

## Why I Don't Have Time to Write an Article for *IVUN News*

Dear Editor, *IVUN News*:

March has been a very busy month for me. I have had many commitments with AVUN (Australian Ventilator Users Network), and have spent a lot of time trying to change my mode of ventilation from the iron lung to portable positive pressure ventilation.

After being unemployed for seven months, I obtained a job, beginning in May, as a health policy and advocacy project worker for the Attendant Care Coalition, a community-based advocacy organization run by people with disabilities. The project is to identify health issues and how they impact on the support needs of people with disabilities, and to develop community supports to enable people who are inappropriately housed in acute care settings and nursing homes to live in the community in their own homes.

Unfortunately, the prospects of me writing an article and getting it to you by the deadline for the summer issue are not good. I have been funded to provide support for a presenter at the People First Self-Advocacy Conference (for people with intellectual/developmental disabilities) in Anchorage, Alaska, in late April. There is a lot of work to be completed by then, including assisting in the information gathering and writing of the paper for the conference, as well as the usual preparation for a first trip overseas. Then there are meetings and tasks for AVUN before I leave. I also must have more tests with the portable ventilator, and make arrangements for using it on the flight.

I have used the iron lung at night for 28 years, and the transition to positive pressure ventilation (Breas 501 with custom-made nasal mask) is not easy. However, with the assistance of the team at the Victorian Respiratory Support Service based at Melbourne's



Austin and Repatriation Medical Centre, I should be advanced far enough to undertake the trip to Alaska. It is a big challenge considering the state of my ventilation, but the opportunity is too good to pass up. The trip was only confirmed in the last few weeks, and I had hoped to still write the article for *IVUN News*, but things have got a bit out of hand. Perhaps I could write an article for a later issue which might be of interest to your readers. ■

Yours sincerely,  
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President, AVUN

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## Timothy Clark

Lea Clark

Our son, Tim, was born with spina bifida in 1989. Due to severe (90-degree) scoliosis, he was trached at three weeks of age. My husband and I immediately went from the joy of being new parents to the horror of the possibility that we could lose our child. We spent seven months in Columbus Children's Hospital before we convinced doctors to let us bring Tim home. (He was the first child they discharged home with a ventilator.)

Tim uses a customized Bivona 7.0 trach tube. He has a huge leak that can't be closed so the Passy-Muir valve does not make much of a difference. He currently uses an LP6 ventilator, but will be switching to the PLV-100 soon. Tim also needs 1L of O<sub>2</sub> and aerosols every four hours.

Tim had a status seizure in June, 1996, that knocked him badly. As a result of the brain damage, he has had to learn everything all over, and has just begun trying to talk again. Communication is difficult, but it is improving with an eye-gaze board. The doctors do not know how much of his former skills he will regain.

Tim attends school at home. He was missing so much education because of the colds and viruses he caught there that we decided it would be healthier for him to learn at home. We are the primary caregivers, but a nurse comes for a 12-hour shift at 9:00 p.m.

Katy, Tim's older sister, has helped to care for him since she was 10 years old. She saved his life once when his trach tube

## Ventilators and Bi-Level Pressure Devices

Alan Fiala, PhD

I developed respiratory problems in 1984, nearly 32 years after the acute phase of polio. Over the next several years, I worked through a succession of ventilators, seeking the right kind to best treat my particular deficiency. Along the way, I did my homework and learned many lessons from which others may benefit.

Whenever I have time, I monitor several Internet discussion groups for polio survivors and ventilator users. It distresses me to read that people who need help get advice on ventilators based on size, weight, noise, or cost — without consideration of the function performed. Similarly, I shudder to read stories from people who blithely say something to the effect that "... a sleep study is where they monitor you overnight and then prescribe a CPAP ventilator for you." In this case, the health care professional apparently gives no consideration to function, either.

I have had the good fortune to have health insurance that lets me choose my own physicians. I take the attitude that I am hiring them on consultation, and if they cannot explain to me their diagnosis of my problem, the physiology, and the purpose of a course of treatment, I go to someone else.

