

My Ventilator and I: Traveling Buddies

Marie B. Latta, M.Ed., Atlanta, Georgia, latta@mindspring.com



Marie and Winnie the Pooh.

Two weeks with grandchildren, Mickey Mouse and Winnie the Pooh. What more could a grandparent ask? I thought the dream was out of reach.

I previously turned down opportunities to travel on the basis of the logistics, but my daughter-in-law finally enticed me to celebrate Christmas with them. In 2008, I was with my son and family getting on a Disney Cruise Line® ship, and when December 2009 rolled around, I was with them again. We also spent time at Walt Disney World® Resort in Orlando, Florida.

My experiences were “magical,” even when traveling with my “mechanical toys.” I carried a ventilator on my lap making room for my twin tubes – the tracheostomy and feeding tubes.

Disney has built accessibility into its planning and daily operations. The staff is prepared for people with all types of conditions and makes you feel happy and special, but never patronized or like an afterthought.

The accessible ground transportation was important to me. My daughter-in-law preplanned and reserved several themed dinners, such as a Polynesian Luau, all over the park. I could go everywhere on the accessible sidewalks and ride the monorail, the boat ferry and the busses. The rides with boats had an accessible boat onto which I could drive my wheelchair.

There was even room for my family to ride with me. Being able to participate with my family in all of the

activities captivated me. (The rides which require a transfer out of your wheelchair are identified.)

Boarding the “Disney Magic” cruise ship is barrier free. Once onboard, your room host will take care of your room and you for the duration of the trip. Cleanliness and safety are ship-wide priorities. Each time you enter a restaurant, they hand you a wipe to clean your hands, and the ship is washed down every night.

The ship’s medical center includes a physician. I did not make it a point to meet the doctor, but in hindsight should have just so he would know my situation. Before the ship sets sail, there is a mandatory fire/emergency drill, so you will know where to go in an emergency.

Mealtime is such a pleasant experience even though I eat totally through my feeding tube using a medically prescribed formula and don’t taste one bite of food. I think that fellowship is as important as food, so I don’t let the tube inhibit me from enjoying life.

You are assigned different restaurants for each evening meal, but the serving staff moves with you. They immediately learn your name and your preferences. For example, when they learned I had the feeding tube and

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

April 2010, Vol. 24, No. 2

ISSN 1066-534X

Inside this issue

My Ventilator and I:

Traveling Buddiesp. 1

Calendar p. 2

Successfully Flying (One Way)
While Using a Ventilatorp. 4

From Vent to Diaphragmatic
Pacing System: Part I p. 5

From Around the
Networkp. 6

Ask the Expertsp. 7

Meet Our Supportersp. 8

Editor: Joan L. Headley, MS
editor@post-polio.org

Designer: Sheryl R. Rudy
webmaster@ventusers.org

Special thanks ...

Judith R. Fischer, MSLS

©2010 Post-Polio Health International (PHI).

Permission to reprint must be obtained from
Post-Polio Health International (PHI).

To be sure you receive email updates from PHI and IVUN, set your spam filters to allow messages from info@post-polio.org and info@ventusers.org.

The Research Fund

IVUN received six Phase 1 applications for its next award to be given in late 2010. The submissions, from Brazil, Israel, United States and Sweden, will be reviewed by an expert panel, which includes ventilator users, to determine which applicants will be asked to submit Phase 2 requirements. The money invested in the fund is on the rebound with a current value of \$550,000.

Manufacturer Letters as Stopgap

Carefusion, ResMed and Philips Respironics have distributed official letters documenting that their devices have been certified for use during flight. Copies of the letters are posted in the Advocacy Section of www.ventusers.org. Check the list because not all of the breathing machines by these companies have been tested. Covidien reports that the Puritan Bennett 540™ has been tested and a letter is expected soon. The letters are a stopgap until the Federal Aviation Agency issues guidelines for labeling devices, i.e. the content of the "sticker."

