

# I.V.U.N. NEWS

International Ventilators Users Network

Spring 1992 ■ Volume 6, No. 1

## Ventilator Use in Japan

by Yasuoka Kikunoshin  
(from "Another Voice," October 1991)

The most urgently needed system now, and at the same time the biggest obstacle for ventilator users, is the problem involved in the purchasing of the ventilator. Ventilators should be provided to users like other everyday equipment, e.g., electric wheelchairs.

Last year, home ventilation treatment became a category under health insurance as "home ventilation instruction and managing fee," counting 1500 points. This means that, if used, the hospital will get 15,000 yen a month. This is slight progress, but no one has used this system and started to live at home. The points are so low that the hospitals wouldn't get any advantage. Some say that hospitals will purchase ventilators by the money they can get from the insurance, but I think that is very unlikely and unrealistic. No hospital would use such low insurance money to provide new ventilators to each individual with a disability who needed one.

Ventilators and expenses can amount to approximately 3 million yen (about \$22,000 USD), and are paid by the individual. Even if you have the money, the medical equipment vendor will not sell it to an individual. Currently, the purchase is performed in a round-about manner. The individual donates the money equivalent to the price of the ventilator to the hospital and then the hospital lends the equipment to the individual for an indefinite period. This is the only way to get a ventilator and live at home in the community.

Some local self-governing bodies, like the Niigata prefecture (since 1990) and Tokyo (from this year), have developed systems of subsidies to the purchase of ventilators. These are systems in which hospitals who practice home mechanical ventilation can ask the local government for subsidies when purchasing a ventilator.

Unfortunately, in Sapporo or in Hokkaido, there are no subsidies. There is only one ventila-

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## Spring Has Come

by Sato Kimiyo  
(from "Another Voice," May 1991)

It is May 1991 and it has been one year since I left the hospital to live at home. It seems almost a miracle to have survived, having the most serious disability with a ventilator and living independently among the community.

I had spent all my days from childhood in hospitals or medical institutions. For years I watched the spring scenery from hospital windows. All that surrounded me were the white ceilings and the prosaic square windows. How I yearned to be in the outside world! When it snowed, I searched for the most beautiful sight I could get from the windows, steering my electric wheelchair.

The longing to see more, to place myself in the scenery seen beyond grew so strong, I gradually became determined to leave the institutional life, and I finally did it at the age of 25.

It was not until I was 20 that I happened to see a leaflet introducing a portable ventilator. At that time I was leashed to my bed by the hospital ventilator. The one in the leaflet was small and could be operated by home electricity. I thought, "If I can get this, I can leave here and step out into the outside world." I started to save money from my pension to make my dream come true, although the money was only a small amount. The price of the device was 2.5 million yen (\$20,000 USD approximately), which meant it would take years and years to reach my goal. But I didn't care, I was determined to get it. Now, as I

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## Ventilator Use in Japan

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tor user equipped in Union of Patients with Obsolete Diseases in Hokkaido. There are only two ventilator users in Sapporo, and I suspect that there are not so many even in Niigata or Tokyo where there are subsidies. There are no statistics for people using ventilators in the community.

The important thing is to make the national government legally admit the ventilator as everyday equipment or subsidiary equipment and

include it in the medical benefit of the welfare project for those who are disabled. The government should also make the ventilator available to individuals, not just medical institutions. The medical institution should support the ventilator user living at home.

**Editor's Note:** The consensus among American ventilator manufacturers who market ventilators in Japan is that the Japanese Ministry of Health is moving slowly toward making ventilator rentals more accessible to those individuals who need them and toward encouraging the use of home mechanical ventilation. The situation is more promising for individuals in the larger cities.

## Spring Has Come

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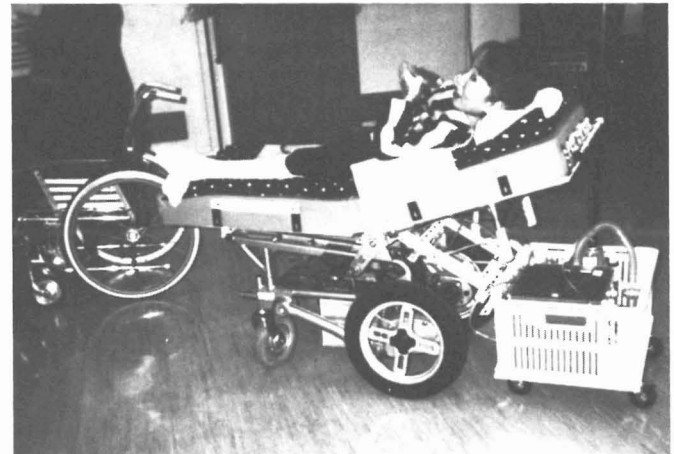
think back, that determination was the first step in my action towards independence.