If you are having respiratory problems, the effects can sneak up on you insidiously, as happened to me. I deteriorated for two years before reaching a crisis of acute respiratory failure. I think anyone experiencing the late effects of polio should consider having a sleep study done as a preventive

diagnostic measure. Most of us are in a weakened state with a narrower margin of health, and we don't need unrecognized and untreated respiratory complications. However, sleep studies must be performed intelligently.

A respiratory problem may be caused by: 1) chronic obstructive pulmonary disease (COPD), which is generalized obstruction of the small airways especially during forced expiration, as in emphysema, chronic bronchitis, and asthma; 2) obstruction or collapse of the upper airway, as in obstructive sleep apnea (OSA); and/or 3) chronic restrictive pulmonary disease (CRPD), which is weakness or limitation in the neuromusculoskeletal structure, as in polio, muscular dystrophy, ALS, etc. Be tested by someone who knows about neuromuscular diseases and who will consider the possibility that your problem is CRPD rather than COPD. In my case, the cause was restriction from kyphoscoliosis. Recognize that you may have a common respiratory problem that is NOT related to post-polio; this is known as co-morbidity.

In respiratory insufficiency, the gases in the blood are out of proportion, thereby providing insufficient oxygenation and perhaps too much CO<sub>2</sub>. The first step is for the physician to explain what might be causing this, and what might be expected after a course of treatment. The minority of post-polio pulmonary problems are COPD, but pulmonologists like to treat it because it is always the same, and treatment is stan-

dard and predictable. Neuromusculoskeletal cases are different from person to person, so a treatment must be chosen and then monitored for effectiveness over time.

One should understand the complete range of treatments and equipment available. Ensure that you understand what your problem is, and that the prescribed treatment will match up with it. In an acute situation, any type of ventilator will deliver air and dream sleep, but it may not resolve the blood gas and respiratory deficiencies in the long run. I experienced this myself when I was hospitalized with respiratory failure. Several types of ventilators were tried on me, and they ALL felt wonderful. Yet the first ventilator prescribed for me was effective only a relatively short time. Beware of respiratory therapists or pulmonologists who prescribe the same type of ventilator for all problems. They may not be knowledgeable, or they may be profiting from the sale.

Different types of ventilators serve different functions and operate with either negative pressure (the iron lung, chest shell or cuirass, and types of body wraps and suits) or positive pressure through a variety of modes currently in vogue. Positive pressure ventilators work noninvasively through an interface, such as a nasal or facial mask, nasal pillows, lipseal, etc., or invasively via a tracheostomy.

A pressure-limited ventilator delivers a continuous positive airway pressure (CPAP) up to the pressure limit set on the machine. The volume varies with an individual's physical condition. This ventilator is typically used in cases of OSA where the airway must be kept open. A bi-level pressure device, e.g. BiPAP® S/T system, delivers a continuous flow of air with pres-

tures set separately for inspiration and expiration. The pressure level tends to make up for air leaks.

A volume ventilator delivers a set volume of air on each cycle. The pressure is then related to chest wall compliance and airway resistance and volume. It changes with physical conditions. In kyphoscoliosis, for example, the lungs expand, but the chest wall is fixed. This system is prone to leakage, but may help to overcome a particular problem such as excessive secretions. A volume ventilator has a range of settings, including range of flow — a setting not available on pressure ventilators.

My physical problem was not an obstructed airway, but thoracic musculature too weak to let me breathe in without assistance while asleep. I needed a strong inspiratory assist to be sufficiently ventilated. I also had some difficulty exhaling completely. I was sent home from the hospital with a negative pressure ventilator (chest shell) and oxygen, for sleeping only. After only a few weeks, this proved insufficient to maintain a correct blood gas balance, and I was switched to a Pulmo-Wrap negative pressure system, still with oxygen. (Note: I was renting these units.) This also proved to be insufficient over time.