Calendar

MAY 13-15. FOCUS on Respiratory Care and Sleep Medicine, 10TH Annual Conference. Disney's Coronado Springs Resort, Orlando, Florida. www.foocus.com

MAY 14-19. American Thoracic Society International Conference. New Orleans, Louisiana. www.thoracic.org

JUNE 24-27. FSMA Family and Professionals Annual Conference. Santa Clara Marriott, Santa Clara, California. www.fsma.org

JUNE 24-27. Parent Project Muscular Dystrophy Annual Conference. Denver, Colorado. www.parentprojectmd.org

FYI: Presentations from the February 26-27, 2010, Sydney Conference coordinated by the Duchenne Foundation, a national non-profit specifically for Australian families affected by Duchenne muscular dystrophy, are available online at www.parentproject.org.au/html/s01_home/home.asp ▲

MORE on www.ventusers.org

A complete list of the
2010 Camps for
Ventilator-Assisted Kids

[www.ventusers.org/net/
calendar.html#camp](http://www.ventusers.org/net/calendar.html#camp)

My Ventilator and I: Traveling Buddies

continued from page 1

needed warm water to flush the tube, they always brought hot water in a Styrofoam cup. It was easier to pour from than the formal cups.

Here are some hints to assist the "magic."

Plan ahead. Any trip takes preparation, but for me, preparation reaches a new level. By shipping supplies ahead to Disney's warehouse in Port Canaveral, Florida, and carefully marking them, my feeding tube formula and supplies were in my stateroom when I arrived. I also shipped formula and a suction pump to the resort.

Don't leave anything to chance. On one trip, the formula was not in my room. The person in guest services said since it was late, they would check on it in the morning. I told her it was an immediate need and why, and the formula was located and delivered within fifteen minutes.

Have your own travel agent. The ideal is to use an independent agent – one which does not charge you but is paid by Disney for the business (not a Disney agent). I use an exceptional problem-solver team from the Fort Worth area, JoAn & Clif Hale, Anthaume Group; 817-448-9404; selah50@sbcglobal.net.

Take advantage of Disney-related services.

Complete forms online. Disney has a number of required forms to be filled out and deadlines to be followed. Having them completed online makes boarding much smoother. For example, <http://disneycruise.disney.go.com/faqs/site-help/my-online-check-in/medical-info-form/> is the link to a form that allows your physician to report any current medical condition(s) and medications and arrange for wheelchair access and/or lift, oxygen

More about Marie ...

Marie Latta is a survivor of bulbar polio she contracted during the 1949 epidemic when she was 8 years old. After a career in special education, she began an ADA (Americans with Disabilities Act) consulting business in 1992.

In 1993, she began using a wheelchair because her breathing no longer supported her walking. In 1994, she added a bilevel device, which she used until 2006, when she had a tracheostomy and feeding tube placed on Mother's Day afternoon. The permanent trach and the feeding tube have both been life changing, and she is stronger because of them. At that time, she was not using a ventilator, but was using a Passy-Muir speaking valve.

In April 2009 after attending the ventilator sessions at Post-Polio Health International's 10th International Conference in Warm Springs, Georgia, she added the LTV® 950 ventilator to her cache of mechanical toys.

Marie has lived alone since the death of her husband from a heart attack in May 1999. In a future issue, she will describe how she manages her tube and trach care and continues her consulting work part-time.

and/or special dietary needs. The form must be received at least 14 days prior to sail date.

I was relieved to know that the ship had four large diesels that power the engines and all the other electrical systems on the ship. If one fails, they can switch the load to another.

Purchase a transportation package.

When you check your luggage at your home airport, it will be tagged for your destination. I checked my luggage in Atlanta, and the next time I saw it was in my room at Disney's Contemporary Bay Lake Resort. The fee of \$69 was worth it not to go through baggage claims and lug baggage around.

Purchase travel insurance. I paid \$199.00 for insurance to cover emergencies, such as onboard illness or medical evacuation. Without insurance, an unexpected event would cost far more than "an arm and a leg."

Airport Security. I flew from Atlanta to Orlando, Florida, to meet my son and his family. I had not flown in ten years, but, at least for me, going through security has greatly improved. I carry my LTV®950 in my lap and it always triggers a search when going through the screening device. The security personnel always drag it out

continued, page 6

Successfully Flying (One Way) While Using a Vent

Lawrence C. Becker, Roanoke, Virginia, lbecker@hollins.edu

I have used mechanical ventilation for sleep and rest since 1952 and a BiPAP machine since 1994. Long periods at altitudes above 5,000 feet have always been difficult, and long ago I gave up vacations in the Rockies. This problem has increased as I age, and I have come to dread airline travel with flights that last for more than four hours, because a good deal of that time will be in air pressurized at the equivalent of between 8,000 and 10,000 feet.

