

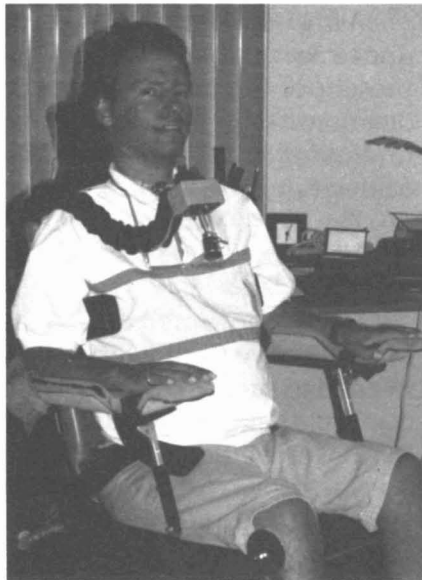
# I.V.U.N. NEWS

International Ventilators Users Network

Fall 1992 ■ Volume 6, No. 2

## Rebel with a Cause

by Randy Haims



I was born in Cleveland, Ohio, in the late '50s, the second boy of three children. My brother was only 13 months older, and when we were old enough to compete in sports, he was Joe athlete and I wasn't, so I became a competitor. By the time I was 14 or so, I became the athlete, the teacher, and the big brother.

While in high school I received numerous awards, medals, and trophies for wrestling, and at the end of my senior year I received an athletic (wrestling) scholarship to attend California State University at Northridge, but two months into my first semester I quit because I was not academically prepared. About a year after I dropped out, I ran into my wrestling coach who helped reinstate my scholarship and get me back in school.

On a rainy night one October, on a long drive home from Disneyland with my brother and friends, the driver fell asleep at the wheel. We coasted into an intersection and were broadsided by a three-quarter ton truck. I was lucky that time; no CNS involvement but a ruptured liver and multiple head injuries. I recovered very quickly and was coaching gymnastics, wrestling, working in construction, and training for the upcoming wrestling season.

On April 29, 1980, while coaching gymnas-

tics, I crashed while performing a one and three-quarter front flip on a mini-trampoline. My head buried into the landing mat, my neck snapped and cracked in every conceivable way possible, and I knew I had broken my neck and was paralyzed. I was all too aware, extremely angry with myself, and more than a little scared of what had happened. I finally ended up at a trauma center, after about four hours of senseless detours, and told I had a severely subluxed C5 vertebra. I was put in Crutchfield tongs under observation, but after 36 hours, I was a code blue. I was in surgery for nine hours, and then my family was told I would probably be a vegetable for the rest of my life.

Imprisoned in the ICU for 2 months (I think the doctors were waiting for me to die), I lost 60 lbs., more than one-third of my body weight. I guess I harassed them enough and showed them that my instinct for survival was beyond them, because they finally released me to the rehab floor. I was in rehab for nine months and when my doctors would not give me a discharge date, I came home on a weekend pass and never went back.

Now I am paralyzed from the shoulders down and use a PLV-100 ventilator (one on my wheelchair and one at bedside). You might say I was lucky that my accident happened on the job, because workers' compensation has paid for the ventilators and 24-hour attendant care. I have about an hour's free breathing time without a ventilator, and I know how to frogbreathe.

Currently, I am coaching wrestling and gymnastics, counseling peer groups and families of people with SCI injuries, and designing recrea-

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This issue printed courtesy of Aequitron Medical, Inc.

# Congenital Central Hypoventilation Syndrome: A Family Profile

by Nancy Stone

Our son Matthew was born after 31 weeks gestation weighing 4 lbs. He was using mechanical ventilation immediately after birth, but was soon extubated. We were told he would probably be in the NICU a few weeks, but a few days later he needed assisted ventilation again, and the process of diagnosing congenital central hypoventilation syndrome (CCHS), also known as Ondine's curse, began.

Matt was transferred to Riley Hospital for Children at the age of one month for a tracheostomy. He had no complications and was healthy and developing as well as expected in the NICU. He finally was able to come home at 6 months, the delay being due to coordinating home equipment vendors, home care nursing, and insurance coverage. If we had to do it over we would become even more involved in the discharge planning process to expedite the homecoming.

