International Ventilator Users Network (IVUN) SAINT LOUIS, MISSOURI USA

> Spring 1998 Vol. 12, No. 1 NOW QUARTERLY

# wum mews

# Kalte Könkkölä

**1** was born in 1950 in Helsinki, Finland, disabled since birth due to a muscle disease. I was able to walk a little from age 5 through age 8, but after that I became a wheelchair user. My parents had good luck in placing me in a regular school. That was not easy to do during the '50s, but I was tutored privately by a teacher who was a first grade teacher in the school.

I had studied math in the Universitu of Helsinki for several years. but my life changed when I began using a ventilator in 1971. I spent five months in hospital trying to adapt to it. It was a very difficult process. Now I am happy euthanasia was not available back then. At that time I felt I was doomed - tied to a ventilator for the rest of my life. There was no reason to live. Some nurses and my girlfriend kept me alive. Today my feelings are a lot more positive. because the ventilator opened the world to me.

Eventually, I met other ventilator users. An older guy told me, "Oh, man, we can be proud of our expensive ties!" That statement opened my eyes.

At that time, I was one of the few people with a disability to have personal attendants at home. I quickly recovered from depression. In 1972, I started questioning why so many things were difficult for people with disabilities. Why were there stairs everywhere? Why was transportation not accessible? I used to think, like many of my friends, that it was my fault I could not walk up the stairs. Then I began to wonder who had built the ugly stairs. In 1973, I founded The Threshold, an educational organization of disabled people, in cooperation with other students who were disabled. We quickly solved the problems we had in university. It did not take us long to realize that we were the lucky ones: the majority of disabled people had almost no education. The Threshold slowly became a human rights organization of people with disabilities, and now runs six independent living centers in Finland.



When I visited the United States in 1975, I learned that what we were doing was part of the independent living movement. I met many highly esteemed disability activists like Judy Heumann and Ed Roberts. It was a relief to meet them — our small group was not alone in the world. There were others who thought the same way.

I became politically active, and joined the Green Party in Finland in 1982. I was a member of parliament for four years. Since then I have been a member of the city council in Helsinki, and am also chairperson of the Helsinki health board. It has not been easy to be a politician with a disability. Last year I ran for deputy mayor of Helsinki, but I never had a chance. The media made a big issue of my disability, saying that a disabled person cannot successfully handle such a high post.

Involvement with Disabled Peoples' International (DPI), a global human rights organization of disabled people, is closest to my heart. Disabled people all over the world, regardless of their disability, have joined together to change the world.

As chairperson of DPI since 1994, I have discovered that traveling to developing countries with a ventilator is an adventure, sometimes dangerous. A ventilator is, increasingly, like just another technical aid, however, breathing has more significance than many other functions in life.

One of the great moments in my life occurred at the General Assembly of the United Nations. In that huge room, an electrical plug was installed, just for me and my ventilator.

Address: Kalle Könkkölä, Chair, Disabled Peoples' International, P.O. Box 267, FIN-00171 Helsinki, Finland (358/9-160-4312 fax).

Assisted Cough ..... Travel with Ventilators ......4 This issue printed courtesy of Nellcor Puritan Bennett, Inc.



# Assisted Cough: Benefits and Techniques

A variety of techniques to improve the ability to clear secretions without tracheostomy

### Manually-Assisted Cough

#### Susan Sortor Léger, RRT

An individual's ability to take a good cough will be hindered by not having good chest musculature to compress a big breath, or by not being able to take a deep enough breath.

If an individual can take a good, big breath, but does not have good chest muscles, a respiratory therapist or caregiver trained in the manually-assisted cough technique can help compress that air by placing one hand over the chest and one hand on the abdomen. The individual takes a big breath, and then the therapist or caregiver compresses manually. The person who is helping should be standing in front of the person trying to cough, because he or she needs to see what is happening, and coordination and timing are very important. One must compress just a few seconds before the person exhales, pushing hard against a closed glottis a split second before exhalation. The push should not hurt, and in some cases, a push on only the chest can be effective.