I recently needed to fly from Washington, DC, to San Francisco and back. Some people in my circumstances apparently use oxygen, but I have been advised by pulmonologists several times that using my BiPAP would be a better solution, because what I need is an easier way to take deeper breaths during flight, rather than pure oxygen.

Initially, I thought the best alternative would be a compact ventilator with its own internal, long-life battery, such as the Puritan Bennett 540™. So I attempted to rent one. Unfortunately, the machine had not been approved for flying by mid-March, when I needed to make a decision. (I still think this is the best solution for me.)

The alternative was to use my bilevel on DC power, with a power connection supplied by United Airlines. The plane was a Boeing 777, and I was booked in the Economy Plus section. Through reservations, I connected with their aeromedical desk and found that my BiPAP was on their approved list. The only information they asked for was the model number.

In due course, United Airlines approved my request to use my BiPAP during flight and said that the ground crew would run a power cord directly to my seat. All I needed to supply was the proper connector – an automobile cigarette lighter connector. In this case, it was the “DC Power Adapter Kit” made by Philips Respironics, purchased for \$200 through my supplier.

On the way to San Francisco, everything worked very smoothly. The power cord was available when I boarded the plane, and I used my BiPAP for the middle three hours of the more than five-hour flight. The Economy Plus seats on the wide-body plane were comfortable, and I arrived rested.

The only glitch was that the flight crew didn't know what the power cord was for, and the installation looked a little formidable. It included what looked like a full-sized car battery on the floor beside my seat, taped firmly to the wall. My attendant and I were obviously as apprehensive about this as was the flight crew. But as soon as things were explained, and we knew the set-up worked, everyone relaxed.

Coming back from San Francisco was a different matter. The first leg was from San Francisco to Chicago on a 757. As it turned out, the crew couldn't run a power connection to the economy section on the smaller plane, and they couldn't upgrade me to first class, because the plane was full. It didn't matter much because the flying time to Chicago was only three hours and 15 minutes.

The moral is that having your own power supply built into a compact ventilator definitely has the advantage of not requiring special services from the airline, which can be a hassle even with the best preparation and the best intentions of everyone. Another plus is that you can travel on every kind of aircraft in any section of the aircraft. ▲

From Vent to Diaphragmatic Pacing System: Part I

Bill Miller, Leesburg, Florida, MaxNWM@aol.com

I am paralyzed from the neck down and use a ventilator due to a high-level (C1-2) spinal cord injury that I incurred in August 1997. I had heard about diaphragmatic pacing systems as an alternative to ventilators and learned of the NeuRx Diaphragm Pacing System (DPS)™ several years ago, but I didn't think this method of ventilation could do much to improve my quality of life and might even decrease it. But I decided to consider the benefits and drawbacks of the DPS to determine whether it might work for me.

The biggest benefit would be growing comfortable enough with the DPS to remove the ventilator and vent tray from my wheelchair. I would like to get a chair that can stand me up which would provide weight-bearing for my bones and let me view the world from my natural height. I also have speaking engagements and plan to teach at the community college level upon completing my Master's degree. Wouldn't it be cool for a quadriplegic to be able to stand up when speaking?

Not having a ventilator on my wheelchair would also enable me to maneuver in tight spaces more easily. And I could drive my wheelchair while standing – I'd love to roll upright across the stage when I graduate.

Another benefit of the DPS is improved speech quality in bed, because it would be like using a Passy-Muir speaking valve all the time. I don't currently use a speaking valve in bed because the valve tends to dry out my airway; I re-humidify my airway while I'm in bed.

The DPS should allow me to either cap my trach or use a small speaking valve, either of which would make getting dressed a bit easier and wearing certain clothes MUCH easier. Now, the vent circuit attached to my trach makes wearing a tie quite difficult. Also, I could wear a turtleneck or mock-turtleneck, which I cannot do currently, and they could hide my trach altogether. (I'm not self-conscious

about my trach or general appearance, but that would obscure a sign of my disability, which is good because I try to not let my disability define what I can do.) Some DPS 24/7 users have had their trachs removed entirely.

