

IVUN News

Camping with a Ventilator

Connie Panzarino

Imagine me and three personal care assistants squashed into my van, which was packed to the roof with tracheostomy supplies, extra ventilator hoses, and batteries for my LP10 ventilators, which I use 24 hours. Not to mention suction machines, blood pressure cuff, oximeter, enough puréed food and potato buds for ten days, and supplies for my G- and J-tubes through which I get hydration and medications. Then there was the camping gear: foam mattresses, tents, sleeping bags, maps, and spring and sterile water.

I carried an "I'm gonna do this!" attitude like a banner. For nearly twenty years I had attended the Michigan Women's Music Festival where I had enjoyed listening to music from three different stages, seeing the crafts of more than 200 vendors, attending workshops, and feeling the sistership of women from all over the world. I had learned to camp in a tent and I loved it. However, I had not used a ventilator then, but 2000 was the festival's 25th anniversary and I just had to be there.

The Music Festival takes place every August not far from Lake Michigan, but more than 900 miles from my Boston home. Since I am only able to tolerate sitting up in my wheelchair six to eight hours at a time, I planned the trip very carefully. Knowing that I would grow more tired as the trip went on,

I scheduled less and less travel each day.

The first day we drove about eight hours to Niagara Falls on the Canadian side. I had planned on staying there for two nights because I knew I would be exhausted. The next day when we went to the Falls, and, after speaking with the parking attendant, we were able to get a special parking spot directly across from the center of the Falls. It was crowded, but it was a clear and beautiful day. The sun baked my skin pleasantly as the breeze and the spray from the Falls cooled me down. People did look at me with my big electric wheelchair with the ventilator and suction machine on the back, but mostly they smiled and made room for me to see past them. It was a little like being an ambassador for life with a ventilator.

We pushed on through Canada the next day, doing only five hours of driving. The last leg of the trip was only a two-hour drive to the festival grounds. When we arrived, we were given permission to drive the van into the center of the grounds to unload. Usually people with disabilities have to transfer to a wheelchair-accessible shuttle bus, but we just had too much stuff. I was met with hugs and kisses from old friends and exchanged greetings with new ones. Some "helping hands" and workers from the DART (Disabled Area Resource Tent) helped us unload and brought us dinner. We were tired

and it was hot, but it was so exciting to be there. We could hear music playing in the background.

The festival carpenters had built a platform bed high enough for transfers. I put my foam mattresses on top and my plastic tubs and milk crates filled with supplies underneath. I hung bags of clothes and medications on bungee cords and set up my bedside LP ventilator on one of the tubs. Extra ventilator batter-



ies were next to the bed in case of power failure, and I had brought a special cable that could run either ventilator off of any car battery. The festival provided two outlets from which we ran two extension cords to my tent. I plugged several power strips into them for my ventilator, battery chargers, nebulizer, electric heater, blender, and hot pot.

The hot pot was crucial, because some of the equipment needed to be washed in hot water. I tried to keep things as sterile as possible, directing my PCAs

New Diaphragm Pacing System

Anthony F. DiMarco, MD, pulmonologist and professor of physiology at Case Western Reserve University (CWRU), is the principle investigator for the research project "Electrical Activation of the Diaphragm for Ventilatory Assist." The purpose of the project is to provide full-time artificial ventilation for those individuals who use ventilators as a result of spinal cord injury (above C5).

J. Thomas Mortimer, PhD, professor of biomedical engineering at CWRU, and his team designed a diaphragm pacing system that uses intramuscular electrodes placed (through a laparoscopic procedure) within the diaphragm muscle to electrically activate the phrenic nerves. They also developed instruments to first locate the phrenic nerve motor points, and then to safely implant the electrodes at these sites.

Laparoscopy is usually performed as outpatient surgery, but the

first patient was kept overnight to monitor his pulmonary status.

Dr. DiMarco noted increases in tidal volumes and vital capacity over 13 days as a result of the reconditioning process.

This pacing system has significant advantages over currently available techniques such as Avery/Dobelle and Atrostim. There is reduced risk of phrenic nerve injury because the electrodes are not placed directly on the phrenic nerve, and the system requires less time to implant due to a minimally invasive procedure, thus making it also less expensive.

