

I.V.U.N. NEWS

International Ventilators Users Network

Fall 1991 ■ Volume 5, No. 2

Ventilator Considerations: Lease vs. Purchase

by Roberta Simon, RN

After being monitored over the past four to five years for respiratory and sleep difficulties related to the late effects of polio, it was decided last fall that assisted night-time ventilation was necessary. I was advised by my pulmonologist that prior to a scheduled sleep study I should obtain a letter of necessity from both my cardiologist and my pulmonologist to submit to my insurance company for their review and approval. I was also told to investigate what the insurance company would and would not consider for payment. All of this information turned out to be very good advice and was something I had not even considered.

I obtained the letters, sent them to the insurance company, and, after obtaining approval from their review board, I received a letter of approval prior to the sleep study. I learned that all insurance companies review non-emergency ventilator use to consider payment and necessity. Their decisions are based upon various considerations of symptoms and diagnosis.

Following up with a telephone call to the insurance company, I learned that they would pay the monthly rental fees up to the purchase price at which time I was responsible for paying the rental fees myself or pay the outright purchase price and subsequent repairs and service as needed. I was glad to learn this, because if I had not, I may have been shocked when my coverage became exhausted after 18 months to two years. (That would have been very costly as I plan to live to be 100 and go skiing on my birthday as my great-grandmother did!) Anyway, I purchased the ventilator, after renting one for two months.

It was nice renting the ventilator for the first month or two because the respiratory therapist from the small medical equipment company stopped by frequently to check on my progress and assist me with problems. The primary reason for renting was to give Bi-PAP another try. I had tried Bi-PAP in the sleep laboratory but it did not ventilate me adequately, and I was swallowing large amounts of air due to pharyngeal weakness. Alas, Bi-PAP was not for me, although many individuals are having wonderful experiences with Bi-PAP.

There were numerous problems with the rental ventilators, including one which set its own breath rate during the night. Needless to say, this caused unpleasant pain and fatigue in my chest. Remember that rental equipment is rarely new and for the most part has been serviced and rebuilt many times.

For the last ten months, I have been using a PLV-100 ventilator with a nasal mask, and know the quality of both my sleep and my life have improved tremendously. I look at my ventilator as a friend and in the same context as the other assistive devices I use. For me, purchasing a ventilator has caused few difficulties.

The main difficulty was related to nasal masks, and many of you know that finding a mask that fits correctly and fits comfortably is a challenge at best. Having been raised in a family with several siblings, I soon discovered that all the doors, toys, elbows, etc., that had connected with my nose through the years had definitely made an impact.

I tried an ADAMS circuit, but a bony prominence on my nose made that very uncomfortable and impossible. I tried a Respironics mask and a Healthyne mask, but discovered that the anatomy of my face was again defective. The space between my upper lip and nose was smaller than average so that during the night the mask would slip over my lip and leak, sounding the ventilator alarm. After fighting the battle for several months, I had a custom mask fabricated for me by the staff of my pulmonologist. What a relief — difficulty solved!

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Ventilator Considerations: Lease vs. Purchase

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Recently, for the benefit of other ventilator users, I decided to investigate the rental vs. purchase conundrum. I called three national home health care agencies for their opinions. My first surprise was their reluctance to share any opinions or information with me.

The first company I called connected me with a respiratory therapist, but when I asked my question, the therapist put me on hold for several minutes (knowing I had called long distance on day rates), then rang an answering machine which asked for my name and telephone number. I have yet to receive a return call.

The second company stated that the advantage of rental was that service for the equipment would be available any time of the day or night, and that ventilators were high service equipment — meaning they break down frequently. When asked if they would service a purchased ventilator at any hour or replace it with a rental, they stated they would — for a charge. The therapist with whom I was speaking then transferred me to the manager of the respiratory therapy section. I was told he was too busy but would call me later. I am still waiting for that return call.

The third company stated they made no follow-up visits after a purchase, and any problems other than equipment-related ones covered by the warranty would have to be taken care of by a home health care company. The advantage of rental from this company was stated to be that they serviced the equipment and the patient and all necessary supplies were included in the rental fee. This latter statement fascinated me because the home ventilator company I had dealt with for two months had managed to run up considerable charges with supplies — over \$500.

I guess that by their anxiety in answering questions, they answered them. Subsequently I had a lengthy talk with my insurance company regarding home ventilator use. They stated that the reason they no longer paid for rental equipment was because they felt they were being gouged by home health care companies. Sleep laboratories are now diagnosing and treating sleep apnea with nasal C-PAP; thus nasal mask and home ventilation are more widely used, and these companies have seen big opportunities for profit. The cost has more than doubled in the past five or six years. Granted, the companies do need to pay respiratory therapists to service both the equipment and the clients, plus provide 24-hour coverage for equipment failure or client difficulties which may justify some of the expense.

