for Weinmann’s VENTiLogic LS, VENTiLogic plus, VENTiLogic, VENTiMotion, VENTiMotion 2, BiLevel ST 22 can be found at www.weinmann.de/fileadmin/weinmann/infoservice/reiseversorgung/Manufacturer_declaration_SafetyInFlight_ventilation_EN_0709.pdf.

All of the above manufacturers assured IVUN that all new products released in the future will be tested and certified for flying. ▲

IVUN's 2nd Educational Conference Call

Understanding How New Generation Portable Ventilators Can Lighten Your Load

Joan L. Headley, Executive Director, International Ventilator Users Network, St. Louis, Missouri, director@post-polio.org

Cyndy Miller, RRT, from Covidien Respiratory and Monitoring Solutions, presented information useful to IVUN Members who had requested background information and advice to assist them in switching from their older, soon to be obsolete, devices. Miller's presentation, shared with Members on a conference call on Oct. 24, 2012, can be viewed at www.ventusers.org/edu/ConfCall2012LightenLoad.pdf.

After reviewing the well-known advantages of the older vents (the PLVs and the LPs), she noted some of the disadvantages. The older ventilators are at the end of their life and parts are no longer made, they were not designed to meet current medical device safety standards, they are heavy, they use a lot of power so batteries don't last very long, they offer very limited breath delivery choices and, unless a special speaking valve is used, they enable speech only during inspiration, rather than during exhalation.

The advantages of the newer vents, such as the HT70® Series (Covidien), the LTV® Series (CareFusion), the Trilogy Series (Philips Respironics) and the iVent Series (GE) include (but are not limited to) readily available parts and service, lighter weight (9-16 pounds), greatly improved power efficiency so that batteries run longer, use of lithium-ion batteries that offer a longer useful life, and built in PEEP (positive end-expiratory pressure), which can sometimes lessen or eliminate the need for oxygen and help to keep lungs expanded properly without the damaging effects of large tidal volumes. The newer vents meet new safety standards for medical devices and a couple of them (like the HT70 Series) are rated for transport (testing demonstrates device durability).

Finally, when PEEP is used on the new devices, a vent user may be able to speak during exhalation without a special speaking valve – or the user may choose to use a speaking valve, whichever is most comfortable.

Older method of breath delivery

With older portable ventilators, selection of breath delivery pattern is very limited because the compressed gas generator inside the device is very basic and incapable of more sophisticated movements. Working with limited options, physicians prescribed big long slow breaths, which allowed for speech during inspiration and helped to keep the lungs open. Since many vent users were not spontaneous breathers, and the ventilators offered no other methods for keeping lungs open, the use of these breath patterns that were unlike spontaneous breathing patterns was common practice.

To accommodate the larger tidal volumes without causing the users' carbon dioxide levels to drop too low, it was common for breathing circuit tubing sets to be equipped with a long length of "dead space (re-breathing) tubing" between the exhalation valve and the trach tube. Typically, PEEP was not used because the only method for delivering PEEP was a mechanical valve that attached to the



Covidien's Newport HT50®

exhalation valve. With no servo-controlling* mechanism, the PEEP leaked out and the resulting pressure between breaths was near or at ambient pressure. Miller also made the point that the older style of ventilators has fewer alarms.

Why change?

New technology has allowed manufacturers to make significant changes to portable ventilators. Miller listed a number of reasons for making the change. Newer portable ventilators:

- Are designed to ventilate a wider variety of people (including children);
- Can ventilate sicker people (this is very important since sicker people are now sent home);
- Can offer a breath that is more like a user's natural spontaneous breathing;
- Are lighter (makes them easier for caregivers to manage at home);
- Can run longer on batteries (this allows vent users more freedom);
- May be safer for the lungs of long-term vent users;

(Studies have shown that stretching the lungs from the beginning to the end of the breath (as with big long breaths) can damage lung tissue. It is thought that holding the lungs open between breaths with PEEP and using smaller tidal volumes can keep lungs healthy and cause less damage.)

- Meet today's regulatory requirements for safety and performance.

Newer method of breath delivery

On newer portable ventilators, breath delivery can be done in a variety of ways because the compressed gas generator that produces the flow is microprocessor-controlled and is capable of variable speeds. Consequently, newer portable ventilators can be adjusted to provide a typical breathing pattern, use a smaller (lower stretch) breath size to ventilate and then use PEEP to achieve

desired end-results for lung health. Servo-controlled* PEEP may keep lungs open without using the larger, potentially damaging tidal volumes. Also when PEEP is used in combination with a cuffless or deflated cuff trach tube, the patient may be able to generate expiratory speech without use of a speaking valve. Since the tidal volumes are not artificially big, "dead-space" tubing is not needed to keep carbon dioxide levels from dropping too low. Vent users who transition to smaller tidal volumes must make sure to shorten or eliminate dead-space tubing so that carbon dioxide levels do not rise above acceptable levels.

*Servo is short for **servo-mechanism**, an automatic device that uses error-sensing feedback to correct the performance of a mechanism.