Currently, the system is an external one. The wires from the electrodes are tunneled through the skin, exiting in the area below the right shoulder and stabilized with a patch. There is a cable that connects to the wires and subsequently attaches to a stimulator, which can be kept in a fanny pack or portable CD case.

The project is funded by the FDA. One person has successfully received the new pacing system and has achieved 24-hour pacing for several weeks, during which he was ventilator-free. Potential candidates must be 16 years of age, mentally alert, and have a good support system at home.

The advantages of diaphragm pacing include possible elimination of the need for mechanical ventilation, improved vocalization and sense of smell, easier transferring, and enhancement of overall quality of life.

For more information contact, Sandra Ferek, RRT, MetroHealth Medical Center, 2500 MetroHealth Drive R429, Cleveland OH (Ohio) 44109 (216-778-3612, sxf23@po.cwru.edu). ■

"Phrenic Nerve Pacing" appeared in IVUN News, Spring, 1999. It is available online: www.post-polio.org/ivun.html.

Respiratory Health Checklist

Linda Bieniek, CEAP and non-invasive ventilator user in the Chicago area, developed a checklist, "Managing Chronic Respiratory Conditions," in preparation for her presentation at the 2001 Home Mechanical Ventilation Conference in Lyon on the panel "Staying Healthy: Communicating with health professionals, maintaining general health and nutrition."

The checklist is divided into three columns labeled Need, Assessment, and Action Plan. It is a useful tool to help ventilator

users to monitor their respiratory status and to be alert for problems with breathing, respiratory infections, and masks, as well as nutritional needs or dietary habits that might be contributing to respiratory problems, such as alcohol intake, caffeine, etc. The sections on weight management and a healthy home environment are also helpful. ■

The checklist is available free through IVUN, 4207 Lindell Boulevard, #110, Saint Louis, MO 63108-2915 USA (314-534-0475, 314-534-5070 fax, gini_intl@msn.com).

Pros and Cons of Home Sleep Studies

A topic under debate among respiratory health professionals is the efficacy of home sleep studies. Ventilator users who have recently had sleep studies performed in the home instead of a sleep lab are asked to submit their experiences to IVUN.

A future issue of *IVUN News* will discuss these pros and cons. Please send your comments to IVUN (314-534-5070 fax, gini_intl@msn.com). ■

Italian Ventilator User Survey

Liana Garini

Adapted from poster presentation, "Home Mechanical Ventilation in Italy: The point of view of 179 ventilator users with neuromuscular disorders," presented at the Eighth International Home Mechanical Ventilation Conference, Lyon, France, March 7-9, 2001.

The Unione Italiana Lotta alla Distrofia Muscolare (UILDM or Italian Muscular Dystrophy Association), concerned about the increasing number of persons affected by neuromuscular disorders using mechanical ventilation, suggested this survey of their quality of life. The research focused on: 1) how the ventilator modified living conditions; 2) the degree of satisfaction about health and social provisions in Italy; and 3) how ventilator users improved their quality of life.

The 179 ventilator users, surveyed from 1997-1998, were located by the UILDM and some hospitals. The largest group included those with Duchenne muscular dystrophy (87), followed by other forms of muscular dystrophy (45), SMA (21), ALS (8), congenital myopathies (9), and other neuropathies (9). Males numbered 144; females 35.

Predictably for Italy, only 10.05% were employed, 89.94% were unmarried, and 92.73% lived at home with the family. Of those living at home, 11.18% responded that it was their personal choice, 55.31% responded that it was their family's choice, and 33.51% responded that the choice had been determined by circumstances.

These results correspond to the traditional Italian situation in which the family is a "good babysitter," even for people who are not disabled.

Different modes of ventilation were used: tracheostomy posi-

tive pressure, noninvasive nasal and mouth positive pressure, and negative pressure with a Poncho.

The necessity for mechanical ventilation was due to the emergency of sudden respiratory conditions (40%), with progressive respiratory failure detected during checkups (57.56%).

A personal decision to use mechanical ventilation was stated by 21.23%, a family decision by 11.73%, and emergencies determined the initiation of mechanical ventilation in 40.22%. Medical advice influenced 25.70% of the decisions. The high percentage of emergencies may explain the low percentage of personal choice and also the young age of the respondents (126 under age 40).