To me, purchase of ventilation equipment for an individual with a chronic longterm need does make more sense from an economical point of view, as long as the insurance company is willing to pay for repairs and a temporary replacement while a unit is being serviced. The disadvantage, of course, is that you may have no backup unit in your home for emergency coverage.

I was fortunate to have a physician knowledgeable about ventilators or I could have faced some serious difficulties. I hope all of you will be able to investigate the services, regulations, and rules of your insurance company *now* so that more decisions and stress will not be facing you in the months to come.

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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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Murphy's Law as It Applies to Ventilators

by Jerry Daniel

Drawings by Audrey King

The Baby Left Him Breathless ...

A man in his late 50's is completely paralyzed by ALS. He lives at home with his wife and has a home health care program. He is dependent full-time on his portable ventilator which delivers 15 breaths per minute through his cuffed trach.

The couple has just barely been able to keep up with all that has happened in the last few years, but one meaningful experience for them is to baby-sit their grandson. It is something they can enjoy together.

Picture a typical Friday evening and they are baby-sitting the grandson. The wife steps out of the living room momentarily. The baby toddles up to Grandpa and impulsively yanks on the bright blue ventilator hose. It disconnects. The man feels near panic waiting for the low pressure alarm to sound. After 15 seconds, the alarm shrieks continuously. The wife hears it and immediately spots the problem when she enters the room. She reconnects the hose and attempts to calm both her husband and the child who is now crying. All three are upset.

This man went through a rough experience. He went almost 30 seconds without a breath. He was scared, but not seriously hurt. Could a better ventilator hose design have saved him from this traumatic event? Probably not.

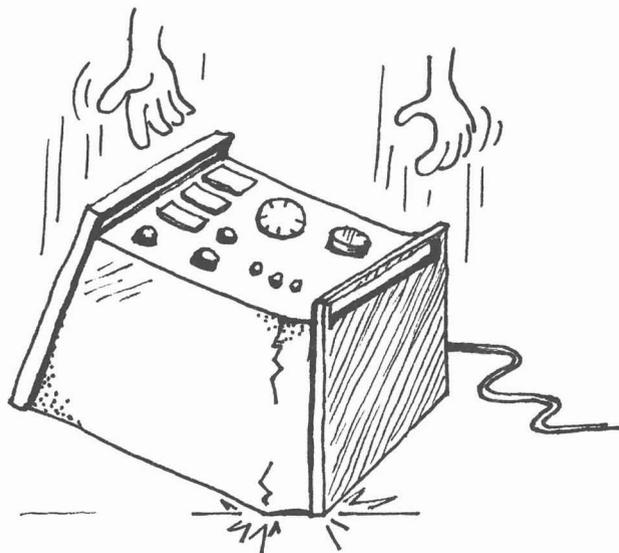


The hose connection to the ventilator is a slip-on. It could be designed with an interlock, but there are at least three other slip-on connections in the total ventilator circuit. Any one could become disconnected at any time. What saved him was the low pressure alarm. When there was no significant

Jerry Daniel, respiratory polio survivor since 1948, is a home ventilator equipment repair expert, especially for Aequitron's LP-3 and LP-4. Psychologist Audrey King, another respiratory polio survivor, provided the drawings while she recovered from a broken leg.

pressure in the system for 15 seconds, the alarm screeched until pressure was restored. The delay is necessary to avoid invalid sounding of the alarm, due to loss of pressure during just one breath. Premature sounding of the alarm could cause it to be interpreted as no emergency.

The ventilator low pressure alarm did just what it is supposed to do, sound loudly and unrelentingly until pressure is restored to the system. The precaution to be taken here is not to leave the child alone with Grandpa — ever.



A Bent Vent ...

A woman who is almost totally paralyzed from polio as a child manages her own apartment and 24-hour attendants. She has a little use of her hands, and breathes about four hours on her own each day. She is quite independent and wants no more help than is necessary from medical and home care professionals. She values her privacy.

Her morning routine is to have her attendant disconnect her from the ventilator to prepare her for the day. Her uncuffed trach is plugged so she is able to talk. After breakfast, she is ready to use the ventilator again. (She has just started using it more during the day due to fatigue.) The attendant, a woman about her own age, carries the 30-lb. ventilator from the bedroom to the living room each morning. This is new to the routine; the ventilator used to stay in the bedroom.