Matt is now almost 6 years old and fortunately is very healthy. He has not been rehospitalized for illness, had no pneumonia, only routine colds and respiratory infections. He was evaluated for phrenic nerve pacing, but we

decided not to pursue it at this time because he only uses ventilation (Matt has an LP6 ventilator) during sleep and illness.

A big impediment has been delayed speech due to the tracheostomy. Matt attends regular preschool and has a communication book to decrease his frustration if the teachers cannot understand him. Most of the time the teachers do understand and if not, the other children usually do. The Passy-Muir valve helps tremendously, but he didn't tolerate it well until he was about 3 years old.

We discontinued night-time nursing when Matt was 3 years old. Since then we have rarely needed to suction him during the night (except during illness) and we attribute this to the Fisher Paykel molecular humidification system — it doesn't drown him with water and there are no water traps to empty. We have only recently started using nurses again for respite care, because the ventilator does inhibit getting a babysitter. Our insurance covers 80 percent of nursing charges for up to 16 hours per week.

The one major frustration we have with Matt's condition is the lack of information and the vast differences in medical treatment. We rely on others to bring to light any new or alternative ideas regarding the management of CCHS. We hope we can have a national conference and bring together all parties concerned.

**ADDRESS:** Nancy Stone, 4260 Melbourne Rd., Indianapolis IN 46208.

**Editor's Note:** A national network of families coping with CCHS has been established. Write or call Mary Vanderlaan, 71 Maple St., Oneonta NY 13820, 607/432-8872.

Simply explained, congenital central hypoventilation syndrome (CCHS), in the absence of neuromuscular or lung disease, is characterized by normal ventilation while the infant or child is awake, but underventilation with normal respiratory rates and shallow breathing during sleep. The specific cause and the mode of inheritance remains unclear. Choices for mechanical ventilation as the child grows older include nasal mask or trach positive pressure; negative pressure; and phrenic nerve pacing. With early diagnosis and careful respiratory management, these children have an encouraging outcome.

For an excellent discussion of CCHS, a reprint of "Congenital central hypoventilation syndrome: diagnosis, management, and long-term outcome in thirty-two children" by Debra Weese-Mayer, MD, et al., is available from Center for Disorders of Respiratory Control, Rush-Presbyterian-St. Luke's Medical Center, 1653 W. Congress Pkwy., Chicago IL 60612, 312/942-2723.

## NEW VENTILATORS QUESTIONNAIRE

Aequitron Medical is requesting the advice and suggestions of ventilator users to help determine their consumer needs for a new portable ventilator. A short questionnaire can be obtained by writing or calling Jan Nelson, Aequitron Medical, 14800 28th Ave., North, Minneapolis MN 55447, 800/497-4979, ext. 256.

## Letter to the Editor: MDA Telethon

Cris Matthews writes "Jerry's Orphans is a campaign of our organization [AccessAbility Associates]. It is encouraging to discover that so many individuals and organizations are concerned about the negativity that [Jerry] Lewis and the telethon foster about people with disabilities. Many people with muscular dystrophy face the real possibility of life with a ventilator. If they watch the telethon, they will not see anyone with a ventilator on the show, let alone leading productive lives. They are told that the only value they have is inspiration for others who are 'more fortunate' and that a cure is the only hope they have for a good life.

"Several friends over the years have lead productive lives with their ventilators. Two years ago, when my bronchitis, took an unexpected turn, I was intubated and briefly used a ventila-

tor. Although the experience was extremely short-lived, I decided that life with a ventilator was better than no life at all. At least for now, that is not an option for me, but I certainly understand some of the concerns of people who use ventilators.

"Without sounding too maudlin or overly ignorant, I have a great deal of respect for those people who have chosen to live outside of the traditional expectations of ventilator users. It takes only one person to defy convention and soon an international organization exists to make life easier for those who follow. It is truly impressive.