Personal assistance in Italy is provided only for disabled persons living alone, but often income does not cover all the expenses. Families have to face the new situation and responsibilities, and mechanical ventilation necessitates more care for a family, already tired from continuous caregiving, often with no or little help from outside. Nursing homes may be the last resort for people with severe disabilities. The use of mechanical ventilation may compromise already unstable relationships.

The most highly rated suggestion for improving quality of life was the provision for personal care assistance, especially provided on an hourly basis. Next was prompt repair service for the equipment.

Regarding the degree of satisfaction about personal assistance, 57.54% considered it sufficient, 22.35% low, 9.50% very low, and only 7.82% high. Again, the high percentage of young people may have influenced these ratings.

Overall, life with a ventilator was considered to be much improved by 60 people; fairly improved by 72; unchanged by 29, and worsened by 12. ■

For more information on the survey, contact Liana Garini, INFORESP (info@inforesp.org) or visit www.inforesp.org/research.htm.

International Ventilator Users Network

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Home Mechanical Ventilation Conference, Lyon, France, 2001

More than 1,300 health professionals, joined by 84 ventilator users and their attendants, participated in the Eighth International Conference on Home Mechanical Ventilation in Lyon, France, in March 2001. The conference was organized by Dominique Robert, MD, Patrick Léger, MD, Allen Goldberg, MD, and Barry Make, MD, with the support of JIVD, Hôpital de la Croix-Rousse, the Association Française contre les Myopathies (the French equivalent of the Muscular Dystrophy Association), and IVUN.

The plenary sessions from the conference (in English) are available on CD-ROM for approximately \$113 USD or 678 FF. Please contact OneScience, 47, rue Marcel Dassault, F-92100 Boulogne, Billancourt, France (+33 1 69 20 97 67 tel and fax, CGIGUET@free.fr).

Barbara Rogers, ventilator user from New York and speaker on the "Travel With Ventilators" panel said, "I was extremely excited to participate. However, I was also a bit apprehensive, because I had never traveled to Europe with a ventilator and did not know what to expect. The staff at JIVD did an excellent job in allaying my fears and making me feel safe. They obtained a list of the equipment I would bring so they could have a backup available. Once I arrived, they provided notes on procedures and emergency phone numbers to call in case of any difficulties, which put my mind at ease. The sharing of experiences and information on a global scale was very uplifting.

The inclusion of ventilator users into the clinical conference encouraged a true exchange of information and learning."

Anthony Giles-Peters, ventilator user and president of the Australian Ventilator Users Network, Inc., states, "There were so many interesting concurrent sessions, but of particular value were the 'Living Arrangements for Ventilator Users' and 'Travel' panels in the ventilator users track, and 'Ethical Issues in Long-term Ventilation' and 'Nonprofessional Caregivers' in the scientific program.

"The exhibits were good, and I had the opportunity to examine the new laptop LTV1000™ and the new CoughAssist™. The

poster display and presentations were excellent. For me, the conference was a great success in providing the opportunity to meet ventilator users from many countries, to learn about the similarities and differences in clinical practice and community support services around the world, and to share our experience in Australia. The organizers did a great job in providing the necessary support to reduce hassles for the ventilator users in attendance."

Frank Hall-Bentick, another ventilator user from Australia, said, "I had the opportunity to see the accessibility features of the French public transport system, particularly the low floor trams (which we are bringing to Melbourne), and the Metro train system.

"I found the conference very interesting, but next time I would like to see the ventilator users sessions integrated throughout the clinical presentations, with more emphasis on informing ventilator users with severe disability about how they can live in the community."

Linda Bieniek, ventilator user from Chicago and speaker on the "Staying Healthy: Communicating with health professionals, maintaining general health and nutrition" panel, was struck with the hospitality and generosity of the Europeans. "As soon as I arrived for the conference, Dominique Robert, MD, and his associates went to great lengths to assist me. To

(L-R) *Hélène Joguet, Barbara Rogers, Patrick Léger, MD, and Dominique Sebbane.*





Anthony Giles-Peters and Linda Bieniek

users' sessions, demonstrating their strong desire to understand our experience, and to learn from and with us.