The attendant drops the ventilator in the hallway. An \$8,000 life support machine has just hit the floor (expletive deleted!). The attendant scoops up the machine in panic and sets it on the table in the

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Murphy's Law as It Applies to Ventilators

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living room. They are both close to tears, but laughing a little. There is obvious damage to the back of the ventilator, and they can hear something rattling around inside the machine. When it is switched on there is a "clunk" and the ventilator only alarms.

The woman is angry. She tells the attendant it is not her fault, and it isn't. She will have to inform the home health dealer about what has happened. It is embarrassing. She is a responsible person; now an expensive repair or replacement will have to be paid.

With the change in routine by moving the ventilator from the bedroom to the living room, it would have been ideal to have a second ventilator in the living room. However, under Medicaid, the woman would not be able to obtain one, because she has some breathing time on her own. A second unit would also relieve the home care dealer of possibly making a night call in case of an emergency.

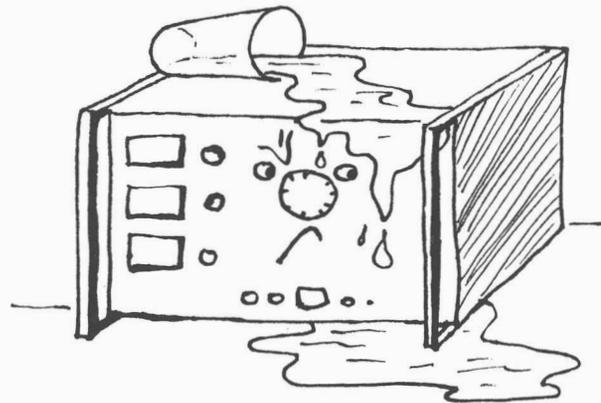
It is easy to strain one's back lifting portable ventilators, and there are dollies and rolling tables suitable for transporting ventilators. Most portable ventilators weigh about 28 pounds. They are constructed of heavy gauge aluminum with plastic cosmetic panels. Plastic construction has been experimented with, but cannot provide strong enough forces inside the machine to render the pressures and volumes needed for adult ventilation.

Oh, No! ...

A fourteen-year-old boy with Duchenne muscular dystrophy is well taken care of by his parents and a part-time attendant. They are a close family that includes three other children. The father earns a good income and has set up a special room for the boy. The father's income and medical insurance pay for a state-of-the-art ventilator and an earlier model. The new unit is at the bedside; the older model is mounted on the back of the power wheelchair.

One day, the father is in his son's room watching a ballgame on TV with him. The boy asks his father to boost him up in bed. Dad sets his cola drink on the ventilator while he helps his son. As he turns around when he is finished, he knocks over the drink. It spills over the top of the ventilator. The father frantically tries to mop up the liquid with his shirttail, but the liquid goes into the crevices of the machine. The ventilator stumbles for several breaths, but does not alarm and resumes normal operation. Worry about using the older ventilator and damage to the \$8,000 machine subsides.

Two months later the ventilator is sent in for routine 6,000-hour servicing. The home care dealer calls and tells the father it is going to cost \$900 for the servicing, considerably more than was expected. The circuit board has a liquid spill and must be replaced. The father is surprised and a little mad. Why does a circuit board have to be replaced? The ventilator was working fine when it went in for servicing.



The customer service representative explains that when evidence of liquid spill on a circuit board is found, it must be replaced in order to certify that the ventilator is ready for customer use. Certain parts of the circuit are very sensitive to contamination. Most liquid spills that are obvious to the servicer are either beverages or medications. The damage can be corrosive or a sticky substance that, over a period of time, with heat can cause high impedance short circuits. With all this explained, the father consented to the cost.

Perhaps portable ventilators can be designed so that it would not be easy to set a liquid container on top of the machine. The surface would have to be irregular, and such a design would probably look awkward and take up more space.

Whether you own your own ventilator or rent one, use reasonable care with it. It's the pits to have to call you equipment dealer and say, "Guess what happened?"

Deadline ...

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

Please send to:

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Negative Pressure Ventilation with Progressive SMA

by Robert Beckerman, MD

Negative pressure ventilation began with the iron lung, which was designed in 1928 and first manufactured for patients with respiratory failure caused by polio. Today, negative pressure ventilators are also used for patients with pulmonary and neuromuscular diseases — like spinal muscular atrophy (SMA) — that require periodic or nocturnal ventilatory support.

For SMA patients, negative pressure ventilation does two things. First, it increases tidal volume and chest expansion in an attempt to prevent the lung from collapsing. Secondly, it decreases the loss of caloric energy caused by an exaggerated work of breathing.