To live among the community is a difficult task. My disability (muscular dystrophy) is worsened. I am unable to use the electric wheelchair and must use the ventilator 24 hours per day. As I think of my future life with all the difficulties of my body, I almost faint. But I say to myself, in this situation, the important thing for me is to live on with my worsening disability and face the reality.



Even if my disability gets more serious, if I want to feel alive and appreciate this precious moment, the hospital life is not the life for me. It simply cannot provide me with such satisfactions.

Now that I am living in an apartment house, I have a window of my own for the first time in my life. This window is one with a small porch.



"I decided to organize Sapporo Ventilator Users Network in December 1990, and started to publish a monthly newsletter entitled *Another Voice*. After one year, it has a circulation of 200 copies."

The sun shines through it and it is very bright. I can see the mixture of winter bidding farewell and spring giving the message of arrival.

**ADDRESS:** Kimiyo Satoh, #101 Shientuimu Hondori, Kita 7-20, 16 Hondori, Shiroishi-ward, Sapporo City, Hokkaido 003, Japan.

### **International Ventilator Users Network (I.V.U.N.)**

links ventilator users with each other and with health care professionals interested in home mechanical ventilation.

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## More on Ventilator Considerations: Lease vs. Purchase

by Jerry Daniel

After reading Roberta Simon's article in *I.V.U.N. News*, Fall 1991, I decided to call the national home care dealers to see, because I have serviced ventilators for all of these companies (mostly LP4s), if I could get better feedback on the subject of ventilator rental vs. purchase.

I contacted Homedco, Lincare, Glasrock Home Health Care, and Abbey/Foster, and received about the same less than enthusiastic treatment that Roberta did. With most of the companies I was directed to the voice mail of a certain person who did not return the call, apparently when hearing the subject of the call.

The one exception was Homedco. Ed Young, National Director of Respiratory Services, answered my questions and stated their policy. Homedco is mainly in business to lease portable ventilators and to provide all the clinical services related to the use of the machine (home care dealers provide respiratory therapists for home visits to assess ventilator usage, and are required to be on call 24 hours per day in order to provide a backup ventilator). They would only consider selling a ventilator to an individual if that individual was already a medically stable, longterm ventilator user requiring a minimum of home care calls. If they did sell, arrangements would have to be made to supply a backup unit when needed. Young summed it up by saying that Homedco is there to serve the ventilator users' needs with whatever is best for them.

Both ventilator home care dealers and manufacturers cite patient liability as a major issue. They pay large sums for liability insurance. As one ventilator manufacturing executive stated in a trade journal, most ventilator users will die while using the ventilator, but that doesn't mean that the ventilator caused the death.

If a liability lawsuit related to a ventilator user arises, usually both the home care dealer and the manufacturer are named in the legal action. For everybody's benefit, it should be emphasized that if the ventilator fails, it is a home care professional or trained family member using an ambu bag that saves the ventilator user from death or

injury. **One hundred percent reliability on any ventilator is not a reasonable expectation.**

Most ventilator failures that do occur are due to lack of maintenance of the motor. Such failures are predictable and not necessary if preventive maintenance is regularly scheduled, usually every 6,000 hours of use. (The maintenance will necessitate the ventilator being out of use for two or three weeks.) Allowing the motor armature and brushes to wear to the point of failure undermines the integrity of the machine.

In the late '70s and early '80s, there were two engineer/manufacturers at work in the Boulder, Colorado area, producing and selling the portable ventilators that have led to the state-of-the-art ventilators of today. They were Tommy Thompson of Thompson Respiration Products (now owned by Puritan-Bennett) and Richard Apple of Life Products (now owned by Aequitron Medical, Inc.). Both Thompson and Apple were freer to sell more directly to individuals because liability was not as much of a litigious problem, and home care equipment dealers were not as widely dispersed throughout the country as they are today.

Communication with the major manufacturers of portable ventilators about their policies on leasing vs. purchase was much better than with the home care dealers, but the policies are about the same.

Terry Preston, Portable Ventilator Product Manager for Puritan-Bennett, stated that, legally, they can sell a ventilator to an individual with a physician's prescription, but they do not ordinarily do so. An exception is when an individual wants to trade in a unit such as the M-25B for the C2801. They need to know which local home care dealer will be supplying a backup ventilator for preventive maintenance and emergencies.