From personal experience, I can tell you that the manually-assisted cough technique can be exhausting for the therapist or caregiver, and does not work for someone who cannot get a big breath to begin with. One way to give a big breath is to use IPPB (intermittent positive pressure breathing) with the volume between 2 L-4 L.

For that volume with someone with a normal compliant lung, the

pressure should be 10 cm for each L. For people with scoliosis or rigid chest wall, more pressure is needed, but not enough to burst the lungs and incur barotrauma. Pressure limited at 40 cm is recommended to give a good deep breath. People need to be relaxed and not tense up, to let the air in and let the machine do the work.

Another way ventilator users can get a deep breath is by using a volume ventilator. Manual resuscitators can give a breath, but the stroke volume capacity is only 800 cc. This is not enough to cough with, so I teach people to stack their breaths — take a breath, hold it, and stack one breath on top of the next.

Address: Susan Sortor Léger, RRT, Respironics Europe, 11, Place Royale, F-44000 Nantes, France (33 (0)2 51 72 96 66, 100416.2406@compuserve.com).

### The In-Exsufflator Cough Machine

### George Emerson

The In-Exsufflator Cough Machine is a device for helping clear secretions in people who have difficulty with coughing. It has been used for people with post-polio, muscular dystrophy, SCI, and ALS. This device is similar to one made in the 1950s called the Cof-flator, designed for polio patients in iron lungs to help clear secretions. About six years ago, Dr. John Bach came to us because he had a number of post-polio patients still using the old Cof-flator, but the machines were breaking down and were no longer manufactured. He asked if our company could make a new machine, and thus we developed the In-Exsufflator Cough Machine.

The machine operates with a blower and a valve that applies a positive pressure first to give a deep breath in, and then shifts rapidly to negative pressure to create a high expiratory flow, like one has with a normal cough. It can be used on a person with a trach or someone without a trach through a face mask or mouthpiece. The circuit is a bacterial filter, a pressure tap, and a hose to the face mask or adapter to the trach tube. There are two

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#### international ventilator users network (ivun)

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IVUN News links ventilator users with each other and with health care professionals interested in mechanical ventilation and home care. ISSUED IN MARCH, JUNE, SEPTEMBER, DECEMBER

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### The Ventilator-Assisted Child: A Practical Resource Guide

by Lynn E. Driver, Virginia Simson Nelson, and Seth Warchausky. San Antonio, Communication Skill Builders, 1997. 222 pages, 8-1/2 X 11, spiral-bound. \$59 plus S & H and tax. To order call: 800/211-8378.

An excellent, comprehensive book for both health professionals and families. Information and resources from a multidisciplinary team about ventilator-assisted children from birth through adolescence in the home, school, and community. Everything in wonderful detail about pediatric home mechanical ventilation, including longterm airway management — the different kinds of trachs and why; speech and communication needs; feeding and swallowing problems; physical therapy, leisure and recreational activities; finding and obtaining financial resources; and a welcome chapter on sexuality for ventilator-assisted adolescents and their families. Replete with diagrams, charts, checklists, tables, case histories, references. Highly recommended.

Darlene Russ's chapter entitled "A Family's Perspective" in The Ventilator-Assisted Child contains much needed in-depth practical information on getting the child home, working with the school, and living in the community. It is also a moving tribute to her son, David Ecker-Russ, who died in June 1996. The following is a letter David wrote to his prospective middle school classmates.

# From the Desk of David Ecker-Russ

#### Hi, my name is David Ecker-Russ.

It's time for middle school, and I'm looking forward to meeting new friends and teachers ...

Mr. Houston wanted a letter to send home for parents and students to tell you about me. I'm 11 years old. I have a rare form of muscular dystrophy. It is severe; many of my muscles work poorly, and some do not work at all. That does not stop me from doing the many things I enjoy. I like going to school and doing things other guys my age like to do. This summer I went fishing, camping, went to a dance, saw many movies, went on a hay ride, swam, and rode horseback for the first time. I love roller skating, birthday parties, and I like girls, of course.

