

Traveling with a Ventilator Can Be an Adventure

Michael Luber, Milwaukee, Wisconsin, msl21@wi.rr.com



Michael Luber and nurses in flight with ventilator.

Michael Luber, 47, was diagnosed with limb-girdle muscular dystrophy at age three, and his brother Scott, 50, at age six. Michael is a clinical psychologist who works part-time for a social service agency in Milwaukee, and Scott is a CPA who serves as administrative director for IndependenceFirst, a non-profit independent living center in Milwaukee. Michael is the father of a one-year old daughter. Accompanied by two nurses, the brothers enjoy traveling and are advocates for the rights of disabled air passengers.

The unpredictable questions have always made traveling with a ventilator an adventure. I have been using the PLV®-100 for 16 years via a tracheotomy while my brother Scott has also been using the PLV®-100 noninvasively for nine years. As frequent travelers, we have come to expect a variety of questions regarding our ventilators and wondered if there would ever come a day where we were not allowed to fly.

We had to cancel our trip to Las Vegas in 2009 because AirTran would not let us use

our ventilators during takeoff and landing, which made it virtually impossible for us to fly with them. So, with our new Trilogy100 ventilators, my brother and I were very excited to be traveling again. Last fall we booked another trip to Las Vegas, this time on Frontier Airlines and, with our FAA-approved ventilators and certification papers, we were prepared for any battle that lay ahead of us.

I wish I could say that the airlines gave us a big hassle, and then we pulled out our certification papers and demanded to be allowed to fly. However, the reality was much less dramatic, as no one even questioned our ventilators.

There were some additional traveling benefits to using the Trilogy which we discovered on this vacation. First, its size and portability make it very easy to transfer on and off the airplane and get the ventilator under the seat in

front of us. (Dimensions are 6.6 inches long by 11.2 inches wide by 9.3 inches high, and weight is 11 pounds.)

In addition, because of its protected electronic panel, we did not have to be concerned about any of the settings being changed as we carried the ventilator on and off the plane and got in and out of cabs, etc. With the PLV, the settings were always being bumped during transfers, and we would have to keep resetting them.

Also, even though we take an extra external gel cell battery, we probably don't have to because the Trilogy has six hours of battery life – three hours of internal battery and three hours of detachable battery – before an external battery would be needed.

Having said all these wonderful things about the new Trilogy, one might ask if there were any negatives about using it. Well, I suppose everything has some downsides. These were very minor and were overcome fairly easily.

continued, page 3

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
February 2011, Vol. 25, No. 1

ISSN 1066-534X

Inside this issue

Traveling with a Ventilator Can Be an Adventure p. 1

From Around the Network p. 2

Ask The Experts p. 4

VACC Camp is "Paradise" for Kids p. 6

Meet Our Supporters p. 8

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From Around the Network

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

New Products

Quattro™FX is ResMed's latest full face mask model. The mask's contoured headgear design and flexible frame insures a good seal. The fitting process and sizing tool simplifies the initial mask adjustment. Available in three sizes. www.resmed.com



Puritan Bennett™ 520 is new from Covidien, designed for partial use during the day or night. An automatic flow trigger eases the work of breathing, and the unit's automatic valve detection reduces the risk of inappropriate setting selection. Lightweight (4.5 kg, 9.9 lbs.) and compact, the unit has an internal Li-ion battery that lasts up to five hours. Insight software can provide up to 12 months of user data easily downloaded to the clinician's computer. Available only in Europe. www.covidien.com



Flight 60® is a new lightweight and compact ventilator manufactured by Flight Medical in Israel. Suitable for use with children (over 10 kg, 22 lbs.), Flight 60 offers a range of modes, a touch-screen monitor and data downloads. It has an internal battery that can provide up to 12 hours of use, as well as the "hot swap" battery capability. It has received both the CE mark and FDA approval. www.flight-medical.com
Flight 60 is available in the western USA through SRC Medical in Northridge, California, www.src-medical.com, and in the eastern USA through Martab Medical, Mahwah, New Jersey, www.martab.com.