DPS users report that senses of taste and smell both improve, though I cannot imagine certain foods tasting any better than they do now. I can smell fairly well when I actively try to take air in through my nose, and selective smelling can be a good thing! These improvements would be of minimal benefit to me.

For me, the main drawback about the DPS is that it doesn't allow the user to initiate breaths. My voice is my primary link to the world; the better my speech, the better my quality of life. Using a Passy-Muir speaking valve, I have almost continuous speech while receiving 13 breaths per minute (BPM) at a volume of 900 cc (just less than half of a 2-liter soda bottle).

However, sometimes I run out of air to speak with before I finish my thought and have learned to use my neck muscles to initiate a breath. That shortens the pause in between scheduled breaths so I can continue speaking. A simple fix with the DPS is to increase the breath rate to 14-15 BPM which should work during the day when I'm speaking but can be lowered for sleeping.

continued, page 7



Bill Miller

C1-2 Quadriplegic with a 221 High Bowling Game

Co-founder of Manufacturing Genuine Thrills Inc. d/b/a MGT

My blog:
<http://powerwheelchairusers.blogspot.com>

Business website:
www.ikanbowler.com

Personal website:
www.lookmomnohands.net

From Around the Network

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

Quality Control for Ventilators

Royal Brompton Hospital's Sleep and Ventilation Unit provides a respiratory support telephone hotline for home vent users to call. The unit followed 1,211 adults and children (using noninvasive ventilation primarily). Dr. Mark Chatwin and his team did an analysis of the phone calls between January and June 2006. They found that vent users had technical problems with the ventilators, some of which could be easily solved in the home or which required replacement or new parts. When no mechanical fault was found, the vent users were found to be unwell and/or needed hospitalization. The team also identified characteristics of vent breakdown: vents used for more than 16 hours per day; vents older than 8 years; and vents new on the market.

An accompanying editorial by Drs. Delguste and Rodenstein called for a quality control system for ventilators in Europe.

References

Chatwin M, Heather S, Hanak A, et al. Analysis of home support ventilator malfunction in 1,211 ventilator-dependent patients. *Eur Respir J* 2010; 35:310-316. M.chatwin@rbht.nhs.uk

Delgado P, Rodenstein, D. Home ventilation: Need a user support number? Editorial in *Eur Respir J* 2010; 35:243-244. rodenstein@pneu.ucl.ac.be

Medicare Rights Center

The Medicare Rights Center, with offices in Washington, DC, and New York City, is a national, nonprofit consumer service organization working to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives. Trained hotline counselors can respond to questions about available health plan options, rights and benefits, and appeals after Medicare denials. If you have Medicare questions, call 800-333-4114 (Spanish-speaking counselors available.) www.medicarerights.org ▲

My Ventilator and I: Traveling Buddies

continued from page 3

of its bag, but I am ready to explain what it is, and now carry a copy of a letter from CareFusion, the company that purchased the maker of my ventilator, stating that my vent is in full compliance of RTCA/DO -160 F Section 21, Category s, Section 21, Category M and can be used during flight. (See IVUN's website – www.ventusers.org.)

Don't stay home! On the last cruise, I spoke with a woman whose family

was on a celebratory trip for Grandma, who used a wheelchair and oxygen. The only thing missing was Grandma. She was afraid she couldn't get around, so she stayed home.

What of my dream? I went to a fantasy world to find an accessible reality, a place where I could go with all my mechanical toys, breathe easily and play with my grandchildren! ▲

Ask The Experts

QUESTION: “I read about new ventilators in *Ventilator-Assisted Living* and would like to get one. I spoke with my current home health care company for durable medical equipment (DME), and they said that if I wanted the Trilogy100 or the Puritan Bennett 540™, I’d have to switch home health care companies because they don’t carry them. How do I find a local home health care company that provides the newer vents? Does it make a difference if I have private insurance or coverage by Medicare or Medicaid?”

ANSWER: First of all, you will need to have a prescription from your physician and agreement from him or her that the new equipment you desire is the best for you.

If you want to get the Trilogy100, call Philips Respironics at 800-345-6443 and ask for Customer Service. Tell them that you would like to find a DME supplier that rents or sells the Trilogy100 in your neighborhood.

You can do the same if you are interested in the Puritan Bennett vent but please be aware that Puritan Bennett products are now sold by their parent company, Covidien Ltd. Call 800-635-5267 to connect with one of the manufacturer’s representatives in the United States.