My nurse and I will attend school together. Please do not be afraid of my wheelchair and equipment. One of my doctors said to think of it as

an astronaut's gear, only we call it a responaut. Just like an astronaut. I take everything that I need to breathe, but instead of in a space capsule, it is in my chair. On the back of my chair, you will see a brown and silver box. That is my ventilator. This little machine breathes for me. I cannot take one breath by myself, but my ventilator pushes air into my lungs. My ventilator will alarm when I am being suctioned or when I am disconnected, but my nurse will take care of it, so do not be worried. The black box under my chair is a battery that runs my ventilator when I am in my chair. My mom plugs it in every night to recharge it for the next day. My suction machine rides on the back of my chair, and is used to clear out my mouth and throat because I cannot cough or swallow. There is a pulse oximeter on my chair. It reads my pulse and the amount of oxygen in my system.

It has a continuous beep, but does not stay on me all the time. It is used every hour and sometimes in between if needed. Finally, there is a small blue respiratory bag on the back of my chair. This is like a bellows and is used to give me breaths of air when I am being suctioned or when the ventilator is not working correctly.

Since I cannot swallow, I am fed through a gastrostomy tube in my stomach. It is connected to a bag of liquid food that runs through a feeding pump and hangs on the handle bars of my chair. I do not taste it; but my imagination is great. I think of it as what everyone else is eating, and it tastes great, but you may not want to trade lunches with me. I love a good joke, and I am a good listener. I would enjoy your company in the lunchroom.

To communicate, I blink for yes and look up for no. I shrug my shoulders for *I do not know*. I understand everything that is said, and keep secrets really well. I have a computer and a special eye blink switch that I will use in class. I enjoy people, and it does not hurt me if you touch or talk to me.

My friend, a respiratory therapist from the university hospital, will come tomorrow. She will show you how the ventilator and suction machines work. She will bring mouthpieces and a ventilator, so if you want, you can see what it feels like to be on a ventilator.

Muscular dystrophy is not contagious, and you cannot get it by touching me. I am thankful for the many friends I made at my last school, and I hope to make a lot of new friends here at middle school.

Your classmate, David Ecker-Russ

From The Ventilator-Assisted Child: a Practical Resource Guide, San Antonio, Communication Skill Builders, ©1997. Reproduced by permission of The Psychological Corporation.

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# Airline Travel with Ventilators

**Lori Hinderer**, ventilator user, updates general suggestions and advice on airline travel with ventilators from *IVUN News*, Spring 1992. Lori has traveled on America West and TWA without problems. Contact Lori Hinderer, 9225 Tanque Verde Road, #52-102, Tucson, AZ (Arizona) 85749-8393 (LoriH@compuserve.com).

### **Making Reservations**

♦ Start early. Make first contact with reservations agent, and explain about the ventilator and battery so that information becomes part of your record. Then ask for a customer service representative. Detail your needs clearly, because most people are not familiar with ventilators. Write down the name of the customer service representative, and the day and time you called. Ask for a seat as close to the front as possible, although you may be seated in a row with an electrical outlet if you are able to use the aircraft's power.

♦ The ventilator and batteries may need to be pre-approved by the airline engineers. Be ready to provide the ventilator name and model number; the manufacturer's name, address, and phone; the type of batteries used. (Have it already written down so you can bring that piece of paper with you.) Most airlines will allow batteries of the dry or gel cell variety on board, as long as they fit under the seat.

Ask for the specifications for under-the-seat space (different for each aircraft and seating class) to ensure that your ventilator or battery will indeed fit there.

 Ask your physician for a brief letter explaining why you need a ventilator and her or his approval of your travel.

### Departure

♦ Arrive at least 2 hours before departure time.

♦ Bring the name and phone number of the customer service representative who booked the flight. Bring all the ventilator and battery operation details. Bring the letter from your physician explaining your diagnosis and approval to make the flight.

• At the gate, ask for any courtesy first-class seats that might be open.

♦ If there is any problem when you are at the gate, ask for a complaints resolution officer (CRO). All airlines are required to have one available at the airport. This person is empowered to act on behalf of the airlines, and may or may not be overruled by the pilot for safety reasons.