"This is the spirit of Jerry's Orphans. Two of us have decided to hand back the negativity to those who invented it and we have discovered hundreds of like-minded people who want to be heard. Perhaps what we all accomplish will give those who follow the message that a cure is the not the only solution; that life with a disability is worthwhile and as much a point of pride as any other lifestyle."

## Rebel with a Cause

(continued from page 1)

tional equipment for high quads. I have built two custom-designed homes. I have lectured on a multitude of topics to various groups from elementary school children to doctoral-level college students.

In the past 12 years, I have had many accomplishments, not without disappointments. I believe each individual must set goals and reach for them, one at a time — surrender is not part of my vocabulary.

ADDRESS: Randy Haims, 10367 Russell Rd., La Mesa CA 91941.

## Ventilators: Alternatives for Long-Term and Home Use

A manual, *Ventilators: Alternatives for Long-Term and Home Use*, will be available in November 1992. This has been prepared by Dr. E.A. Oppenheimer and Adrienne Baldwin-Myers, RN, to assist people who are considering home mechanical ventilation. It is also designed to help physicians as the options are discussed with patients and their families, in the process of decisionmaking. The manual can be obtained for \$15.00 (checks payable to: Dr. E.A. Oppenheimer) from: Dr. E.A. Oppenheimer, Pulmonary Medicine, 4950 Sunset Boulevard, Los Angeles, California 90027-5822.

### 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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# Respirator Use in Denmark

by Bente Madsen

As a reader of *I.V.U.N. News* and an interested student in the treatment of and the attitude toward people with chronic respiratory insufficiency, I should like to tell about the conditions of respirator users in Denmark.

I am 43 years old, female, with a diagnosis of muscular dystrophy. In July 1975, I had a tracheostomy and I have been a permanent respirator user ever since. I live in my own apartment with round-the-clock help. I employ six helpers, each working 24 consecutive hours per week and taking turns about weekends and holidays.

In the last few years discussion about permanent respirator use has been increasing, and this in turn has led to better counseling and to an increasing number of people being treated. Within the last two years, treatment of respiratory insufficiency has been centralized in two of the largest hospitals in Denmark to secure the users an optimum treatment by experts. These hospitals also take care of the instruction of both the user and the helpers in the equipment and everything concerned. After having been discharged from the central ward, the respirator user is attached to his/her local hospital, which is responsible for providing the necessary respiratory aids, repairs, and maintenance.

Most of the respirator users live in their own homes, with round-the-clock help, as I do. The county pays the salary of the helpers, but the user can hire his/her own helpers and has the possibility of firing them if it doesn't work out.

In Denmark, positive pressure ventilation with a tracheostomy is the most common treatment of chronic respiratory insufficiency. But some people may for a number of years make do with positive pressure ventilation with a nasal mask during the night and periods of rest.

LIFECARE's PLV-100 is the most common type of respirator for home use. A few people, mostly polio survivors, use a Fulsula, which is a

Danish-manufactured respirator invented in the early '60s. The machine is portable, as is the PLV-100, but of a much simpler construction, which means that in most cases the helpers can repair it themselves and take care of the maintenance. I personally use a Fulsula because of that reason. I want to live as independently as possible and using a Fulsula I do not need to consult the hos-

pital unless I am sick.

I am active in the Danish Association of Muscular Dystrophy and spend much time writing articles and reviewing books, especially for the Association's magazine. Sometimes I give lessons to nurses, medical doctors, and social workers in the subjects "How to live independently with a severe disability" and "Chronic respiratory insufficiency."

I love to travel, and in the summer of 1987, two of my helpers and I crossed

the United States by car. It was a long trip, but the greatest experience of my life. I hope to return someday to meet again all the nice and helpful people that I met during the trip.

**ADDRESS:** Bente Madsen, Betty Nansens Alle 61, 7.th., DK-2000 Frederiksberg, Denmark.



*Bente Madsen on the dance floor with her attendant during the 1987 G.I.N.I. conference in St. Louis.*

## In Memoriam

Karan McKibben, regular columnist for *I.V.U.N. News* with her "Musings" column, died April 24, 1992, of cancer. Readers will miss Karan's clean style and refreshing, common sense commentary. Anyone wishing to offer condolences to Karan's parents, Jean and Joseph McKibben, may write to them at 113 Aztec Avé., Los Alamos NM 87544. The family requests that memorials in Karan's name be directed to the donor's local March of Dimes chapter.