Negative pressure ventilation may be delivered in several ways. One is with a chest cuirass or ridd shell, which frees patients from being forced to lie face up and doesn't require that they be placed in a total body shell. The chest shell comes in a variety of sizes and can be custom-fitted, which may be expensive.

A poncho-type chest piece, called a Pulmowrap, is also an option. Pulmowraps are prone to problems, however, because they don't always fit properly and thus may leak around the neck, arms, and hip areas.

Portable lungs are now available for adaptation to infants, children, and adult patients. While the Porta-Lung creates some problems with access to the patient, it is still a viable option for nocturnal ventilation in patients with weak respiratory muscles who hypoventilate at night.

These types of ventilators are very simple to operate. The negative pressure is produced by a vacuum-type blower that acts as a controller or rheostat. Three controls adjust the negative pressure level, inspiratory rate, and expiratory rate. Backup equipment is generally not necessary unless the patient is completely ventilator-dependent.

Porta-Lungs work well. The Tulane Pediatric Pulmonary Center currently follows four SMA patients, ranging in age from 22 months to 10 years, who have been supported at home and when hospitalized with negative pressure devices. The duration of negative pressure ventilation has been between two months and three years. All four patients now use a Porta-Lung chamber at home. Since we began using negative pressure ventilation with these patients, three of them have experienced improved weight growth velocities.

We have also had success using negative pressure ventilators in the hospital. Porta-Lungs were used to wean two patients from endotracheal

tubes within 36 hours following major corrective spinal surgery that had required prolonged general anesthesia.

Negative pressure ventilation may not be the most appropriate form of therapy for all patients. Some patients with neuromuscular disease or acute or chronic respiratory failure have problems with severe pain and require high doses of narcotic analgesics. These analgesics, however, may depress ventilatory drive and cause excessive and thick secretions. They may also cause the chest wall to become rigid. These patients may need additional airway support to help mobilize and eliminate secretions.

In selected pediatric patients with progressive SMA, regular nocturnal and even intermittent daytime ventilation may be effective for certain clinical situations as follows:

- recurrent pneumonia/atelectasis/respiratory failure when secretion load and mobilization can be managed without endotracheal intubation;
- chronic nocturnal hypoventilation leading to cor pulmonale and cardiac failure;
- weaning from positive pressure ventilation through an endotracheal tube after the patient has undergone serious orthopedic surgical procedures;
- minimizing caloric energy loss by decreasing work of breathing and thereby improving weight growth.

If negative pressure ventilation is to be recommended on a wider scale for patients with progressive SMA or similar neuromuscular diseases, prospectively designed and well-controlled studies evaluating risk versus benefit of this therapy must be undertaken.

As expected with any serious and progressive chronic disease such as SMA, a comprehensive management plan for home care and follow-up needs to be stressed. Such a program should ideally include an interdisciplinary group of health care professionals, such as specialized nurses, nutritionists, respiratory therapists, physical therapists, physicians, and social workers. A home care dealer should also be available to provide the initial durable equipment and detailed instructions to the patient and family, as well as a 24-hour hotline so that technical equipment problems and access to medical advice may be facilitated.

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Musings: The Question Earthquakes Ask

by Karan McKibben

This summer I was awakened by the rattling of closet doors. Once again the earth beneath the Los Angeles area shook, this time enough to crack walls in Pasadena and to bring out the disaster experts with their worrisome predictions about "The Big One."

The predicted scenario is alarming indeed. Transportation will be impossible because roads will be either split in two or buried beneath falling rock and crumbling concrete. Communication will be impossible because telephone lines will be either disconnected or jammed. If your house stands, surviving the subsequent days will require considerable innovation and self-sufficiency because gas, electricity, and water service will be disrupted. The experts ask, "Are you prepared to be self-reliant under these conditions?" For ventilator users, the question suggests more than preparing to rough it for a few days with flashlight batteries and a backyard barbecue.

Primarily the question raises concern about alternative power sources. Storage batteries immediately leap into mind because they are already on hand in power drive wheelchairs and in the cars in the garage, and might well be an easy solution if the power need is not too demanding and power service is restored in a day or two.

Storage batteries, however, have the distinct disadvantage of requiring periodic charging even when they are unused. Consequently, if the survival strategy rests on storage batteries sitting in the corner of the garage, an easily maintained charging routine will have to be followed forever. The routine will have the best chance of being followed if it is connected to a mnemonic device like the routine often proposed for checking smoke alarm batteries — twice a year when the clocks in the house are changed to adjust to Daylight Savings Time.