After about two years of negative pressure ventilation, my respiratory therapists recommended that I switch to a positive pressure volume ventilator, the PLV-100. This delivers a controlled volume of air in, and lets me breathe out on my own. They also stated that bi-level pressure device ventilation was inappropriate for me, because I needed a device that would trigger to assist inhalation only, and deliver a volume against the resistance of my chest wall.

I did not need assistance to keep my airway open, and could not

tolerate continuous pressure working against exhalation. With time, my chest wall compliance was changing. I discontinued oxygen therapy also. I had learned that oxygen was considered counter-productive for people with neuromuscular disease, and when I queried my pulmonologist about it, he said to stop using it to see what happened. I noticed no effect at all, and never used oxygen again.

The fact that my chest wall compliance was changing illustrates another key point. Your ventilator needs may change over time, and you might have to consider changing the type of equipment used. If at all possible, rent for a long term before buying, and discuss eventual purchase with your insurance carrier. My insurance company finally decided to purchase my ventilator instead of renting it. Fortunately, this happened after I had stabilized on the type of ventilator that best suited me and before the company imposed a lifetime limit on expenditures for medical equipment.

For the first several years that I was using different ventilators, I kept asking the respiratory therapists how to find the optimum settings. The only answer was trial-and-error. I learned about sleep studies through post-polio sources, but then learned that the preponderance of sleep study laboratories would not conduct studies to tinker, but only to prescribe. I finally did find a laboratory in Philadelphia, where I had a two-night study on my own ventilator, and learned that my trial-and-error settings were, indeed, optimum. I was also fortunate that my insurance covered it, as typically only a one-night study would be authorized for detection of sleep apnea. The value of one night is suspect, since there is a strong "first-night" effect, and it doesn't

allow for trial of a variety of ventilators and adaptive interfaces.

I have been very fortunate in my learning experiences. The resources of GINI and my local polio society were invaluable. I hope my report will help others in making informed choices when they develop pulmonary problems. ■

ADDRESS: Alan Fiala, PhD, 7250 Idylwood Rd., Falls Church, VA (Virginia) 22043-2702 (71044.3671@compuserve.com).

#### REFERENCES:

"Post-Polio Breathing and Sleep Problems", Judith R. Fischer and Joan L. Headley, *Polio Network News*, Fall 1995, Vol. 11, No. 4, p. 2.

"Aging Polio Survivors and Changing Ventilation Needs", Dr. August Alba, *Polio Network News*, Fall 1997, Vol. 13, No. 4, pp. 6-7.

### international ventilator users network (ivun)

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## International Airline Travel

**Lori Hinderer**, who uses 24-hour trach positive pressure ventilation due to muscular dystrophy, traveled to Lyon, France, in 1993 to attend an international conference on home mechanical ventilation. Contact Lori Hinderer, 9225 Tanque Verde Road, #52-102, Tucson, AZ (Arizona) 85749-8393 (LoriH@compuserve.com).

Concerned about the voltage conversion from American to European current, I contacted my ventilator manufacturer, Aequitron (purchased by Nellcor Puritan Bennett, now owned by Mallinckrodt). They suggested I borrow two LP10 ventilators because my LP6 didn't have a built in 220v converter switch. I don't carry an extra ventilator on domestic flights, but it was safer to have a back-up for the 10-hour plus flight from St. Louis (where I was living then) to France.

Although Air France was the official carrier of the conference, they had not approved the ventilator for in-flight use. TWA is the "official carrier" for my domestic flights, and because of their knowledge of my needs, I made the reservation with them. The representative entered all my medical needs into my flight record, including taking an extra ventilator and non-spillable batteries on the plane. After the reservation was made, I called a customer service representative at TWA. She alerted supervisors in all my departing and returning connections of my needs, requesting they assist me through customs and to connecting flights.

The next priority was determining what mode of transportation would be used to get from Paris to Lyon and back. The conference organizer, suggested I fly AirInter from Paris to Lyon. AirInter, however, was a foreign carrier, and required an international medical

document called an Incad form to be filled out by my physician and then approved. For the return to Paris, I would take the high-speed train (TGV).