• Bring a traveling companion. Some airlines require that you have an attendant with you. If you are traveling alone, request a flight attendant to assist you in an emergency situation.

### **United States Airlines**

Foreign airline carriers' policies will be detailed in the summer issue of *IVUN News*.

Alaska Airlines. 800/426-0333. No electrical hookup. Ventilator and dry or gel cell battery accepted on board, if each will fit under the seat and overhead. Explain about battery to gate agent upon check-in. Battery operation permitted in-flight, apart from take-off and landing.

America West. 800/235-9292. No electrical hookup. Ventilator and dry cell battery accepted on board. Battery operation permitted in-flight, apart from take-off and landing. For more information, call Mollie Crawford, 602/693-8643.

American Airlines. 800/ 433-7300. No electrical hookup. Ventilator and battery must be pre-approved by American's engineers. Must provide ventilator name and model number, manufacturer's address, and phone.

**Continental Airlines.** 800/523-3273. No use permitted in-flight. Ventilator and dry or gel cell battery accepted on board, if each will fit under the seat and overhead.

**Delta.** 800/221-1212. No electrical hookup. Ventilator and battery not permitted on board, but can be checked from gate to gate.

Northwest Airlines. 800/225-2525. Electrical hookup permitted in flight if compatible with aircraft type and 115V/400Hz. Battery (dry or gel cell) operation permitted in-flight, apart from take-off and landing. An attendant must accompany passenger. Medical statement from physician required.

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*New Horizons for the Air Traveler with a Disability.* Free from the Department of Transportation, Office of Consumer Affairs, 400 Seventh St., SW, Washington DC 20590 (202/366-2220).

The Air Carrier Access Act: Make It Work for You. Free from Paralyzed Veterans of America. Phone toll-free: 888/860-7244.

# Ventilator Transport: More Than a Little Red Wagon

Gail Anderson

Born in 1944, I experienced respiratory problems due to kyphoscoliosis throughout my childhood. When I was 22, my blood gas studies looked poor, and I began to use supplemental oxygen while working. Frequent lung infections and congestive heart failure, accompanied by decreasing energy, made me realize that I could no longer be effective as an occupational therapist. I signed on for disability insurance, and pursued other interests. including jewelry-making. In 1981. I went into respiratory failure while hospitalized, and awakened in intensive care, intubated. The next day I received a tracheostomy.

I used the ventilator mainly at night until 1995, when extreme fatigue hit. My breathing became worse and worse until I needed to use the ventilator more during the day. If I were to be at all active, I would have to find a way to take the ventilator with me while walking about. It seemed that my problem was unique because of my being ambulatory. A wheelchair with a ventilator tray was not an option, because the wheelchair could not be collapsed with the ventilator tray, and I did not have a van. With the combined knowledge of my brothers (one computer programmer and two engineers) and myself, we set out to come up with something that would meet my needs.

Mobility and transportability were the key requirements. I had to be able to move all the equipment around my apartment with ease, but then everything had to come apart to load into the car. Strength was another factor; the combined weight of the ventilator, the gel cell battery, and portable oxygen is about 70 lbs.

My occupational therapy background made me think that we



could probably purchase something already manufactured which could be adapted. I had seen sturdy four-wheeled walkers with adjustable handles and baskets, and at a local medical equipment supply store, my brother obtained pamphlets and measurements of different walkers. Drawings were then made of possible shelving that could be custom-made and attached to the walker to carry all my equipment.

At first, it seemed that the weight of the ventilator on the front of the walker would shift the center of gravity so far forward that the entire walker would tip over. Thanks to some respiratory therapists, I found that I could tip the ventilator onto its back side, setting it on plastic projections. This position brought the weight farther back behind the front wheels of the walker.

After testing several walkers at the medical equipment supply store to see how they folded up and how they would fit into my car, I ordered a heavy duty walker (manufactured by Walker Works Manufacturing, Inc., 7670 Winston Street, Burnaby, British Columbia V5A 2H4, Canada, 800/667-4111) that seemed best suited in design and durability. A letter from my physician to Medicare, explaining the unique purpose for the walker, resulted in 80% reimbursement.