For 24-hour use over several days, a gasoline-powered generator obviously is the preferred alternative power source. Home generators are becoming cheaper and easier to use with some even capable of being plugged into the house wiring system. However, as our utility company has warned in threatening language, the utility company must be con-

sulted before you even think about plugging a generator into the house wiring.

A generator also has the advantage of not requiring as much vigilance as storage batteries although it too should be tested periodically to make sure it will be operable when "The Big One" suddenly strikes. A more vexing problem with generators, especially for apartment dwellers, is figuring out how to store an adequate gasoline supply safely.

Thinking about maintaining the food and water supplies that the experts recommend also brings to mind the question of medical supplies. Distilled water, if it is needed for humidifiers and so forth, can be stored right next to the extra bottles of drinking water. A month's supply of such medical supplies as suction catheters is probably not too much to keep on hand, considering that a widespread disaster will severely tax the resources of medical supply vendors, who are slow and inefficient even in the best of times. And finally, as the disaster people have suggested for everyone, it would be prudent always to keep extra bottles of essential medicines, remembering to rotate the bottles, and to make sure no medicine is kept beyond the expiration date.

This perpetual vigilance is the most difficult part of disaster preparation, for while it is easy to get the preparations collected, it is extremely difficult to keep them usable as the months and years pass without the "Big One" occurring and as complacency sets in.

Still, if you do resist complacency and you do maintain a reasonable level of disaster preparation, your self-confidence will rise as you realize you have reduced significantly your vulnerability not only to catastrophic natural disasters that may never occur, but also to the many little disasters that do occur frequently.

When a mysterious glitch in the power network suddenly cuts off your house current, an alternative power source keeps the incidence from ruining your whole day. When the neighborhood pharmacist fails to keep up adequate supplies of your prescription medicines, an earthquake supply will enable you to wait patiently instead of frantically rushing around for another source. When your medical supply vendor loses your order, your earthquake supply will prevent you from being held hostage to ineptitude.

(continued on page 11)

Karan McKibben uses trach positive pressure ventilation.

I.V.U.N. Directory 1991

Longtime ventilator users and health professionals who are experts about and advocates for home mechanical ventilation are listed below. Send additions, deletions, and corrections to I.V.U.N., 5100 Oakland Ave., #206, St. Louis, MO 63110 USA (314/534-0475).

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Musings (continued from page 6)

Thus, while earthquakes expose our vulnerability to the wondrous powers of nature and the not so wondrous frailties of human endeavors, earthquake preparation enables us to express our refusal to be victimized by disasters, large and small. By being prepared like good Boy Scouts, we assert our willingness to take responsibility for our own survival. Of course, trying to prepare for all circumstances that may occur can become an obsession that ensnares rather than frees us from circumstances. However, with a little vigilance and a few precautions, we can enhance our sense of self-reliance. So when those little temblors shake, we can check our batteries and answer in the affirmative when earthquakes ask, "Are you prepared to be self-reliant in the face of disaster?"

ADDRESS: Karan McKibben, 800 Daffodil Dr.,
Riverside CA 92507.

Editor's Note: *I.V.U.N. News* readers may remember Jerry Daniel's article "Don't get caught with your battery down!" in the Spring 1990 newsletter. Readers who have discovered other tricks that might help others to reduce their vulnerability to disasters, large and small, are urged to send them in to *I.V.U.N.*, 5100 Oakland Ave., #206, St. Louis, MO 63110.

Medicaid: U.S. Drops Nursing Restrictions

In an out-of-court settlement August 7, between the Federal Government and attorney Lewis Golinker of New York, Medicaid now permits persons with severe health care needs, who require the assistance of nurses in their daily lives, such as "technology dependent children," who rely on medical equipment such as ventilators to survive, to have the freedom to come and go throughout their communities with the assistance of their Medicaid nurses. Previously, Medicaid had restricted nurses to provide services only within recipients' homes, "effectively denying such individuals the opportunity to go outside, even to sit on a park bench in the sun, go to family functions, and to go to school. The 'home only' restriction was challenged because it saved Medicaid no dollars and because it made no sense," asserted Golinker. The agreement, effective immediately, eliminates the restriction in its entirety in all the states.

SOURCE: *Word from Washington*, United Cerebral Palsy Associations

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Camps for Ventilator-Assisted Children

SKIP Camp Family Retreat

Camp Courage, Maple Lake, Minnesota. Five days in mid-August. No charge to families; travel stipend. 1991: 20 families (14 ventilator-assisted children). SKIP camp '92: August 16-21, 1992. Barb Donaghy, CRTT, SKIP Camp, 11208 Minnetonka Mills Rd., Minnetonka MN 55343. 612/220-6002.