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## California Budget Hurts Ventilator Users

California's In-Home Supportive Services (IHSS) program serves about 170,000 people who are elderly, visually impaired, and disabled. The program provides funds to hire home care attendants who perform a variety of domestic, personal care, and paramedical services. Many ventilator users rely on IHSS to live independently in their own homes.

The recent budget crisis in California has placed many IHSS recipients at risk. The budget passed by Governor Pete Wilson in early September '92 includes a cut of 12 percent for IHSS. Cuts of this magnitude may force many IHSS recipients into nursing homes or other institutional settings. However, if an individual can show that the reduction in hours of attendant care may

force him/her to move out of the home, the individual can apply to be reinstated, although the mechanism for this is unclear.

In other bad news, Richard Daggett, longterm ventilator user and President of the Polio Survivors Association in Downey, California, reports that Los Angeles County is expecting a large reduction in funds from the state. All departments, including Rancho Los Amigos Medical Center, are preparing for a reduction in hospital clinic services by 35 percent. It is hoped that the outpatient clinics, especially the respiratory and polio clinic, will be spared. Bill Tainter, Director of the California Department of Rehabilitation and another longterm ventilator user, reports that budget cuts will also impact his department.

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## Ventilator Adaptations

*by Mary Miller*

**B**ecause of the late effects of polio, it is necessary for me to use a ventilator for about 9-10 hours during the night and rest periods. My ventilation system includes a Thompson negative pressure ventilator and a custom-made chest shell, plus some adaptations. I tried a positive pressure nasal mask, but I could not adjust.

I contracted polio in 1951 at age 6 and used an iron lung for about three months. I had no breathing problems until 1987 when I needed to use a ventilator again. Due to severe kyphoscoliosis, it was hard to get a good seal with a standard chest shell. Finally, out of desperation, I enlisted the services of a local orthotist in Tulsa who made his own body cast of me and created a chest shell which, with a little additional padding, worked the first time.

There were two important problems: 1) the harshness of the pressure from the shell, and 2) the abruptness of the breathing cycle. I am not referring to the rate, but the action of the cycle. A smooth cycle is more comfortable and more natural feeling to me.

The adaptations that my family and I have come up with have been ones to increase my comfort, to protect my body, and to enhance my ability to rest while using the ventilator.

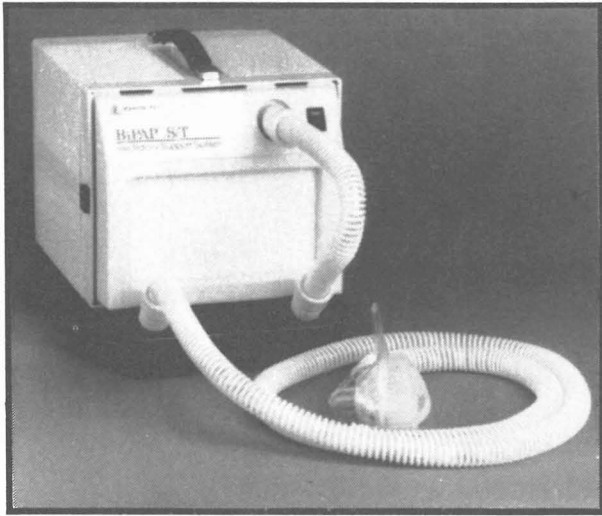
To deal with the problem of pressure from the shell, I made what I call plastic blocks to slip

between the edge of my chest shell and the bed to help absorb the excessive pressure. I use one block on each side of my hips and one along my left side below my arm. The blocks are simply square caster cups such as those used to prevent furniture from marring floor, and duct tape. Stacking one on top of another, I tape together whatever number of cups is needed to achieve the desired height.