The health insurance that each supplier accepts varies. Most accept Medicare as the primary insurance carrier. Not all accept Medicaid as the primary carrier but may accept it as the secondary carrier. Private insurance offers a vast array of plans, both in-network and out-of-network.

Check with the supplier to determine your coverage. ▲

Diana Guth, RRT, Owner, Home Respiratory Care, Los Angeles, California, diana@hrsleep.com

Do you have a question about ventilator-assisted living?

Are you a health professional with a question for ventilator users? Send it to info@ventusers.org, and IVUN will find experts to answer it.

From Vent to Diaphragmatic Pacing System: Part I continued from page 5

I was also leery about having only battery power for the DPS. It’s comforting to know I have unlimited vent time when plugged in to a standard outlet, as well as vent batteries that provide about 12-14 hours on a full charge, and charge simply by being

plugged in. However, a friend who has used the DPS essentially 24/7 for more than five years hasn’t had any issues with the batteries.

After thoroughly investigating the system and with the issues resolved in my mind, I decided to proceed in converting from conventional assisted ventilation to the DPS. Stay tuned for Part II. ▲

MORE on www.ventusers.org

Bill Miller
www.ventusers.org/edu/valnews/val14-2.html#nob

Diaphragm Pacing System
www.ventusers.org/edu/valnews/VAL_24-1p4.pdf
www.ventusers.org/edu/valnews/VAL_20-3p1-3.pdf

Meet Our Sponsor ...

RESMED 800-424-0737, www.resmed.com

ResMed Corporation is a leading developer and manufacturer of products for the treatment and management of acute and chronic respiratory conditions for both adults and children. ResMed is committed to developing innovative and effective ventilation solutions, including masks and accessories, to offer assistance to health personnel and improve the quality of life of patients around the world.

Meet Our Supporters ...

COVIDIEN 800-635-5267, www.covidien.com/PB540

At only 9.9 lbs., Covidien's new Puritan Bennett 540™ portable ventilator is a weight off your mind. The real-time battery life indicator shows how much time you have until you need to recharge (up to 11 hours* - depending on settings and other factors).

* Fully charged battery at room temperature, set to $V_t=200$ ml (± 5 ml), $PIP=10$ cmH₂O (± 2 cm H₂O), $R_{tot}=15$ bpm. Level adjustments, environmental conditions and physiological characteristics of the patient affect battery operating time.



DALE
Patient Care Incorporated 800-343-3980, www.dalemed.com

Dale Medical Products, Inc.'s Dale® Tracheostomy Tube Holders have always provided the quality you demand for maximum security, patient comfort and ease of use. With Dale® the frustrations associated with twill ties and other holders are eliminated while minimizing secondary complications. The Dale® Family of Tracheostomy Tube Holders includes the Dale® 240 Blue™, which fits most; the Dale® 241 PediStars™ which fits up to an 18" neck; and the Dale® 242 PediDucks™ which fits up to a 9" neck. *FREE evaluation SAMPLE available upon request.*

Passy-Muir Inc. 800-634-5397, www.passy-muir.com
Tracheostomy & Ventilator
Swallowing and Speaking Valves

The Passy-Muir® Swallowing and Speaking Valve is the only speaking valve that is FDA indicated for ventilator application. It provides patients the opportunity to speak uninterrupted without having to wait for the ventilator to cycle, and without being limited to a few words as experienced with "leak speech." By restoring communication and offering the additional clinical benefits of improved swallow, secretion control and oxygenation, the Passy-Muir valve has improved the quality of life of ventilator-dependent patients for 25 years.



PHILIPS
RESPIRONICS 800-345-6443, www.respironics.com

Philips Respironics is expanding the company's solutions for patients who suffer from chronic respiratory diseases with the introduction of the new BiPAP AVAPS noninvasive homecare ventilator. Released the week of February 15th, the ventilator automatically delivers optimal therapy even as patient needs change. For more information, check out <http://bipapavaps.respironics.com>



BiPAP AVAPS

How to contact IVUN ... International Ventilator Users Network (IVUN), An affiliate of Post-Polio Health International (PHI)
4207 Lindell Blvd., #110, Saint Louis, MO 63108-2930 USA, 314-534-0475, 314-534-5070 fax
info@ventusers.org, www.ventusers.org