When the walker arrived, a prototype shelf was constructed initially of fiberboard with reinforcement on the bottom, later replaced with 3/4-inch plywood. It was made to fit snugly on the front framework of the walker and on a custommade metal L-shaped bracket screwed into the rear framework. A longer bolt replaced one already being used as part of the rear folding mechanism; it now holds the support bracket as well as the folding mechanism — no additional drill holes were needed to attach the shelf. A handle was made around the gel cell battery with webbing, Velcro, and foam pipe insulation to make it easily transferable from place to place. Bungee cords hold the ventilator in place on the walker shelf.

When the walker is pushed up to the passenger side door of my Honda Civic (the passenger seat was removed and a raised wooden floor put in its place), the shelf is level with the car door sill. The hand brakes of the walker are Assisted Cough: Benefits and Techniques CONTINUED FROM PAGE 2

models: one with automatic timing and one manual.

Typically, a session of coughing with the machine involves cycling the unit positive, then negative, in quick succession about five to six times. Then the patient is allowed to rest for a minute in order to prevent hyperventilation which can occur after more than five to six times in a row. This pattern is repeated four to five times. When secretions arise, they come out into the mask or are spit out. The endotracheal tube can be suctioned for a patient with a trach.

Pressures should start low, about 10-20 cm as tolerated, and then build up to 40-45 cm to get deep insufflation. The timing for the positive-negative is one to two seconds. The positive and negative pressures are set about the same, though some people like the inspiratory pressure to be slightly less.

A cough session takes about 10-15 minutes for secretion removal. Many therapists are afraid to use higher pressures, but to be effective, pressure should be in the 40-45 cm range. For home use, Dr. Augusta Alba recommends the automatic version, although it is more expensive. Dr. Bach has suggested using the In-Exsufflator in the manual mode along with a manual thrust to combine the effects of the high flow from the machine and the positive pressure buildup from the thrust.

Many patients do not need to use the In-Exsufflator continuously, just for respiratory tract infections. Many have avoided pneumonias that required hospitalization and intubations by using the device. Dr. Alba has advised home health care agencies to stock the machines to be able to rent them out for just such emergencies. She also hopes more hospitals will make them available. She advises people to try the In-Exsufflator before they need it so that they will know what to expect.

The cost for the automatic unit is \$3,700; the cost for the manual is \$2,800. Medicare does not have a code for the In-Exsufflator; Medicaid is more likely to pay for it. Some private insurers will pay. The In-Exsufflator is available on a weekly rental basis through most of the Respironics Customer Satisfaction Centers. (Call 800/669-9234 for the one nearest you.)

Address: George Emerson, Vice President, J.H. Emerson Co., 22 Cottage Avenue, Cambridge MA (Massachusetts) 02140 (800/252-1414, info@jhemerson.com, Web site: www.jhemerson.com).

### Functional Electrical Stimulation (FES) for Cough

Steven Linder, MD, FCCP

I work on a service with patients with traumatic spinal cord injury (SCI), which is upper motor neuron disease, and tends to be spastic paralysis. Therefore, problems with respiratory insufficiency are different from those in people with post-polio because they are problems with spasms in the respiratory muscle. Our respiratory management includes incentive respiratory muscle training, inspiratory spirometry, and visual incentives because the patients cannot feel their chests expanding, but can see the chest and abdomen rising and falling with their inspiratory efforts.

With cervical SCI, there is paralysis of the abdominal wall and ineffective coughing. We see a reduced ability to cough, and therefore patients at increased risk for ventilatory insufficiency and lower respiratory tract infections. Monitoring the ability to deep breathe and cough and the need for aggressive respiratory therapy (if necessary, tracheostomy) are important parts of our work.

One of the simplest things we can do is to supply these patients with an abdominal binder. When they sit up, we find that their ventila-tory insufficiency is worsened. Therefore we encourage them to wear an abdominal binder, because this not only helps them take a deeper breath when they are sitting up, but also helps them cough. We teach our patients assisted cough, and how to teach their attendants to deliver forceful abdominal thrusting to help them cough.