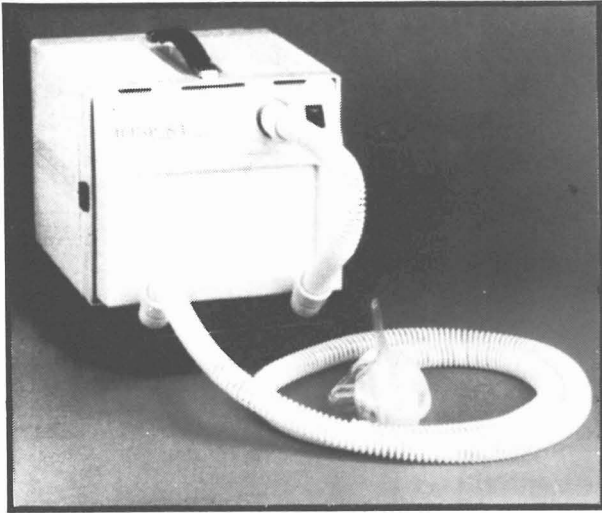
Jerry Daniel

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*Jerry Daniel owns and uses two LP4s, one in the bedroom and one in the living room. He services the complete line of LP ventilators under the business name of VENTEK.*

(continued on page 4)

## A simpler solution.



**The BiPAP® S/T Ventilatory Support System is a less complicated alternative in home ventilation.**

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## More on Ventilator Considerations

*(continued from page 3)*

They prefer to work through a dealer; now the C2800 and C2801 models are widely available through dealers.

Bob McCoy, Product Manager for Aequitron Medical, stated they have taken in many LP3s, LP4s, and LP5s, for the LP6 and now the LP10. They do not deal directly with individuals, but offer trade-in allowances on the LP6 or LP10 through a local home care dealer. McCoy stated Aequitron was offering trade-in allowances on LP6s for the LP10, but discovered from the low response that the LP6 was too valuable a commodity to trade.

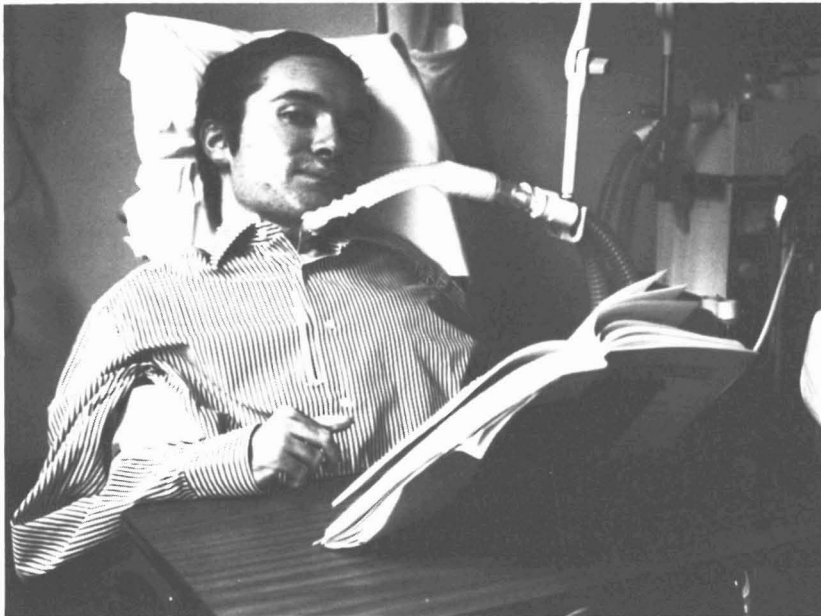
LIFECARE started in the late '60s when it took over possession and servicing of ventilators from the National Foundation of Infantile Paralysis (March of Dimes). LIFECARE is both a ventilator manufacturer and home care dealer with 18 district offices throughout the U.S. and in Europe. They sell their ventilators to other home care dealers and occasionally to individuals. Geoffrey Waters, Senior Vice-President, believes rental is better for ventilator users because all maintenance is taken care of, with either an exchange unit or a loaner supplied during servicing, and should the ventilator need to be changed or updated to a newer model, there is the flexibility to supply what is currently best for the user.

In conclusion, an individual can own a ventilator if he or she has the financial resources and the skills to manage most of the day-to-day usage of the equipment. State-of-the-art ventilators list price for \$8,000-10,000 as compared with about \$600 per month for rental, and prices have remained relatively stable for the last six years. The services of a local home health care dealer are still necessary from time to time, but there will be many months when they will not be needed at all.

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## Face Mask Directory Update

Bud Blitzer is planning to update his *Directory of Sources for Ventilation Face Masks*. If you know of any mask in successful use anywhere in the world that is not listed in the Directory, please send the information to Bud Blitzer, 400 South Saltair Ave., Los Angeles, CA 90049, or, if you prefer, call 310/476-9343 or FAX 310/472-5820. He'll be glad to send a Directory without charge on request.