Carnival night with magician

SKIP of Louisiana

Camp in Biloxi, Mississippi. Four days in mid-August. No charge to families; travel stipend. Limited to Louisiana state residents. 1991: 19 families (10 ventilator-assisted children). Judy Abney, SKIP of Louisiana, 118 Ned Ave., Slidell LA, 70460. 504/649-0882.

CHAMP (Children Have A lot of Motivation and Potential) Camp

Camp Isanogel, Muncie, Indiana. Weekend in late August. No charge to families. 1991: 5 families (in 1992, 12-15 families); four ventilator-dependent quadriplegics, one burn patient with a trach. Most memorable quote: "I'm having so much fun even without a TV." CHAMP camp '92: early June 1992. David Carter, RRT, Lifelines, Children's Rehabilitation Hospital, 1707 W. 86th St., P.O. Box 40407, Indianapolis, IN 46240. 317/872-0555, ext. 114.

Pool time at CHAMP camp

When I was 10 and not much more,
I went to camp — gee, what a bore.
I packed my bag and stowed my gear,
With medical equipment piled to my ears.

For 14 hours we drove and drove,
I fought with my brother over and over.
When what to my wondering eyes should appear,
But a camp made for me this very year.

There were horses, respirators, and friends galore,
Many things to do — it wasn't a bore.
When I walked about the camp,
I found the ground was wet and damp.
But on my face I wore a smile - I had found a
friend that was just like me.
She had a tracheostomy.

I swam in the water. I rode on the lake.
No one minded I had my trach.
When at night I went to bed,
The nurses knew just what to do.
They plugged me in, they suctioned me out.
They gave me a grin before the lights went out.

When the sun rose in the sky,
I thought I might give camp another try.
I hope they invite me again next year,
For if they do, I'll give a cheer.
Sorry to say but this is the end,
I hope to see you at SKIP camp again.

Love,
Scott Pankratz

Michigan Summer Camp for Ventilator-Dependent Children

Trail's Edge Camp. Five days and nights in June. No charge to families. 1991: 24 families. Contact Mary Dekeon, RRT, Mott Children's Hospital, University of Michigan, 1500 E. Medical Center Dr., F1421, Box 0208, Ann Arbor, MI 48109. 313/936-7339.





Ventilator Assisted Children's Center (VACC), Miami

Cottages in county park near hospital. Week-long camp in April (to avoid Miami's summer heat and humidity). No charge to families; families must provide transportation to and from Miami. Total capacity: 10 families. VACC Camp '92: April 4-10, 1992. Call Cathy Klein, 305/662-VACC for application or write VACC, Miami Children's Hospital, 3200 S.W. 60th Ct., Suite 203, Miami, FL 33155.

Seal greets camper at Miami Seaquarium



I.V.U.N. Survey Replies

We were pleased that many I.V.U.N. surveys have been returned from ventilator users across the U.S. and from as far away as Japan, Spain, Israel, and South Africa. While the data is being computed for later publication, many of the comments and replies can be shared now.

Several ventilator users requested information on dealing with sore marks and spots, usually on the bridge of the nose, as a result of using masks. Willa Schuster of Connecticut offers one remedy: bacterial ointment on bridge of nose covered by one-inch telfa pads secured with paper tape. Bi-PAP enthusiasts James Thompson of Indiana and Barbara Carter of California give high marks to Puritan-Bennetts ADAMS (Air Distribution And Management System) circuit, a mask that uses a soft nasal "pillow" to seal and direct air into each nostril without creating irritated, pressure areas. Other remedies received by I.V.U.N. readers will be published in future newsletter issues.

"It was reading your *I.V.U.N. News* that helped me have my trach removed and use a nasal mask at night. I wish more P.P.S. (post-polio syndrome) people and doctors had this information. It would keep a lot of trachs from being put in."

C.P., Hawthorne, Florida.

"As a caregiver (spouse) I would appreciate similar interaction with other trached ventilator users (polio). Lucky I am retired now, but caregiver's hours are first thing on awakening and last thing at night ... It is exhausting."

Mrs. W.L.H., Grass Valley, California.

"S. is paralyzed (ALS) from head down with a little movement in shoulders and hips. He has good

communication since we have his cuff with a minimum of air. Although life is restricted, we've been very grateful for the added time we've had together. We've had enormous support from therapist and nurse and home health aides."