We have measured expiratory pressure (the force of cough) in cervical SCI. We found values of about 200 cm of water pressure with a normal cough, but values of about 30 cm of water pressure when an individual with guadriplega coughs. Several years ago, we looked at ways to restore the ability of these patients to cough. one being functional electrical stimulation (FES) of the abdominal wall. Electrical stimulation had been used before, but it had been surgically implanted in the diaphragm, as a diaphragm pacemaker. This was only for the inspiratory effort, this had nothing to do with cough. Diaphragm pacers are still used in selected cases of high cervical SCI injury as a way of restoring ventilation, but they do not address the issue of cough.

We observed that when we applied electrodes to the abdominal wall, we could stimulate abdominal wall contractions in patients with upper motor neuron disease. (We did not try this with patients with lower motor neuron disease and myopathies, because we did not think it would be as effective.) We placed the unit in conjunction with an abdominal binder and the electrodes, the patients lying on their backs. We measured three cough modes: spontaneous cough, cough using abdominal thrusts, and cough using abdominal wall FES. We delivered the stimulation to four-six electrodes simultaneously. In one patient whose spontaneous cough was only 30 cm of water pressure, FES stimulation in-creased the cough to 80 cm. a marked enhancement of the patient's ability to cough. We showed that we could improve expiratory pressure by application of abdominal wall electrical stimulation.

With the unit we have now developed, known as Quik-Coff<sup>™</sup>, the advantage is that patients can use the unit independently. They can take a deep breath, hit the switch with their chin causing abdominal wall stimulation, and cough. The unit is portable, about the size of a pager, and is powered by a 9V battery. Several sites are testing the Quik-Coff<sup>™</sup>: the VA spinal injury unit in Hampton,Virginia, and in California at University of California-Davis and Kaiser Permanente-Vallejo.

The Quik-Coff<sup>™</sup> is manufactured by B & B Medical Technologies, Inc. (P.O. Box 1503, Orangevale CA (California) 95662-1503 (916/635-5221, www.BandB-medical.com), and is now available in Europe. Availability in the United States is pending FDA approval. Market price for the unit including all accessories is \$1,400. ■

ADDRESS: Steven Linder, MD, FCCP, VA Medical Center, 128 SCI, 3801 Miranda Avenue, Palo Alto, CA (California) 94304 (415/493-5000, x643, ssl@icon.palo-alto.med.va.gov).

## Attendant Care Legislation: MiCASA

Designed to amend Medicaid, the Community Attendant Services Act (H.R. 2020), known as MiCASA, would redirect longterm health care funding, now restricted to institutional use, toward a consumer-controlled system. MiCASA is hailed by Americans with Disabilities for Attendant Programs Today (ADAPT) as a long overdue first step towards future and expanded national attendant care legislation. A similar bill (S.879) has been introduced in the Senate by Senator Russell Feingold (D-WI).

MiCASA would create a new Medicaid service called "qualified community-based attendant services." It would enable any individual eligible for nursing facility services (NF) or intermediate care facility services for the mentally retarded (ICF-MR) a choice of institutional services, communitybased services, or attendant services. In an attempt to rein in Medicaid spending on longterm funding of nursing home care, the bill's cost control measures would make it possible for two people with disabilities to receive funding for in-home or community-based care for every one person with a disability who now receives the same care in a nursing home.

Based on an assessment of functional need, the services are to be selected, managed, and controlled by the consumer with voluntary training on how to select, manage, and dismiss attendants. Included are backup and emergency attendant services. A key provision allows health-related tasks to be assigned to, delegated to, or performed by unlicensed personal attendants. The bill also covers individuals with incomes above the current institutional income limitation, if a state chooses to waive this limitation, because the potential for employment would be enhanced by providing these services.

Once passed, the bill requires each state to develop a long-term care services transition plan, with major participation by independent living councils, developmental disabilities councils, and councils on aging. The plan must include specific action steps and timetables.

MiCASA hearings were held in March 1998 by the House Subcommittee on Health and the Environment, headed by Representative Michael Bilirakis (R-FL). Ventilator users are urged to become involved in the debate.