## *Saludos from Spain*

*by Daniel C. Vilaseca Dreischer*

*I think I start from my early childhood. Due to the fact that I didn't show any interest in walking and had difficulties in getting up from the floor, my parents started to worry. They visited with me many physicians and didn't get a convincing diagnosis until I was 4 years old. Then they were told that I was suffering of MD Duchenne.*

*Now* the problems with schooling started. Not easy to convince educational people to accept that me being physically limited didn't mean that I also was mentally retarded, and therefore there was no reason why I shouldn't go to the same school as my brothers. Anyway we managed all right.

As I couldn't participate in any sport activities, I needed something different to occupy my free time. I started very early to play chess, bridge, party games in general, reading (especially all concerned with history), but my favorite hobby is doing jigsaw puzzles.

I have a very big collection of puzzles from many parts of the world. It is a great effort for me to put the pieces together because of not being able to use my hands and fingers properly. I use a stick to push the pieces together, not very easy mind you, particularly as I must do this on my little wheelchair table. At the moment, I am doing a 3,000-piece puzzle.

Now you might think, what has this to do with ventilation? Due to this hobby, I got in contact with a countess in Germany, and she was so nice to invite me to her castle in southern Germany.

In September 1985, I celebrated my 18th birthday, it was holiday time, and I thought it would be a good idea to accept the invitation. Somehow I didn't feel very well, but I thought it

might be the summer heat and the high humidity in Barcelona; therefore a change in climate should do me good, thought my family. My mother was going to accompany me on this trip.

We got on the plane, and soon the trouble started. I thought I would die; I felt terribly ill. Arriving in Zurich airport, I felt better. There, a big car with chauffeur was waiting to take us to the castle, but first we had to cross the Lake of Constance by passenger boat. A beautiful journey, nice and interesting, but I didn't feel well enough to enjoy it. We arrived at the beautiful castle, where a nice reception was prepared for me, but I had to be rushed to the hospital emergency ward where I ended up in intensive care with acute respiratory failure.

Here a tracheostomy was made and I became a ventilator user. I was terribly weak and suffered of mental fatigue. I was desperate, especially about the fact that I was unable to speak and communicate with the hospital staff. (I am using a tracheostomy tube armoured with a cuff.) The only thing I managed to do in my condition was to draw — with many difficulties — a little code-table made to my necessities. With plenty of patience from my side, but mostly from the doctors and nurses, we found the solution for my speaking — when I am on the ventilator I speak normal and when I am off the machine I whisper.

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## Saludos from Spain

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My family and nearest friends understand me.

It was a pity that what should have been a remarkable holiday for me turned out to be an absolute nightmare. It is not fair that a Duchenne patient has to be rushed into the next hospital to have a tracheostomy done and find himself on mechanical ventilation for life without any previous preparation. After all the technique is there — why not use it adequately but inform the people involved in time so they can get used to the idea of ventilation or no-ventilation. In my case, it is not only that I suffered a lot, also my parents and brothers. My parents had great financial problems too, because insurance troubles started straight away.

Time has passed, I am 24 years old, and I am back in Barcelona, where I live in an ordinary intensive care ward of a clinic. In this clinic I managed to finish my last year of schooling, did my exams for entering the university, and now I am a student at the Open University where I study law in my 4th year. I also was able to do my final exams in German language.

I have managed to get a portable ventilator, which could make my life in the future more interesting, but I noticed the difference between the old and new ventilator and did not feel comfortable with this difference. Switching over to a new ventilator after 6 years of using the same ventilator, I expected a little difference but not to the extent that I felt uncomfortable. The company that sold me the ventilator came to the same reason that I did: different flow patterns. They supplied me with an external pressure limiter and this seems to be an acceptable solution.

I want to say how pleased I am that *I.V.U.N. News* exists, to know that many more people live with ventilation and manage their lives as good as possible, with their ups and downs.

**ADDRESS:** Daniel Vilaseca Dreischer, c/Elisa 17, 08023 Barcelona, Spain.

"Musings," a regular column contributed by Karan McKibben, will appear again in the Fall issue. A bout with a respiratory infection prevented Karan from meeting the deadline for the Spring *I.V.U.N. News*.

## Camps for Ventilator-Assisted Children

**April 4-10, 1992. Ventilator-Assisted Children's Center, Florida.** Contact Cathy Klein, VACC, Miami Children's Hospital, 3200 S.W. 60th Ct., Suite 203, Miami, FL 33155. 305/662-VACC.

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**June 7-12, 1992. Trail's Edge Camp, Michigan.** Contact Mary Dekeon, RRT, Mott Children's Hospital, 200 E. Hospital Dr., F3064, Box 0208, Ann Arbor, MI 48109. 313/936-7339.