The flights to and from Paris went smoothly. TWA suggested sitting in first class where the seats were softer and easier to access, and were very accommodating with regard to all the equipment I needed with me in-flight.

Despite all the planning, I could have been better prepared. While I can recommend air travel (international and domestic) for ventilator users, the key is to PLAN, PLAN, PLAN.

- ◆ Remembering passports, documents, adapters and transformers, and extra medical equipment was easier with a travel checklist to refer to when packing.
- ◆ Most critical is knowing the electrical conversions for all the equipment, not only the ventilator.
- ◆ Availability of electrical outlets in hotel rooms is also important; one hotel room had only one outlet.
- ◆ It helps to know someone who speaks English where you are traveling, especially if one has medical needs, or to stay in a hotel with some English-speaking employees.
- ◆ Compile a list of important numbers to carry with you always, numbers for emergency medical help, 24-hour on-duty nurses, medical equipment companies, and accessible van services. ■

### Veteran Traveler

**Anne Isberg**, respiratory polio survivor, has traveled frequently since 1983 between Copenhagen, Denmark, and Houston, Texas, and will soon be making her 100th trans-Atlantic crossing. She uses KLM as her "official carrier," and after all these years, the KLM agents have it down to a system. Anne uses an older Danish Pulsula ventilator with no electronics so that when it is plugged in there is less interference with the airplane's power system. She has a special narrow wheelchair which she uses to get on-board and to transfer to the seat, usually on the aisle. The wheelchair is stored in the coat compartment in-flight. Her ventilator fits under the seat in front of her, and she uses the power outlet under the adjacent seat. Anne's address is Castbergsvej 20-b, DK-2500 Valby, Denmark (Isberg@sprynet.com).

## International Airline Carriers

*Compiled by IVUN.*

**Air Canada.** 800/776-3000. Medical desk 800/667-4732. Must approve medical form they will send to passenger's physician. No electrical hookup. Non-spillable batteries permitted.

**Air France.** 800/237-2747. Ask for medical desk. No information received by publication deadline.

**Alitalia.** 800/223-5730. No information received by publication deadline.

**British Air.** 800/247-9297. Medical information provided by passenger's physician must be approved by medical department in London. No electrical hookup. Non-spillable batteries permitted.

**Cathay Pacific.** 800/233-2742. Medical form must be approved by Hong Kong office. Electrical hookup permitted.

**China Airlines.** 800/227-5118. No electrical hookup. Non-spillable batteries permitted. Must bring letter from physician stating approval for travel.

**El Al.** 800/223-7600. No set policy. Medical form must be approved by El Al physicians.

**JAL.** 800/525-3663. Must be approved on case-by-case basis by medical desk in Japan. No electrical hookup. Non-spillable batteries permitted, except for take-off and landing.

**KLM.** 800/374-5774. No information received by publication deadline.

**Lufthansa.** 800/645-3880. Medical information must be approved by Lufthansa physicians. Permission must also be received from operations department regarding type of ventilator and batteries.

**Mexicana.** 800/531-7921. No ventilators permitted.

**Qantas.** 800/227-4500. Medical form must be approved by medical desk. Electrical hookup

for LP3, LP4 approved for connection to 12/24 V DC aircraft power; LP6 approved for connection to 115V/400Hz if internal switch set to same; PLV-100, PLV-102 approved for connection to 115V/400Hz if units are 110V models. Other units are accepted with non-spillable batteries. Some CPAP systems approved for connection to 115V/400Hz air-craft power.

**SAS.** 800/221-2350. Medical desk, 201/896-3565. Both medical desk and engineering department must approve. Bear volume ventilator pre-approved.

**South African Airways.** 800/722-9675. No electrical hookup. Medical form must be approved.

**Swiss Air.** 800/221-4750. Must approve medical form they will send to passenger's physician. They provide ventilators. Electrical hookup in specific seats.

**Thai Airways.** 800/426-5204. No set policy. ■

popped out. She stuck her finger in the stoma, and kept bagging him until the paramedics arrived.