Mrs. S.A., Ogden, Utah.

"I am interested in trading experiences travelling with ventilators."

Alan Fiala, 7250 Idylwood Rd., Falls Church VA 22043.

"I'm a C-3 quad who has weaned myself off 24-hour use of the ventilator and now use it only when I go to sleep at night ... Living independently is definitely possible with a ventilator, and for me poses no problems or difficulties — it is just a quiet little machine near my bed. I don't let it run my life. I just accept it."

P.A., Princeton, New Jersey.

"I have three rocking beds — one at home owned by LIFECARE; one at my vacation home which I purchased secondhand; one in my motorhome which I miniaturized from a junk bed and doubles as a sofa. Has to be seen to be believed."

R.E., Denville, New Jersey.

"I own or use 26 respirators of various types — oldest one from 1957 and still working. Spread among here and relatives in Switzerland and Italy (vacation). About 10 will revert to invalid insurance companies upon my death."

C.F., Switzerland.

"I am quadriplegic, and have been living outside hospital since 1973, when I got married. We moved to a very small town (pop. 1000) in 1974. Being far way from all the high tech services and the bureaucracy is great. ... A polio home care assistance pro-

(continued on page 14)

I.V.U.N. Survey Replies

(continued from page 13)

gram, started in the mid-'70s provides enough funding for me to employ part-time home help. I am responsible for hiring, training, etc., with no interference from any outside agency. (I do have very low cost home care services available if I need them, if my husband is ill or away on business.) Ventilator (PLV-100) is provided by Respiratory Home Care Unit of University Hospital in Edmonton. ... I use an E&J recliner wheelchair (circa 1973) which has been extensively modified and strengthened by my husband. As well as trays below my legs and back for ventilator equipment, suction machine, battery, etc., the chair has hub brakes, stronger axles, and an attachment for mountain bike. ... For transfers between chair and bed we have a homemade sling and endless loop chain hoist running in a track bolted to the bedroom ceiling. We also have made a stretcher type sling which we use for chair to bed transfers when away from home ... For transfer to aircraft or train seats we have a situp type sling suspended from two stretcher poles. ... I must emphasize that I (and my other polio friends who are in this program) believe that this is by far the best kind of life to live. We have dignity, independence, and the respect of our communities, and are able to live and contribute to our local societies."

*Jean & Gordon Packer, P.O. Box 232,
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Letter to the Editor ...

Susan Ray of Georgetown, Texas writes:

" ... just a comment of agreement with Karan McKibben's article, 'Musings: About a Fatal Cliché' in the Spring issue. One evening in our church's discussion group, the subject was the dilemmas posed by new medical advances, with comments about the meaninglessness of sustaining life on a respirator. When I gently reminded them that I was at that very moment 'on a ventilator,' they had never even connected my situation and that being discussed. I think people know that it's the state of consciousness, the ability to respond mentally and emotionally that determines quality of life, but they don't say it that way. I'm not for maintaining 'vegetables,' but we must be careful of our definitions."

How to Survive in Today's Hospitals

by Claude Poisson

Today's hospital system is overloaded. You may get better in hospital or you may get worse. Most physicians will agree that the key to good health is to stay out of hospitals. But if you have to be there, here are a few tips which may come in handy.

Survival begins at home. Do not wait until you are sick to prepare for your next hospital stay. You may not have the strength, the will, or the time. Not every hospital will be prepared for you either. Home ventilator users are still a new phenomenon for most hospital staffs, especially in the emergency room.

Write down all the settings for your ventilators along with the names and phone numbers of the health professionals who specified them. Carry this information on your person, along with your personal physician's address and phone number, your health insurance and social security cards. Make a list of all the medical appliances and equipment you must bring with you, all the supplies required for maintenance, and all the personal care items you would be most likely to forget.