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**June 21-27, 1992. CHAMP Camp, Indiana.** Contact David Carter, RRT, Life-lines, Children's Rehabilitation Hospital, 1707 W. 86th St., P.O. Box 40407, Indianapolis, IN 46240. 317/872-0555, ext. 114.

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**August 16-21, 1992. SKIP Camp Family Retreat, Minnesota.** Contact Jacque Guze, SKIP Camp, 11208 Minnetonka Mills Rd., Minnetonka, MN 55343. 612/935-5581.

\*\*\*

**September 3-6, 1992. SKIP of Louisiana.** Contact Judy Abney, SKIP of Louisiana, 118 Ned Ave., Slidell, LA 70460. 504/649-0882.

## Moving?

Please send both your old and new addresses to:

**I.V.U.N.**

5100 Oakland Ave., #206  
St. Louis, MO 63110 USA

The post office does not automatically forward *I.V.U.N. News* to your new address. Instead, the undelivered copy is destroyed and, if known, your new address is sent to us with the label section of the back cover from the lost copy ... and we are charged 30¢.

When you add this charge to that of the replacement and re mailing, you can see that the process becomes rather costly. Please remember to let us know in good time of an address change.

**Thank you!**

# TRAVEL & VENTILATORS

## Travel by Air "With Air" Is Possible

by Lori Hinderer

It was June 1990, when I faced a turning point — I had to learn how to live with a tracheostomy and a ventilator for the rest of my life. Out of frustration, I vowed to myself and family that I was never going out in public again. However, after only one week at home, four trips later (two by airplane), and a busier lifestyle than ever, I have eaten those words infinite times.

Learning to lead as quality a life as I did before the ventilator was just another challenge to overcome; I had overcome many associated with having muscular dystrophy. Today I am thirty, and seem to have done more since the tracheostomy and ventilator than ever. I owe my activities to my "friend," my LP6 ventilator.

My ventilator goes everywhere I go. Thanks to some restructuring under my wheelchair, a sliding tray holds the batteries and the ventilator — a modification that enables easy mobility. Hence, I go essentially everywhere I used to go, including driving to Orlando for vacation. But when a business trip beckoned me to Las Vegas, I thought, "No way! That's too far to drive from St. Louis."

My cousin, who is my business partner and who cares for my medical needs around the clock, suggested we fly. The notion of getting there in three hours instead of a few days did make more sense. I knew air travel was possible with a wheelchair, but travel with a ventilator as well?

After flying to Las Vegas on America West and just recently to Tucson on TWA, I learned that travel by air with air (the ventilator) was indeed possible. But, because one flight went smoother than the other, I thought it important to research the regulations required by several other airlines, too. The following guidelines are suggested when making reservations with any airline:

➔ Know the dimensions, weight, manufacturer (and phone number), model number of the ventilator, and type of batteries it uses. Batteries should be the non-spillable type. Make sure the ventilator fits under the seat; I sat in bulkhead seating and the ventilator was strapped in the seat beside me during takeoff and landing. Take backup ventilator batteries. (Of the airlines I researched, none appear to offer any electrical outlet use, *except United*.)

➔ Talk with a supervisor, preferably in the medical/special needs department. ***Always write down the name and exact title of the person you spoke with and bring the name and title with you.***

➔ Detail your needs clearly, because needs associated with ventilators are not common knowledge. It is not fair to simply appear and expect an airline to accommodate you.

➔ Oxygen is not provided by all airlines. It appears that no airline allows one to carry his or her own oxygen. (Do check with the airline about carrying your tank, without oxygen, in cargo, or overhead.) When oxygen is provided, all airlines require 48 hours advance notice and a doctor's prescription/letter. On average, the cost is an additional \$50 per flight.

➔ Arrive at least one hour prior to departure with the name and title of the supervisor you spoke with ... just in case.

➔ If an electric wheelchair is used, batteries must be clearly marked. If an airline accepts spillable batteries (not all do yet), they will be removed and packed properly in cargo. Non-spillable batteries will not be removed.

These steps may help insure an easier flight. A miscommunication and a failure to obtain the supervisor's name was directly related to the



## Travel by Air "With Air" Is Possible

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problems I encountered on my second flight. I always have a companion travelling with me to assist with any needs related to the ventilator. If you travel alone, you might try asking a flight attendant to assist you in an emergency situation.

I wish anyone considering air travel a great trip. Please don't let the ventilator stop you from enjoying life. If anyone has any questions concerning air travel with a ventilator, feel free to write or call me, Lori Hinderer, 2417 Wallis Ave., St. Louis, MO 63114 USA, 314/429-3386.

Next time, I'm trying ventilator travel on Amtrak ...



## Flying with Your Ventilator

(reprinted with permission from LIFECARE's *Alert*, Summer 1991)

**D**reaming of a vacation but afraid to travel with your ventilator? Go ahead! That dream vacation can become a reality.