Covidien manufactures two newer models of vents: HT50® and HT70® series. These devices use dual micro-pistons to compress room gas. The micro-pistons move back and forth many times with each breath, moving faster when the flow is higher and moving slower when the flow is slower. The sound changes as the flow increases. These ventilators need no supplemental gas to be connected but 50 psi or low-flow (cylinder, liquid or concentrator) oxygen may be attached if needed by the patient. Unlike turbine devices, the HT50 and HT70 series ventilators deliver room temperature gas. This may be important when using a heated humidifier since the humidifier's humidity output may be compromised by pre-heated gas.

The HT50 and HT70 series ventilators have passed durability transport testing and are cleared for transport. They are intended for use with invasive (endotracheal or trach tube) or non-invasive (mask or mouthpiece) patient interfaces during continuous or non-continuous ventilation.

HT70 Series Ventilators offer the convenience of three default and three programmable ventilation settings presets (day/night, well/sick). The built-in oxygen analyzer with high and low alarms ensures that the caregiver is alerted to changes in oxygen delivery that fall outside the intended range. Compared with direct connect systems, the HT70's Low Flow Oxygen Reservoir conserves oxygen use so that supplies last longer. And batteries last longer because these ventilators draw very low power. The HT70 Series can be powered by AC, by external DC or by the hot swappable (up to) 10-hour built-in battery. The built-in battery and emergency 30-minute backup battery both recharge in just three hours from either AC or external DC power.

The HT70 Plus Ventilator may be set up with an on-airway flow sensor if that is clinically appropriate.

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Do you have suggestions for other topics? If so, please send them to info@ventusers.org.

Upcoming Educational Conference Calls

IVUN's series of hour-long educational sessions via telephone are continuing. The call is free, but reservations are required, and available space will be first-come, first-served. To reserve your place to participate in the call, send an email to info@ventusers.org or call 314-534-0475.

Wednesday, January 23, 2013, at 1:00 pm CST

Tell Me about a Trach Before I Need One with Linda K. Dean, RRT, Educational Consultant and Clinical Specialist, Passy-Muir, Inc.

Third week in February 2013

How Do I Know When I Need a Trach? With professional to be announced. ▲

IVUN's 2nd Educational Conference Call

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Problems when transitioning

In Miller's experience, vent users are bothered most by the change in breathing pattern, new feel of a breath, new sounds, getting flow when not expected or wanted, the use of PEEP, new alarms and new labels/names for buttons on the newer machines.

Three ways to transition

Method 1: Use the new ventilator like the older ventilator, adjust to the new sound and learn how to avoid nuisance alarms.

Method 2: Use the new ventilator like the new ventilator is designed to be used right away.

Method 3: Make the transition gradually and work with your RT and physician to fine-tune ventilation settings as you go.

Many people find it easiest to use Method 3 and make the change at a pace that is comfortable. There are several parameters on a ventilator that can be fine-tuned so that the ventilator feels more comfortable to you. Even very small changes in flow rate, volume, pressure, breath timing or trigger sensitivity can make a world of difference.

It is very important to work with a respiratory therapist and your

pulmonary physician to make small changes until *you* feel comfortable.

Good battery care ensures the longest battery life.

Miller made a point of how important it is to care for batteries in order to ensure that the service replacement interval is maintained. It is best to keep ventilator batteries charged. That means leaving the ventilator plugged in to external power whenever possible, even when not in use. Users should connect the ventilator to external power right after using the batteries, even if the battery is not fully discharged. Then, every three to six months, the user should discharge the battery to the low battery alert level and then enter the time it takes to do so into a log. Batteries should be replaced at the manufacturer's specified interval or sooner if the use time is half or less than the original (new battery) use time from a full charge. Specific information about a particular ventilator's battery care is usually found in the manufacturer's Operation Manual. ▲

Cyndy Miller welcomes your questions via email at Cyndy.Miller@covidien.com.



Covidien's Newport HT70®

Conference Calendar through June 2013

MARCH 19-21	Medtrade Spring. Mandalay Bay Convention Center, Las Vegas, Nevada. www.medtrade.com/medtrade-spring/
MARCH 23-29	Ventilator-Assisted Children's Center (VACC) Camp, Miami, Florida. Contact Bela Florentin, VACC, Miami Children's Hospital, 305-662-8222, bela.florentin@mch.com, www.vaccamp.com.
APRIL 11-13	"A Breath of Fresh Air," Canadian Respiratory Conference. Québec City Convention Centre, Québec City, Québec, Canada. www.lung.ca/crc/home-accueil_e.php
APRIL 11-13	Sleep and Breathing. European Respiratory Society and European Sleep Research Society. Berlin, Germany. www.sleepandbreathing.org
APRIL 26-28	Parent Project Muscular Dystrophy West Coast Connect Meeting. San Diego Marriott Mission Valley, San Diego, California. www.parentprojectmd.org
MAY 9-11	Spring FOCUS on Respiratory Care, Sleep Medicine, and Critical Care Nursing Conference. Gaylord Opryland Hotel, Nashville, Tennessee. www.foocus.com
MAY 17-22	American Thoracic Society Annual International Conference. Philadelphia, Pennsylvania. www.thoracic.org
JUNE 13-16	FSMA Annual Conference. Disneyland Hotel, Anaheim, California. www.fsma.org
JUNE 27-30	Parent Project Muscular Dystrophy Annual Connect Conference. Baltimore, Maryland. www.parentprojectmd.org

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