Respiratory Therapy Model

"Optimizing Respiratory Therapy Services: A continuum from hospital to home" is the 110-page final report from the College of Respiratory Therapists of Ontario, Canada. The report details a respiratory therapy model that was developed for use in transitioning patients with complex respiratory needs from critical care into the community. Thirty patients were successfully moved back into their communities. A training manual on CD-ROM is also available. www.crto.on.ca/pdf/ProfPractice/HFO_Final_Report.pdf

ALS, MND, and DMD

"Respiratory Care Update," a presentation by Lisa Wolfe, MD, FCCP, at the 2010 ALS/MND Nursing Mini-Symposium in December in Orlando, is now available online. Dr. Wolfe is in the department of Pulmonary and Critical Care, Northwestern University, Chicago, Illinois. She discusses diaphragm muscle strength, airway clearance, ▶

Traveling with a Ventilator Can Be an Adventure

continued from page 1

I thought that the alarm was not quite loud enough in certain settings, such as a concert or loud casino. After getting home from vacation, I got another Trilogy for my bedside and noticed that this alarm was noticeably louder than the Trilogy on my chair. I am not sure what accounts for the discrepancy, but in the future I will just use the bedside unit on my chair.

Since I use a Passy-Muir speaking valve during the day but not at night, I noticed a difference in the trigger sensitivity when I was not using the Passy-Muir. Therefore, I had to adjust settings at night which was easy enough to do, since there is a dual setting on the Trilogy, and it's very easy to switch back and forth between two different settings, called Primary and Secondary.

Lastly, the exhalation valves for the new Trilogy are a bit noisier than the old ventilators. However, the Trilogy itself is quieter, so it is basically a tradeoff: the puff of air that comes



Luber's Trilogy100 ventilator fits under the airline seat.

<http://trilogy100.respirionics.com>

out of the exhalation valves for the Trilogy versus the noise that comes from the back of the PLV.

All in all, the benefits of the new Trilogy far outweigh the few cons. The biggest benefit for me is a consistency in performance, specifically with the trigger sensitivity. Since I have my sensitivity set very low because it is difficult for me to initiate a breath, my old PLV was always auto-cycling at random times throughout the day. With the Trilogy, I have not experienced any of this auto-cycling, and it is very easily triggered.

I am happy to report all thumbs up with the new Trilogy100. For those who travel a great deal, it is definitely the ventilator of choice in my book. ▲

See "Airlines Give Disabled Passengers the Boot," www.tradingmarkets.com/news/stock-alert/dalw_airline-gives-disabled-passenger-the-boot-1467867.html

noninvasive ventilation and masks, oxygen therapy, travel, tracheostomy invasive ventilation and ethics of discontinuation of ventilation. Go to <https://alsa.webex.com/alsa/lsr.php?AT=pb&SP=MC&rID=61334572&rKey=dfd07a2b41b0fd31>. The annual ALS/MND Nursing Symposium sponsored by the Les Turner ALS Foundation is scheduled for October 21-23, 2011, in Chicago. For information, email meetings@lesturnerals.org.

Surveys

The Muscular Dystrophy Association is soliciting feedback from patients and families who use its network of 200 neuromuscular specialty clinics across the United States and in Puerto Rico. MDA wants to hear more about local MDA clinics and clinic visits – both praise and/or suggestions about how

the clinics might be improved. To participate in the survey, go to www.mda.org/clinics/ and click on the box that reads "Tell us about your MDA clinic."

Competitive Bidding's Round One has been completed. The American Association for Homecare is surveying physicians, HME providers, case managers and discharge planners and Medicare beneficiaries about complaints and problems encountered in Round One's competitive bidding process. To access the survey forms, go to www.aahomecare.org and click on "Problems with Competitive Bidding."

Round Two, which will target different metropolitan areas, is expected to begin in the summer of 2011. www.cms.gov/DMEPOSCompetitiveBid/01A1_Announcements_and_Communications.asp ▲

Ask The Experts

QUESTION: When is a sleep study necessary in people with neuromuscular disorders (NMD) in order to diagnose breathing problems? Are the screening devices such as ApneaLink™, for example, useful in diagnosing sleep apnea?

ANSWER: Barbara Phillips, MD, MSPH, FCCP, Professor, Division of Pulmonary, Critical Care and Sleep Medicine, and Director, Good Samaritan Sleep Center, University of Kentucky College of Medicine, Lexington, Kentucky

Screening studies such as ApneaLink and others are very good at ruling IN people with obstructive sleep apnea. However, hypoventilation and central sleep apnea, which are frequently seen in people with neuromuscular disorders are NOT well identified by portable or home sleep studies. Portable oximetry (simply measuring the oxygen level with a skin clip at night) can help screen and identify a person who is having significant drops in oxygen at night, but this may be a late sign. A person who has a neuromuscular disorder should consult with a respiratory sleep specialist (usually a pulmonologist who is board-certified in sleep) if he/she has shortness of breath at rest or with trivial exercise, if he/she wakes up gasping for breath, light-headed, with a racing heart or a headache. Sometimes simple pulmonary function testing can give us an idea about when more extensive testing, such as a sleep study, will be necessary.