"Because this was my first trip abroad, the travel itself was a learning experience. In her useful suggestions on the 'Travel With Ventilators' panel, ventilator user Barbara Rogers cited the wide disparity of airline fees for using oxygen in flight – something I had already encountered when reserving my flights.

"As is often the case at conferences like this, some of the best learning and networking takes place 'off-line.' I came away from the conference with a renewed appreciation for the universality of the challenges ventilator users face, and how much we can learn from each other at an

international forum, despite vast differences in our cultures and health care systems." ■



(L-R) Judith Fischer, editor, IVUN News; Conference Organizer Dominique Robert, MD; and Joan Headley, Executive Director, GINI.

relieve the untimely pressure sores that developed just before I left the US, they found masks for me, and even made one. They also taught me how to position the humidifier to prevent humidity from collecting in the tubing and waking me during the night.

"I was pleased to see Patrick Léger, MD, one of the conference organizers, along with several other physicians, in attendance at the ventilator

Potpourri

◆ **GINI Research Fund Call for Proposals.** The GINI Research Fund awarded its first grant in 2000 to a Toronto-based team to study "Ventilator User Perspectives on the Important Elements of Health-Related Quality of Life."

The next grant will be awarded in 2003, with proposals due and reviewed in 2002. For information on applying for the grant, contact Joan Headley, GINI (314-534-0475, gini_intl@msn.com).

◆ **The Department of Health and Human Services (HHS)** announced the release of nearly \$70 million in grants to states (before October 2001) to increase services and supports for people with disabilities to

live in their communities, further implementing the Americans with Disabilities Act. The four grant categories that comprise the "Systems Change for Community Living" are: Nursing Facility Transition grants – \$10-14 million; Community-Integrated Personal Assistance Services and Supports – \$5-8 million; Real Choice Systems Change – \$41-43 million; and National Technical Assistance Exchange for Community Living – \$4-5 million. For more information, see www.hcfa.gov/medicaid/systemschange and www.hcfa.gov/medicaid/realchoice.

HHS also released a report entitled "Understanding Medicaid Home and Community-Based Services: A Primer." The full text is available at www.aspe.hhs.gov/daltcp/reports/primer.htm.

◆ **Travel.** *Emerging Horizons* featured a column "Stretcher and Ventilator Travel" by Candy Harrington with good suggestions and information. Check their Website: www.emerginghorizons.com.

◆ **With Every Breath I Take**, a semi-autobiographical book by Canadian ventilator user Gary McPherson, relates Gary's decision to be responsible for his own health. It is an excellent and detailed health and wellness guide. Available for about \$25 Canadian from Laurie Greenwood's Volume II, 12433-102 Avenue, Edmonton, Alberta T5N 0M2 Canada (780-488-2665, 780-488-8729 fax, volumeii@telusplanet.net). Visit Gary's Website: www.garymcpherson.com. ■

to use gloves more often than usual because of the difficulty in washing their hands between procedures. With my little rainbow flag planted in front of the path to our tents, our "home" for the next five days was ready.

Using the vent in the tent was not much more difficult than using it at home. While traveling around the festival, enjoying the crafts, concerts, parades, and dances, I made sure I had plastic bags and extra rain ponchos to cover myself and the ventilator when it rained. I always carried my Ambu bag and my suction machine with extra suction catheters, medications, inhalers, and extra water and snacks in case I could not get back to my tent for several hours. A roll of tape and a small toolbox also lived with me. I scheduled my PCAs so one would be off, one would be on, and one would be assisting an hour here or there with things that were more difficult in a camping situation. The festival workers also helped with washing the dishes, getting ice for the cooler, and lending muscle when needed.

I enjoyed fine performances, bought lots of ceramics and other crafts, and was able to lead a workshop on "Ableism, Isolation, and Networking." I ended it with a pināta party in the DART area, where women had a grand old time beating it with crutches, canes, branches, etc. I networked with many of the 400 women with disabilities and with some of the other 7,000 women there. I got tanned and felt good that, because we were all women, I could actually go topless when I was hot. Nobody stared at the two catheters protruding from my stomach.

I felt nurtured, exotic with feathers and beads in my hair, and triumphant that even though I now had a trach and used a ventilator fulltime, I was still there. It was like coming home.