To do so, contact Rep. Bilirakis, House Committee on Commerce, 2125 Rayburn House Office Building, Washington DC 20515 (202/225-2927, commerce@mail.house.gov). ■

### IVUN Resource Directory

**1997/1998,** compiled by *IVUN News* editor Judith Raymond Fischer, is an excellent networking tool for health professionals and both longterm and new ventilator users. Sections include listings of 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).

#### Airline Travel with Ventilators CONTINUED FROM PAGE 4

**Southwest Air.** 800/435-9792. No electrical hookup. Ventilator and dry or gel cell battery accepted on board. Battery operation permitted in-flight, except for take-off and landing.

**TWA.** 800/221-2000. Case-bycase basis. Must be approved by medical services and engineering departments.

United. 800/241-6522. Electrical hookup permitted in some cases. Must provide ventilator and battery names and model numbers, manufacturer's address and phone. Dry cell battery accepted on board if it will fit under the seat. For more information, call Aero-medical Department, 800/825-6331.

**US** Air. 800/428-4322. No electrical hookup. Battery must be stored in cargo hold. ■

### Ventilator Transport

CONTINUED FROM PAGE 5

then locked prior to the transfer of equipment from walker to car. I slide each piece into the car. ventilator-still operating - first, next battery, then oxygen. (Wooden blocks screwed into the flooring and more bungee cords hold the equipment in place.) The shelf is removed from the walker and positioned alongside the ventilator and battery. Finally the walker is folded up, placed on top of the other equipment, and strapped down. I disconnect myself from the ventilator, walk around to the driver's side, and reconnect myself to the ventilator.

The equipment and walker weigh almost 100 lbs., and it is a lot of work to transfer everything back and forth, but I am able to get out and about unassisted. I choose my trips carefully. One concern was that I would automatically lock the passenger door before walking around to the driver's side, leaving all my vital equipment unavailable inside. Now I unlock the driver's side first before I even unload the equipment on the passenger side. I also wear a spare car key around my neck, just in case. An ambu bag and a cellular phone accompany me on any journey. The setup works perfectly.

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

Watch for more information on ... Noninvasive Ventilation: Across the Spectrum — From Critical Care to Home Care, March 14-17, 1999, Caribe Royale, Orlando, Florida.

> 4207 Lindell Boulevard, #110 Saint Louis, MO 63108-2915 USA

### Gazette International Networking Institute

### 1998 CAMPS FOR VENTILATOR-ASSISTED CHILDREN

APRIL 3-9. Ventilator-Assisted Children's Center (VACC) Camp, Miami. Contact Bela Florentin, VACC, 3200 S.W. 60th Court, Suite 203, Miami, FL 33155-4076. 305/662-VACC.

MAY 31- JUNE 6. Trail's Edge Camp, Mayville, Michigan. Contact Mary Dekeon, RRT, C.S. Mott Children's Hospital, University of Michigan, 200 E. Hospital Dr., F3064, Box 0208, Ann Arbor, MI 48109. 313/763-2420.

JUNE 15-19. CHAMP Camp, Recreation Unlimited, Ashley, Ohio. Contact David Carter, RRT, CHAMP Camp, P.O. Box 40407, Indianapolis, IN 46240. 317/787-4555.

JUNE 19-21. Adolescent Retreat for CHAMP Campers 17 years and older.

JUNE 21-26. Pennsylvania Vent Camp, Camp Harmony Hall, Middletown, Pennsylvania. Contact Debra Ranler or Michael Dettorre, DO, Pennsylvania Vent Camp, P.O. Box 850, Hershey, PA 17033. 717/531-5337.

JUNE 28-JULY 3. Camp Inspiration, Rocky Mountain Village, Empire, Colorado. Contact Monte Leidholm, RRT, The Children's Hospital, 1056 E. 19th Avnue, Denver, CO 80218. 303/837-2502.

SEPTEMBER 3-6. SKIP Camp, Seashore Methodist Assembly, Biloxi, Mississippi. Contact Judy Abney, SKIP of Louisiana, 118 Ned Avenue, Slidell, LA 70460. 504/649-0882.