ANSWER: Lisa Wolfe, MD, FCCP, Assistant Professor, Division of Pulmonary & Critical Care, Northwestern University Feinberg School of Medicine, Chicago, Illinois

NMD patients will most commonly develop nocturnal hypoventilation and REM-associated central sleep apnea and, less commonly, obstructive apnea. These ventilatory issues disrupt sleep quality, decrease oxygen saturation (SaO₂) in the blood and elevate carbon dioxide (PaCO₂) in the blood. The symptoms (see sidebar) are gradual, and waiting for all the symptoms to manifest is not recommended, because then the patient can be in respiratory failure. Reduction in lung function **or** low oxygen saturation **or** elevated carbon dioxide is sufficient to qualify an NMD patient to start ventilatory support.

Guidelines from Medicare do not require a sleep study in order for a physician to prescribe a ventilator. In some cases, polysomnography is still recommended for diagnostic purposes, but most sleep labs have no protocols for the treatment of those with NMD.¹ Recently the American Academy of Sleep Medicine has released standards for the care of those with hypoventilation. If an NMD patient is referred for a study, they should confirm that the lab is aware of the new standards and is prepared to follow the guidelines.²

Many devices are now available to facilitate home testing for obstructive sleep apnea, and although they are very accurate for both screening and diagnosis, these devices have not been tested in and are not indicated for those with NMD. This does not mean they have no role in NMD. If oxygen saturation is 88 percent or less for more than 5 minutes during the recording, this would suggest that hypoventilation is present, and ventilatory support should be initiated.

It is important to remember that home apnea testing is not meant to replace pulmonary function testing as the primary screening tool in NMD. ▲



SLEEP AND BREATHING TERMS

OSA or obstructive sleep apnea occurs when a person stops breathing periodically during sleep because muscles in the throat collapse and block the airway.

CSA or central sleep apnea occurs periodically when the brain fails to send the appropriate signals to initiate breathing. There is neither air flow or chest wall movement.

Mixed apnea is a combination of OSA and CSA.

Apneas are repeated episodes during sleep when breathing ceases for at least 10 seconds. More than 10 apnea episodes per hour indicate a need for further evaluation and treatment. **Hypopneas** are repeated episodes during sleep when air flow in and out of the lungs occurs, but is reduced. The apnea-hypopnea index (**AHI**) counts the number of apneas and hypopneas that occur per hour of sleep and is useful in quantifying the severity of sleep apnea.

Polysomnography is the study of an individual's sleep cycles and stages with a device that records information such as air flow, brain activity, blood oxygen levels, body position, breathing efforts and eye movement.

Hypoventilation or underventilation typically begins during sleep as the level of oxygen in the blood decreases and is offset by an increase in the level of carbon dioxide. This is due to the inability of weak inspiratory muscles (the muscles of breathing in) to allow the individual to take a deep breath. Signs and symptoms include: fatigue, shortness of breath, morning or continuous headaches, daytime drowsiness and falling asleep frequently, sleep awakenings with shortness of breath or heart racing, difficulty swallowing, poor concentration and impaired cognition, frequent nightmares, frequent arousals from sleep to urinate and heart failure, such as cor pulmonale, due to breathing problems.³

Are you a ventilator user or health professional with a question about home mechanical ventilation?

Send it to info@ventusers.org, and IVUN will find experts to answer it.

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1. Finder JD, Birnkrant D, Carl J, Farber HJ, Gozal D, Iannaccone ST, Kovesi T, Kravitz RM, Panitch H, Schramm C, Schroth M, Sharma G, Sievers L, Silvestri JM, Sterni L. Respiratory care of the patient with Duchenne muscular dystrophy: ATS consensus statement. *Am J Respir Crit Care Med* 2004; 170(4):456-65
2. Best Clinical Practices for the Sleep Center Adjustment of Noninvasive Positive Pressure Ventilation (NPPV) in Stable Chronic Alveolar Hypoventilation Syndromes. *J Clin Sleep Med* 2010; 6(5):491-509
3. Bach JR. *Guide to the Evaluation and Management of Neuromuscular Disease*. Philadelphia: Hanley & Belfus, Inc, ©1999.

VACC CAMP IS “PARADISE” FOR KIDS WITH VENTILATORS

“It’s a week where he gets to feel special – treated like royalty,” said Mario Ortegon about his son Elliot’s experience at the Miami Children’s Hospital Ventilation Assisted Children’s Center (VACC Camp).