To smooth out the breathing cycle, our aim was to increase the volume of air. My father built what we call a "surge chamber." By using a 4-foot long piece of 4 and a half inch diameter PVC pipe with a cap on one end and the appropriate fitting on the other end to accommodate both the machine end of the hose and the shell end of the hose, a cylinder-shaped chamber was created. The fittings were taped with duct tape to secure and seal. Two hoses are needed — one running from the ventilator to the surge chamber, the second running from the surge chamber to the chest shell. Generally the surge chamber slips under the bed out of the way.

**ADDRESS:** Mary Miller, Rt. 1, Box 821, Collinsville OK 74021.

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## Dentist Visits

*by Jack Genskow, PhD*

**W**hat do you do when you need to see a dentist and you rely on glossopharyngeal breathing (frogbreathing) as an aid to respiration? It is impossible to frogbreathe with your mouth wide open and full of dental instruments, cotton packs, and suction tubes. Beyond this, what if you use positive pressure ventilation with a mouthpiece as your respiratory aid? Your mouth must be closed to use the mouthpiece.

In the past, when I was confronted with a visit to the dentist, I needed to supplement my "regular" breathing after a few minutes with periodic frogbreathing. Thus I had to keep interrupting the dental process by looking down and briefly frogbreathing. But my "regular" breathing has diminished to some degree, and I was not sure how well my old method would work.

I tried another method that worked well for me and made the dental process much simpler. I replaced the mouthpiece on the ventilator hose with a pair of nasal pillows which fit into my nostrils and deliver positive pressure ventilation. This allows my mouth to stay open as long as necessary and it greatly speeds up the dental work. Both my dentist and I were pleased.

Nasal pillows can be obtained through respiratory therapists. The pillows must be held in place by a head harness with velcro straps. They may dry out the interior of the nose, but this is not a problem for short periods.

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## ECRI Evaluates Portable Ventilators

ECRI has completed a comprehensive evaluation of six portable ventilators from four manufacturers: Aequitron's LP6 and LP10; Bear Medical Systems' 33; LIFECARE's PLV-100 and PLV-102; and Puritan-Bennett's 2801. ECRI, a nonprofit research and biomedical engineering organization dedicated to improving the quality of health care, published its evaluation in the August 1992 issue of *Health Devices*. The issue is available for \$95.00 postpaid from ECRI, 5200 Butler Pike, Plymouth Meeting, PA 19462, 215/825-6000. A format geared for clinicians and consumers will be published later this year. *I.V.U.N.* will keep you posted.

# I.V.U.N. Directory 1992

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 or call 314/534-0475.

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(continued on page 8)

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(continued from page 7)

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# From the Brink

by Maggie Tyson

On 16 September 1989, I became extremely ill and, if it had not been for friends calling in that frightening night, I would not be here. The ambulance arrived and took me to Prince Henry's Hospital where I was admitted. During the following day I went into respiratory failure. I stopped breathing on two occasions and on one of those I had something which can only be described as a near death experience.

I recall being held and being drawn down a black tunnel going towards the beautiful sound of a choir of voices, not singing, but chanting my name over and over again in a melodic fashion. I can remember thinking and saying to myself and to the voices, "I am coming." I cannot describe the immense calmness I felt. My mother had died nine years before, and I felt that she was indeed waiting for me. I was so happy. Then suddenly I was thrown back, and, even though I could not see, I became aware of the medical staff around me shouting as they intubated me.

My next awareness was waking up in the ICU using a ventilator. My prognosis was not good: I had been born with a form of muscular dystrophy and had used a wheelchair from age 16. I had lived a fairly "normal" life in that I worked and did many of the things that were initially thought impossible. Now I was told that if I did survive this phase, the chances of breathing on my own again were thought to be, ah ... that word again, impossible.

I tried desperately to prove them wrong, that it was possible, that I would breathe again unaided. Fortunately for me, Dr. Hugh Newton-John, an expert in longterm home mechanical ventilation, was called in. He assessed me and asked me what I wanted to happen. I remember writing down, as I was unable to speak, that I was 36 years young and wanted to live, as I still had a lot of living to do.