Travel, both domestic and international, can be exciting and rewarding. Jack Hoffman of Evergreen Travel in Seattle offers the following recommendations to make your travel easier. Internationally, all nuts and bolts are measured on the metric scale; therefore, it is a good idea to take a spare of every U.S. standard nut and bolt found on your equipment. He also recommends you check with at least three people in your hotel to make sure the hotel has acceptable accommodations before you arrive.

It is also advisable to carry a variety of electrical connectors and a transformer suitable to power your ventilator. In Europe, LIFECARE recommends an auto transformer with a minimum of 350 VA output and an input capability of 220-240 volts. Hoffman adds, "Do not leave anything to chance and always be cautious!"

Never travel *without* a spare ventilator, tubing, and connectors. If you do not require a ventilator during flight, it is a good idea to carry one on board. It would be a horror story if the airline lost or damaged your ventilator.

A pilot is considered the captain of the ship, and as such, has the authority to determine whether or not a piece of equipment or passenger

should be allowed on board. Pilots can deny travel even after a passenger has boarded.

Book your flight as early as possible. When making the reservation, notify the reservation clerk of the ventilator use, as well as other special requirements. Also, check with the reservation desk on the available seat space beneath your assigned seat. This can be different for each aircraft and each seating class. For example, in business and first class, while there may be more "seat" room, it may come out at the expense of the underseat space. One way to get more underseat room is to ask for the last seat in a section. There may be extra space between the seat and the bulkhead.

When boarding, every ventilator user should carry several copies of approval letters from his or her physician stating the diagnosis, prescribed piece of equipment and settings, plus the latest blood gases, or oximetry reading, on those settings.

Despite the positive government rulings regarding use of ventilators on airlines, any airline still has the right to refuse boarding, citing a safety issue. This will more likely pertain to the battery, rather than the ventilator. It is best for ventilator users to bring along any approval information from their particular battery manufacturer.

The good news is that many more airlines are willing to carry ventilator users. Contact our home office at 655 Aspen Ridge Rd., Lafayette, CO 80026, 303/666-9234, if you are interested in receiving a copy of approval letters, or for the name of the contact person for your airline.



## Airline Criteria

**L**IFECARE contacted several airlines with information about the PLV-100 and PLV-102 portable volume ventilators. This included information about radio frequency interference, size, weight, product photos, and other specifications. Representatives from each airline were asked to read the information and determine whether a PLV-100 or PLV-102 would be allowed on board. LIFECARE is waiting for information from Air France, British Airways, Delta, Lufthansa, Singapore Airlines, and U.S. Air.

Lori Hinderer also contacted several airlines for information on oxygen, batteries, and impor-



tant phone numbers. Her information is printed in *italic*.

**American Airlines.** 800/433-7300. *Request the Special Assistance desk. Ventilator must be approved. Oxygen provided. LIFECARE ventilators are accepted, check for adequate underseat space. A list of batteries accepted on board is available through American.*

**America West.** 800/247-5692. *Request a supervisor. Ventilator must be approved. Spillable batteries for wheelchair accepted in cargo. If any problems arise, call Diana Lawson, 602/693-5212; she is in charge of the program and training for passengers with special needs. She was as helpful as another supervisor in making my first flight so smooth; she is herself a person with a disability. No oxygen provided.*

**Continental Airlines.** 800/525-0280. *A reservation representative can take your request, but make sure your needs are understood. Try to get through to a supervisor. No oxygen provided.*

**Delta.** 800/221-1212. *Stan Whitehead, 404/715-1735, thinks a customer representative can handle the reservation. Accepts spillable and non-spillable wheelchair batteries. Oxygen provided.*

**KLM, Royal Dutch Airlines.** When AC power is required, a KLM adapter cable and transformer (from 28-120 VAC) must be used as interface.

**Northwest Airlines.** Ventilators must fit under aircraft seat. Area underseat varies with aircraft; check with the reservations staff. All batteries need to be either dry or gel cell type. Some aircraft have electrical hookup capabilities. Advance notice is required for this services, but because of aircraft changes, Northwest cannot guarantee electrical hookup until the day of travel.

**Qantas Airways.** Will look at each individual case as the need arises. Contact any reservations clerk.

**Scandinavian Airlines System (SAS).** For final authorization, a ventilator user needs to file an application (Internationally Approved Medical Information Form — MEDIF) with a SAS office. All air-craft supply either 115V/60Hz or 220V/50Hz. A passenger needing this electrical service should apply early. Passenger must also carry EMI approval.