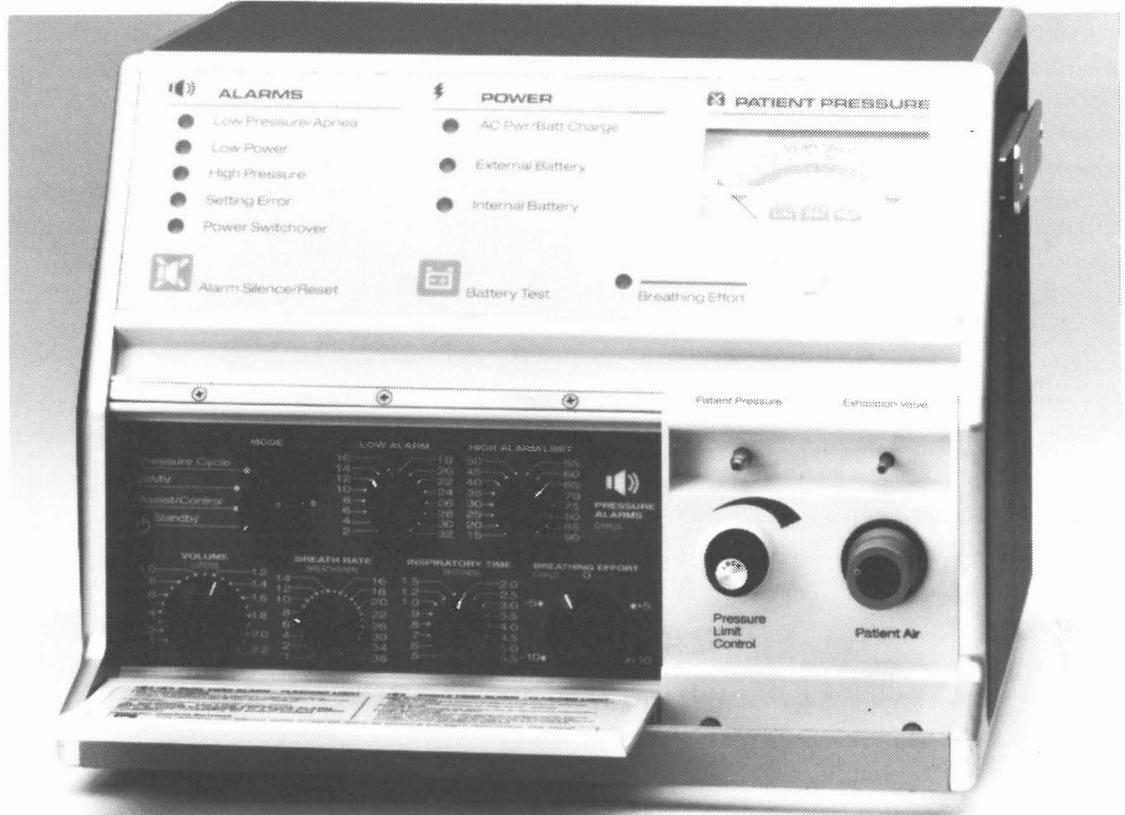
Every admitting procedure involves a long and painful session when, at a time you feel the least inclined to comply, you are required to forage through your reluctant memory to provide every detail of your medical history. Do it now, at leisure. Whenever you think of the approximate date of any previous illness, surgery, etc., write it down. When the opportunity arises, ask relatives or your physician to help with the missing dates and details. List all your current medications, including dosage and frequency.

Surviving your hospital stay begins now, when you are relatively healthy, when can conjure up the thoughts, the state of mind that will give you strength in adversity. Indeed, survival is a state of mind, a way of life, a philosophy.

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Claude Poisson is a ventilator user (CPAP) due to the effects of radiotherapy many years ago.

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 - step down unit

*The LP10 is backed by the full customer support and
technical services from Aequitron that you always depend on
for consistent performance.*

Aequitron Medical Inc.
14800 28th Avenue North
Minneapolis, MN 55447
(612) 557-9200
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Address Correction Requested



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Calendar

- ◆ **Noninvasive Ventilatory Management of Respiratory Failure**, American College of Chest Physicians Annual Scientific Assembly, November 8, 1991, 12:15-1:45 pm, Moscone Center, San Francisco. Contact ACCP, 3300 Dundee Rd., Northbrook, IL 60062, 708/498-1400.
- ◆ **Pediatric Users Network Meeting**, December 7, 1991, 5:00-7:30 pm, Atlanta Marriott Marquis. Call Jan Nelson, Aequitron Medical, 800/824-7203, ext. 256.
- ◆ **International Conference on Home Mechanical Ventilation**, March 3-5, 1993. Palais des Congres Internationaux de Lyon, Quai Achille Lignon, Lyon, France. Contact Brigitte Hautier, Hôpital de la Croix-Rousse, Service de Réanimation et Assistance Respiratoire, 93, Grande Rue de la Croix-Rousse, 69317 Lyon Cédex 4, France.

Social Security Announces New Toll-Free '800' Number

Social Security's toll-free telephone number is changing. Beginning October 1, 1991, the number to call is

**1-800-SSA-1213
(1-800-772-1213).**

MOVING?

Please send both your old and new addresses to:

International Ventilator Users Network

5100 Oakland Avenue, #206
Saint Louis, Missouri 63110 USA

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