For activities, Tim loves to go to the zoo. He hasn't mastered the computer yet, due to his motor disabilities, but we are working on a switch-controlled computer.



Timothy Clark

Our church and community have been very supportive, and I know that we are lucky. Over the last nine years, I have learned so much about life and unconditional love from my son. In spite of all Tim's medical problems, he is still the happiest child I have ever known. ■

ADDRESS: The Clark Family, 915 North 5th Street, Ironton, OH (Ohio) 45638  
(bunnie1@bright.net).

## Bibliography

Bach, J.R., Rajaraman, R., Ballanger, F., Tzeng, A., Ishikawa, Y., Kulesa, R., & Bansal T. (1998). Neuromuscular ventilatory insufficiency: effect of home mechanical ventilator use v oxygen therapy on pneumonia and hospitalization rates. *American Journal of Physical Medicine & Rehabilitation*, 77 (1), 8-19.

Six hundred eighty-four users of assisted ventilation were surveyed by mail and twice by telephone over a four-year span. Diagnoses included polio sequelae, muscular dystrophies, SMA, SCI, and ALS. People who used noninvasive intermittent positive

pressure ventilation (NIPPV) via mouthpiece, nasal interface, or some combination, even when it was required around-the-clock, had significantly fewer hospitalizations, hospitalization days, and pneumonias than people with indwelling tracheostomy tubes. This holds true whether or not the people with tracheostomy tubes used a ventilator parttime or fulltime. Polio survivors who received supplemental oxygen therapy instead of using NIPPV to correct their blood gas levels had the most hospitalizations, hospitalizations days, and pneumonias. Noninvasive methods can be used safely, and deserve more widespread use for the up to 24-hour ventilatory support of patients with neuromuscular ventilatory insufficiency. ■

## CALENDAR

**JUNE 25-27, 1998. CCHS Family Conference.** Holiday Inn Select at Vanderbilt, Nashville, Tennessee. Contact Carol Neely, 615/848-0546.

**JULY 31-AUGUST 2, 1998. Families of SMA Annual Family and Professional Conference,** Hyatt Regency Tech Center, Denver, Colorado. Contact Families of SMA at 800/886-1762 (sma@interaccess.com).

## Which Ventilator to Use?

In the Fall, 1997, issue of *IVUN News*, I read Dr. E.A. Oppenheimer's article "The American Experience." My name is Patricia Folkerth, and I had bulbar polio in 1950 at the age of 6. I was diagnosed with post-polio syndrome last year. After a sleep study, I was advised to use a CPAP (continuous positive airway pressure) machine, set at "9," which is about average, to correct my sleep apnea.

Dr. Oppenheimer's article states that persons with a neuromuscular disease should use "assisted ventilation" rather than CPAP, because CPAP puts a greater burden on respiratory muscles. (I am assuming that by "assisted ventilation" he means a Bi-PAP® S/T system or other bi-level pressure device.)

After several months of using CPAP, I have begun experiencing a heaviness or tightness in my chest, as have some of my friends who are also experiencing the late effects of polio. Does this heaviness mean that we should explore other options for ventilation at night? What kind of test will help us decide which system we should use? I have been hesitant to use a bi-level pressure device because my friends who use them seem to have a great deal of trouble. Is there any other option to support our breathing at night? ■

ADDRESS: Patricia Folkerth,  
31 Shearwater Dr., Irvine, CA  
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### DR. E.A. OPPENHEIMER RESPONDS ...

Your questions focus on important issues: whether there is breathing muscle weakness or whether there are reasonably normal breathing muscles but obstructive sleep apnea (OSA).

As one ages with the late effects of polio, respiratory muscle strength may decrease. This may be particularly evident when you lie down, because in this position, the diaphragm has to work harder both to pull air in and also to push the intestines and other abdominal organs which are out of the way when one is upright due to gravity. Thus, night-time breathing abnormality due to muscle weakness is best treated with a device that assists ventilation, such as a small portable bi-level pressure device, e.g. BiPAP® S/T system, or a volume ventilator, e.g. PLV-100, LP6, or LP10.