**Southwest Airlines.** 214/904-4223. *Kay Caldwell and Bob McNeal think any representative can make the reservation as long as medical needs are clearly stated. Accepts spillable and non-spillable wheelchair batteries. No oxygen provided. Moveable*

*armrests to be added soon to ease transferring. Ventilators accepted without additional requirements. Oxygen and electrical hookups are unavailable.*

**TWA.** 800/221-2000. *Medical needs must be stated. Ventilator must be approved by engineering department. Accepts spillable and non-spillable wheelchair batteries. Oxygen provided. Approves in-flight use of dry or gel cell battery powered ventilators. Check with reservations for underseat space.*

**United Airlines.** 800/825-6331. *(Medical Department, 6:30 am — 1:00 am, EST). Will try to accommodate almost any need. Accepts spillable and non-spillable wheelchair batteries. Oxygen provided. Need to make ventilator request known to reservation representative so information can be forwarded to the Medical Department. If needed, electrical current is 28V/400Hz; a passenger supplied connector is necessary. Check to see if it is available on your flight. Batteries are accepted and must be dry or gel cell type.*

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**Editor's Note:** Ventilator users with additional information about airline travel or with travel experiences they would like to share are invited to send them to I.V.U.N., c/o G.I.N.I., 5100 Oakland Ave., #206, St. Louis, MO 63110.



## Travel Insurance for Ventilators?

*Arthur Stern, of Pine Bluff, Arkansas, writes with the following query:*

“When I travel by commercial airline, I check through my PLV-100 packed in the original carton with good foam packing. But the airlines require me to sign a waiver absolving them of responsibility for damage in transit. They require this for all electric or electronic equipment. The ventilator can be shipped insured by air cargo on the same flight for about \$50 — a bit much for three hours of insurance, and an unreasonable hassle.

“Further, I am unable to find private insurance for accidental damage to the ventilator. My homeowner’s policy and other policies I have inquired about will cover it for fire, storm, vandals, and thieves, but the companies will not accept ventilators for an ‘all risk’ floater, as is available for personal photographic equipment, for instance.

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## Travel Insurance for Ventilators?

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"Does anyone know of a solution to my airline problem? Is there a source of 'all risk' insurance for ventilators? Can the new Americans with Disabilities Act be brought to bear on these problems?"

Readers with solutions for Mr. Stern are invited to write to him in care of I.V.U.N., 5100 Oakland Ave., #206, St. Louis, MO 63110 USA.



## DOT Issues Air Travel Booklet for People with Disabilities

The U.S. Department of Transportation has issued a pocket-sized booklet, "New Horizons for the Air Traveler with a Disability," informing individuals with disabilities who travel in planes about how recent legislation affects air travel. These changes result from the passage of the Air Carrier Access Act of 1986 (P.L. 99-435) and The Americans with Disabilities Act (ADA, P.L. 101-336).

Sections cover how carriers now may not refuse transportation to a passenger solely on the basis of a disability; how air carriers may not limit the number of individuals with disabilities on a particular flight; and when a carrier may refuse transportation; how carriers must provide information upon request concerning facilities and services available, including seat location, storage limitations, accessible lavatory availability, advance notice requirements for electric wheelchairs, batteries and other technological assistance; where ADA or other rules pertain to accessible parking, baggage handling, shuttle facilities, or other amenities including details about security screening; and information about medical certificates, communicable diseases, handling of mobility aids and devices, boarding and deplaning, personnel training, seat assignment, service animals, in-cabin service, and describes those instances when additional charges for optional services are allowed. Another section addresses complaint procedures.

Copies are available from the Office of the Secretary, U.S. Department of Transportation, 400 7th Street, S.W., Washington, DC 20590. Tel: (202)366-4220 or FAX 202/366-7618.

## I.V.U.N. Directory Update

This directory update is to be used in conjunction with the directory published in *I.V.U.N. News*, Fall 1991, Vol. 5, No. 2. Corrections and changes are underlined.