As we traveled back through the States, I visited a younger friend in Ohio with the same disability as me (SMA II), whom I had mentored through letters and telephone calls for many years. I also spent a day in the Catskills, where I used to live, visiting old friends and telling

them all about the festival. We finally returned to Boston with much less in the van but lots of memories to carry me through the winter when it is more difficult to go out. ■

ADDRESS: Connie Panzarino, MA, ATR, 282 Lamartine Street, 1st floor, Jamaica Plain, MA (Massachusetts) 02130 (617-524-0921, www.members.aol.com/panzarino/index.html).

Editor's Note: Connie Panzarino is an author, artist, and lesbian and disability rights activist. Her article is adapted with permission from Access Expressed!, No. 28, 2001.

Percutaneous Tracheostomy: My Choice

Steve Fowler

In March 1997, after noticing a peculiar weakening of the right hand and breathing capabilities, I was diagnosed with ALS. At that time, acceptance of the use of mechanical ventilation early in the progression of ALS was not as prevalent as it is today. Several doctors, including my ALS specialists at UCLA, refused to write me a prescription for a bilevel unit. In some respects this was fortuitous because I acquired a volume ventilator by visiting John Bach, MD (an ardent advocate of noninvasive mechanical ventilation for people with ALS) in Newark, New Jersey.

I successfully used the volume ventilator noninvasively for 40 months, but weakening speech and the feeling of nocturnal suffocation made me aware that I needed to consider a tracheostomy ... or die.

On March 5, 2001, I underwent a percutaneous tracheostomy at Barlow Respiratory Hospital in Los Angeles. I was given

a combination of valium and morphine in order to induce a state of "conscious sleep." I was then intubated and a camera was passed through my mouth into my trachea. A needle was inserted into my trachea after the camera ensured that the needle was properly placed. A wire passing through the needle was expanded by running a series of dilators through it until the aperture became the size of the trach tube. The tube (cuffed) was then inserted and the procedure was complete.

The entire process lasted about twenty minutes, and the doctors were willing to send me home after 24 hours, but I stayed four days while I set up nursing care at home. During my stay I only took four Tylenols for pain.

Aside from chewing my lip to pieces against the intubation tube, the operation was painless. Among my vaguely acknowledged concerns was speculation about how I would

react to air bypassing the nasal passages that had been bathed by every breath I had ever taken. Strangely enough, like amputees who report feeling sensation in missing appendages, my sinuses perceived a passage of air that did not exist, but within a week this illusion ended.

I have now had the trach for two months. It is clearly less painful than the masks I had been using, and my nose is now reverting to the size and shape of an earthling's. Tracheal suctioning takes some getting used to, but is no more stressful than the choking and assisted coughing that I had been experiencing for years using noninvasive ventilation. Nursing costs are about the same.

I have not been able to talk yet because of heavy secretions and subsequent choking but will continue to try. My biggest hurdle has been communicating my needs to an entirely new staff of nurses while trying to adjust to a sudden loss of speech. I use the Morse code function of EZ keys for typing on the computer, and this program includes a voice synthesizer.

All in all, my tracheostomy is a significant change, in some ways positive and in some ways negative, but it clearly is not the disaster that people with ALS are led to fear – from the moment of diagnosis – as the acknowledged and inevitable end point of the disease. ■

Steve Fowler is an accomplished flute and saxophone player, with several solo CDs on the market. His fascinating biography can be found on his Website: www.emdbd.com/stevefowler. Steve's email address is cottano25@aol.com.

Interfaces and Equipment

CPAP/PRO®, a new patented "mask replacement" for CPAP users, features comfortable foam-filled nasal puffs and a mouthpiece. Created by Joel Goldstein to alleviate his own sleep apnea, CPAP/PRO® is the only device that uses a simple boil-and-bite mouthpiece that attaches to the upper teeth, eliminating cumbersome straps, claustrophobic feeling, and the annoying leaks into the eyes from traditional masks. The mouthpiece is recommended to be changed every six months, the nosepiece and tubing every three months, and the nasal puffs/seals twice a month. The device is Medicare reimbursable. Contact the distributor, Sharps Compliance, Inc. (800-772-5657, 713-432-0555 fax, sharps@sharpsinc.com, www.cpapro.com).