If the upper airway tends to close off during sleep, OSA episodes occur. These are often successfully treated by continuous positive airway pressure (CPAP) that delivers a constant flow of air to keep the airway open. This requires somewhat more work for the respiratory muscles during the expiratory phase, but the inspiratory phase is assisted by CPAP. It is certainly possible to have weakness in the throat/pharyngeal area that produces OSA, without weakness of the breathing muscles. If this is the case, CPAP is the appropriate treatment.

Pulmonary function tests that show a reduced vital capacity (VC) below 50% of normal and a significant reduction of the maximum inspiratory force (MIF) and maximum expiratory force (MEF)

would be indicative of weakened respiratory muscles. It is important to measure the VC in both the supine and upright positions, because with muscle weakness, VC is significantly lower in the supine position. If the tests show significant abnormality indicating weak breathing muscles, then I would consider using a ventilator rather than CPAP.

When there are night-time breathing problems in someone with neuromuscular disease, it is most likely due to respiratory muscle weakness, rather than OSA. However, some individuals may have only OSA or have both neuromuscular weakness and OSA.

Whether to use a portable volume ventilator or bi-level pressure device is an important decision. Sometimes the choice reflects the experience and training of the pulmonary physician or respiratory therapist. Often cost is a factor — in Europe, the costs of the bi-level pressure devices and the volume ventilators are not as disproportionate as they are in the United States. There is a wide range of practice, in some cases questionable, such as using bi-level pressure support for tracheostomy ventilation. Currently, the FDA only authorizes the use of a bi-level pressure support system for not more than 12 hours per day, even though some ventilator users report good experience using it almost 24 hours per day.

The ventilator which is most comfortable for the user and fits his or her individual ventilatory needs best should be the overriding choice. The physician, respiratory therapist, and ventilator user should collaborate on determining the best system, although ventilator users are not often given the opportunity to try different ventilators and systems.

## Volume Ventilators

**ADVANTAGES:** 24-hour use, well-suited for tracheostomy ventilation, overcomes airway secretions and resistance, delivers a set volume of air at higher pressure to help cough, easier wheelchair mounting, works off battery power easier, internal battery, external battery can be used also, safety alarms.

**DISADVANTAGES:** Higher cost, heavier.

**EQUIPMENT:** Nellcor Puritan Bennett LP6, LP10; Respironics PLV-100, PLV-102; Bear 33; Brompton PAC; Breas 501; EV 801; Monnal D, Monnal DCC; Eole 2, Eole 3.

## Bi-Level Pressure Devices

**ADVANTAGES:** Lightweight, lower cost, easier to use, adjusts better to leaks.

**DISADVANTAGES:** Not FDA-approved for more than 12 hours per day, not well-suited for tracheostomy ventilation, no internal battery, not as commonly used with external battery, no safety alarms, noisier, expiratory pressure unnecessary for some patients and may cause thoracic discomfort.

**EQUIPMENT:** Respironics Bi-PAP® S/T, Healthdyne Tranquility PSV model 7700, Nellcor Puritan Bennett Knightstar 335, ResMed VPAP® II ST, Taema DP90, AirSep Remedy.™ ■

ADDRESS: E.A. Oppenheimer, MD, Southern California Permanente Medical Group, 4950 Sunset Boulevard, Los Angeles, CA (California) 90027-5822 (eaopp@ucla.edu).

## Trach Changing Tips

Gail Anderson

I have been changing my own tracheostomy tube for 10 years. I order a specialized thin cuff (PRV Cuff from Shiley) to cut down on the resistance of the tube going in. This has always been a rather anxiety producing procedure for me, especially after one occasion when I could not get the tube in and had to visit the emergency room. After I could no longer breathe on my own, I knew it was critical to get the tube in place quickly after removing the old one. Now, when I disconnect the ventilator from the trach before I pull out the old tube, I place the swivel adapter in my mouth, and breathe through my mouth. The respiratory therapists did not think it would work ... the low pressure alarm would go off, I would lose too much air through the open stoma, etc. ... but it does.

