

Traveling with a Ventilator Can Be an Adventure

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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

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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 ▲