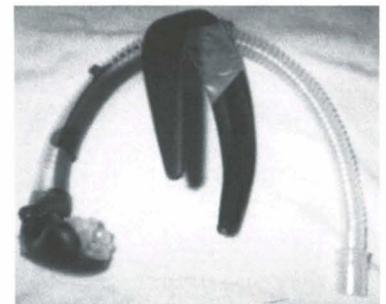
Total™ face mask from Respironics covers the entire face and eliminates pressure points around the nose that can cause skin breakdown. The soft flexible sealing layer is inflated by air pressure from the system and minimizes leaks. The mask is attached by cloth side straps and a mesh crown strap to keep the mask securely in place. Contact your local home health care dealer or Respironics (800-345-6443, www.respironics.com).

Creative Adaptation of Breeze™ SleepGear™ Nancy Baldwin Carter (n.carter@worldnet.att.net) writes, "As a polio survivor whose neck has little muscular strength and who is unable to tolerate any weight above the shoulders, I redesigned the Breeze™ SleepGear™ so that I could use it without causing a lot of pain to my spine.

"First, I removed the back part of it, losing about 2¼ oz. To keep the nasal mask on my head, I duct taped it to earmuffs, but they weighed about as much as the piece I had removed from the mask. Then I removed another piece of the mask that I thought helped stabilize the mask on the head, but, after I had removed it, I discovered that it made no difference in this regard. I removed the rabbit fur from the earmuffs, losing about 1½ oz. I kept the ear portions on the earmuffs as a stabilizing influence and because I thought that removing them would create pressure on my temples, which I cannot tolerate. The mask was still a little too heavy.

"I finally bought a plain, plastic headband, 1½" at the widest point so there is enough width to stabilize the mask. I place this behind my ears, thus avoiding the problem with my temples. Now the entire mask weighs about 3½ oz. and seems to work fine."

The Newport HT50® is the newest ventilator (approved for home use) from Newport Medical Instruments, offering both volume and pressure control, plus pressure support. Applicable for both children (over 10 kg) and adults, it weighs only 15 lbs., internal battery life is 10 hours, and an integrated humidifier is optional. Contact Newport Medical Instruments (949-642-3910, www.NewportNMI.com). ■



UPDATE: INSPIRATORY MUSCLE TRAINING STUDY

Millennium Man Bill Miller (C1-2 quad)

The setting: Gainesville, inside the University of Florida Physical Therapy building, the day of Bill's big breathing endurance finale and the third and last of three visits for this inspiratory muscle training research project for SCI ventilator users.

HOW DID IT GO? Very well. In the previous issue of *IVUN News*, I recounted that I breathed for three hours and fifteen minutes ventilator-free during the initial endurance test. Then, after six weeks of inspiratory muscle training, I went back to Gainesville and breathed for ... four hours and thirty-five minutes!

HOW DID YOU ARRIVE AT FOUR HOURS AND THIRTY-FIVE MINUTES? For the final test, I wanted to *finish* watching two movies. Remember that for the first test, I was told to bring a movie to watch which would not only help to pass the time, but would also create a more

normal environment by taking my attention at least partially away from breathing. I had brought along two movies from which to choose. I had no idea how long I would last because I had breathed ventilator-free for three hours more than a year earlier, but not for that length of time in months. The maximum duration outlined in the research protocol was three hours, but I reached that midway through the second movie and went on for another fifteen minutes to establish a new personal record.

Bringing three movies did cross my mind, but being able to watch two movies all the way through and breathing ventilator-free for

four hours and thirty-five minutes was a good indication that the inspiratory muscle training project was successful. My weightlifting buddies will understand that, on a bench press, this kind of progress in less than two months is awesome.

WHAT'S NEXT? Although my part in the study is over, I will continue with the training exercises and prepare for the next step, whatever and whenever it may be. ■

ADDRESS: Bill Miller (MaxNWM@aol.com, www.lookmomnohands.net)

Editor's Note: Danny Martin, PhD, PT, says that he is looking for more recruits from the northern Florida area for the project. Contact Dr. Martin by phone or email (325-265-0085, Dmartin@hp.ufl.edu).

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