I also prepare the tube differently before inserting it. In the past, I had tapered the cuff distally while removing the air from it, but this presented a rather thick section at the proximal end of the cuff. Now as I remove the air from the cuff, I grasp the cuff tightly and twist it around the tube. The distal end is still tapered, but the bulk of the cuff is spread out, rather than bunched at the proximal end.

I schedule a visiting nurse to be present when I change the trach tube, just in case my other techniques do not work. ■

ADDRESS: Gail Anderson, 111 Country Club Boulevard, Apt. 210, Worcester, MA (Massachusetts) 01605 (beadgander@juno.com).

## The Ideal Machine

John W.H. Watt, MB, ChB, FRCA, MD

As a practising anesthesiologist, I treat people with spinal cord injuries who use ventilators at the Southport Regional Spinal Injuries Unit. After 1981, the unit began receiving referrals of people with acute high tetraplegia and long-term ventilator dependency (LTVD).

The need for a LTVD programme was initially unexpected, but fortunately we had many semi-redundant East Radcliffe pressure-generating ventilators. (I am indebted to Dr. Geoffrey Spencer, former head of the Lane-Fox unit at St. Thomas's Hospital in London, for demonstrating the value of these old ventilators.) Because the East Radcliffe was safe and simple, we initially used them in the homes for bedside ventilation. The portable version was extremely limited for use as a wheelchair-mounted ventilator, but both are virtually unobtainable now.

This necessitated the search for a substitute ventilator which would maintain an inflation pressure if used with an uncuffed tube while having the advantage of adjustable alarms for leaks or obstructions. I have now evaluated 17 ventilators for tracheostomy ventilation. I would be interested in readers' comments about an ideal ventilator. ■

ADDRESS: Dr. John W.H. Watt, Southport and Formby NHS Trust Hospital, Spinal Injuries Unit, Town Lane, Southport PR8 6PN England (jwhwatt@mauriceg.demon.co.uk).

If there is someone you would like us to send a complimentary issue of *IVUN News*, please contact International Ventilator Users Network, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915 USA (314/534-0475, 314/534-5070 fax, gini\_intl@msn.com).

**IVUN Resource Directory 1997/1998**

is an excellent networking tool for health professionals and both longterm and new ventilator users. Sections are dedicated to health professionals, ventilator users, equipment and mask manufacturers, service and repair, organizations, etc. The cost is \$5 USA; \$6 Canada, Mexico, and overseas surface; \$7 overseas air (US funds only).

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**7th International Conference on Home Ventilation  
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From Critical Care to Home Care**

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American Association  
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International Ventilator  
Users Network (IVUN)  
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and Research Center

This is a very important meeting for ventilator users to attend. Here is an opportunity to interact with pulmonologists and respiratory therapists, to let them see how you live and breathe. Discussion groups and round tables will enable ventilator users to meet each other and to network.

Attendance at the scientific program meetings will be open to ventilator users and spouses/attendants. IVUN sessions during the meeting will feature ventilator users as panelists. Topics include sleep-disordered breathing, oxygen therapy, bi-level vs. volume ventilators, nutrition, swallowing, assisted coughing, frogbreathing demonstrations, attendant care, policy issues, pediatric noninvasive ventilation, camps for ventilator-assisted children, etc. There will also be exhibits of masks and new ventilator technology.

Registration fee for ventilator users is \$100 before the deadline of January 15, 1999; \$125 after the deadline. Attendants and spouses are free. The rate for a queen double room is \$159 per night, plus applicable taxes. Free breakfast is included. The Caribe Royale Resort Suites is a new hotel and in compliance with the ADA. All wheelchair accessible rooms with roll-in showers will be blocked out for the conference.

For registration information, contact International Ventilator Users Network (IVUN), 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915 USA (314/534-0475, 314/534-5070 fax, gini\_intl@msn.com).