Elliot “Spiderman” Ortegon at VACC Camp.

Elliot has attended the week-long camp every year for the last seven years. Now 19 years old, he was diagnosed with transverse myelitis, a neurological disorder caused by inflammation of the spinal cord, two months before his 11th birthday. It left him paralyzed from the tongue down and ventilator-assisted through a trach.

“He is nonverbal, so it gives him happiness to go and interact with people,” said Ortegon. “He totally enjoys it.”

VACC camp is a free, week-long, community-based camp program providing

recreation and social support for families with children who need to use oxygen and/or ventilators long term.

And a full week it is. Campers and their families are kept busy with activities including music and shows, pizza and pajama parties, movies, a Hawaiian luau, a day at the beach, boat rides, bowling, art and games, to name a few. A volunteer staff of nurses and respiratory therapists and local teenagers are on hand to provide parents and families with some leisure time.



2011 Camps for Ventilator-Assisted Kids

March 12-18. 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.

May 29-June 5. Camp Pelican, Lion’s Camp, Leesville, Louisiana. Contact Cathy Allain, 985-764-0343, cathyallain@cox.net, www.camppelican.org.

June 1-5. Light the Way Camp, Children’s Harbor, Alex City, Alabama. Contact Kara Bishop, 205-370-9605, karabishop@ventkidsofalabama.com, www.ventkidsofalabama.com.

June 5-10. Trail’s Edge Camp, Camp Fowler, Mayville, Michigan. Contact Mary Buschell, RRT, Camp Director, 231-228-3371, mkbuschell@yahoo.com, www.med.umich.edu/mott/trailsedge/index.html.

June 8-12. Camp Inspiration, Double H Hole in the Woods Ranch, Lake Luzerne, New York. Contact Tara Bogucki, Admissions Coordinator, 518-696-5676, ext. 222, theranch@doublehranch.org, www.doublehranch.org. *Admissions deadline: April 15 (later admissions accepted if there are vacancies).*

June 12-17. Fresh Air Camp, Camp Cheerful, Strongsville, Ohio. Contact Kathy Whitford, MSN, RNP, Cleveland Clinic Foundation, 216-721-7159, whitfok@ccf.org, www.freshaircamp.org.

June 19-23. CHAMP Camp, Bradford Woods, Indianapolis, Indiana. Contact Jamie Mitchell, 317-679-1860, admin@champcamp.org, www.champcamp.org.

June 26-30. PA Vent Camp, Camp Victory, Millville, Pennsylvania. Contact Robin Kingston, MSN, CRNP, 717-531-5337, rkingston@hmc.psu.edu.



Elliot relaxes at the beach with camp volunteers.

“Camp is an extraordinary experience for everyone involved – the staff, the campers and their families, and all the volunteers, adults and teens. Your life perspective changes after experiencing VACC Camp for the first time. I know that through camp we all make a difference in every camper’s life and that of their families too. You just have to see the smiles on the children’s faces to understand,” said Bela Florentin, VACC Camp Program Coordinator.

“That week at camp is paradise for Elliot,” said his father. ▲

CONFERENCE CALENDAR 2011

March 24-26. FOCUS on Respiratory Care and Sleep Medicine Annual Conference. The Town and Country Resort, San Diego, California. www.foocus.com

April 28–30. “A Breath of Fresh Air” Canadian Respiratory Conference. Sheraton on the Falls Hotel & Conference Centre, Niagara Falls, Ontario, Canada. www.lung.ca/cts

May 13-18. American Thoracic Society International Conference. Denver, Colorado. www.thoracic.org

June 23-26. FSMA Family and Professionals Annual Conference. Walt Disney World Swan and Dolphin Resort, Orlando, Florida. www.fsma.org

June 29–July 2. CCHS Family Conference, San Diego, California. www.cchsnetwork.org

July 6-10. Parent Project Muscular Dystrophy Annual Conference. Baltimore, Maryland. www.parentprojectmd.org

August 31 – September 2. “Post-Polio Syndrome – A Challenge of Today.” Copenhagen, Denmark. The Danish Society of Polio and Accident Victims, and European Polio Union. www.poliocconference.com

September 24-28. European Respiratory Society Annual Congress, Amsterdam, Netherlands. www.ersnet.org

October 22-27. CHEST, American College of Chest Physicians Annual Conference. Honolulu, Hawaii. www.chestnet.org

November 5-8. AARC International Respiratory Congress. Tampa, Florida. www.aarc.org

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