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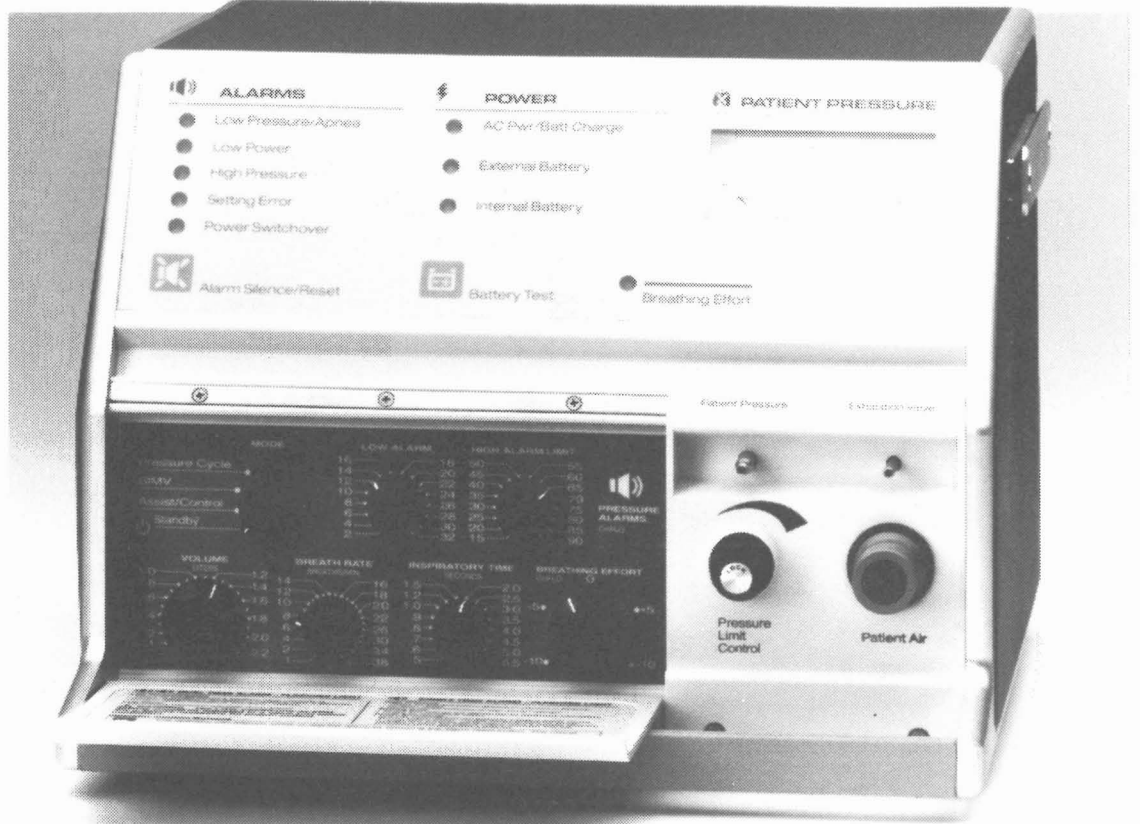
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\*ventilator user

\*\*pediatric interest

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## ◆ I.V.U.N. Potpourri ◆

### Ventilator Videos ...

#### **"My Symptom is Stillness: An ALS**

**Story,"** produced by Ellen Pulleyblank and Tish Valva, describes ventilator user Ron Pulleyblank and his fight for 24-hour home care coverage from his HMO (Kaiser). The 29-minute video is available for \$29.95 postpaid from The Ronald W. Pulleyblank Trust, 6333 Pacific Ave., Suite 105, Stockton, CA 95207.

**"It's Your Choice,"** or how to make an informed decision about whether to use a ventilator, was produced, written, and directed by Ismail Tsieprati, filmmaker and ventilator user. Edward A. Oppenheimer, MD, Director of Kaiser Permanente's Regional Home Ventilator Pilot Project, is the medical advisor and host for "It's Your Choice," presenting information, answering questions, and offering advice to those considering the ventilator decision.

The video also presents the viewpoints of two people who have made the decision: a man who has been a ventilator user for more than 16 years and a woman with neuromuscular disease who has decided not to use a ventilator should she face respiratory distress in the future, but who reserves the right to change her mind if she feels her quality of life would be acceptable.

The 26-minute video is available to *I.V.U.N. News* subscribers for a special price of \$11.95 plus \$3 shipping and handling from Valona Productions, 14621 Titus St., Suite 108, Van Nuys, CA 91402, 818/785-9982. (When ordering, be sure to mention you are connected with I.V.U.N.)

### Calendar ...

#### **Pediatric Ventilator Users Network**

**Meeting,** April 22, 1992, 10:30 am — 12:30 pm, Hyatt Regency Hotel, Cincinnati (in conjunction with AARC's Region II meeting). Call Jan Nelson, Aequitron Medical, 800/824-7203, ext. 256.

**Mechanical Ventilation,** June 26, 1992, Northbrook, IL. Call ACCP 708/498-1400.

**Mechanical Ventilation: Principals & Practice,** September 25-27, 1992, Minneapolis, MN. Write CME, University of Minnesota, 615 Washington Ave., S.E., Suite 107, Minneapolis, MN 55414.

### Classifieds ...

Puritan-Bennett C2800 ventilators (2) available. Call G.I.N.I., 314/534-0475.

### **Deadline ...**

for submission of articles, stories, information, etc., for the Fall 1992 issue of *I.V.U.N. News* is August 15, 1992.

Please send to:

**I.V.U.N. News**  
5100 Oakland Ave., #206  
St. Louis, MO 63110 USA