Dr. Newton-John thought I had a chance and accepted me into his rehabilitation programme in the respiratory ward at Fairfield Hospital. Before the move, I had to agree to allow a tracheostomy. Had I been fully aware of the struggle ahead — who knows?

I spent the next three months in the ICU at Fairfield learning to breathe again. For a long time, when I became fully aware of my situation, I prayed that I would not survive and felt ex-

tremely angry that I seemed to have no way out of this horrendous nightmare. Thanks to the wonderful, patient, and caring staff, I began to breathe on my own minutes at a time. One minute turned to five, to twenty, until I was able to breathe for two to three hours.

I left the ICU when I was breathing nearly five hours on my own and told that if I could sustain that time and extend it to 12-14 hours per day, the tracheostomy tube would be removed. I would then be fitted with a nasal mask to wear at night.

Thus I transferred into the rehabilitation section. The next few months were extremely difficult for me, both physically as well as psychologically, as I was trying hard to achieve my goal of 14 hours breathing on my own. At one point in my recovery, when it seemed that it was taking too long, the suggestion was made that I would recover better at home. The idea of being home alone unable to communicate totally terrified me. I had tried to learn to speak with my tracheostomy, but had found it an impossibility. Was there any point going on? I made up my mind that I was not going to throw myself into the Yarra River [on the hospital grounds], after all the hard work that I had done to get this far.

*"We have taught you how to breathe again. Now it is up to you to go out and live."*

I finally achieved my goal. I was now breathing 14 hours on my own. The morning the tracheostomy tube was removed was one of the most memorable and happiest days of my life. I was nervous, however, not knowing what the sensation of breathing through my nose and mouth was going to feel like or whether the process would be successful.

Dr. Newton-John and two nurses were with me. One held the tube while the other cut the tapes which had held it in place all these months around my neck. A nurse held my hand tightly, and I felt the excitement and nervousness welling inside me and in the people around me. Dr. Newton-John held the tube and carefully and slowly pulled it out. He held the tracheostomy opening shut and told me to say something. All

*(continued on page 13)*

Dr. Gumerman contracted polio in 1955 at age 21, the week before his second year of medical school. He was in an iron lung but graduated to a cuirass and rocking bed during the night. He went back to medical school in 1956, getting around in a motorized wheelchair, gradually working up to fulltime. In 1960, he was hospitalized again, probably with carbon dioxide narcosis. He began a residency in nuclear medicine in 1961, married in 1963, and moved to Pittsburgh in 1965 to join the faculty of the University of Pittsburgh, eventually becoming head of the nuclear medicine division of the radiology department.

"It took pneumonia in 1971 to teach me the importance of adequate respiratory muscle support (frequent ventilator use during the day) and adequate rest. In 1982 I noticed increasing difficulty doing some things that I had done easily before. I began to reduce my work day, resigned as head of the nuclear medicine division, and by 1987 retired on disability."

Dr. Gumerman uses intermittent mouth positive pressure during the day and a cuirass at night. He says, "I have not



switched to any form of positive pressure ventilation at night in part because I dislike not being able to talk when lying in bed, and this would be difficult to do with a nasal mask."

## Florida or Bust!

*by Lewis Gumerman, MD*

I traveled by air in March, 1992 — the first flight I have taken since 1977, when my strength was greater and my ventilator dependence less. About a month earlier, my recently college-graduated son said he thought it was time that he and I went on vacation (he had had a vacation with Mom a year earlier).

I had great doubts that a trip would be possible, because March is not the time to find a good vacation spot within reasonable driving distance from Pittsburgh, Pennsylvania. I really didn't think an air trip was an option, because I now use a motorized wheelchair and travel on the ground only in my van with wheelchair lift. I remembered Evergreen Travel\* listed as a travel agent for one of the G.I.N.I. meetings in St. Louis. Jack Hoffman of Evergreen opened my eyes.

The two main things I learned that eventually made the trip possible were that airlines not only would take me but would take my batteries also, and that there is at least one company with a number of locations around the country renting full-size vans with lifts. Jack made the arrangements with Wheelchair Getaways\* near Miami (our chosen destination), and I hammered out the details with US Air.

I do not want to minimize the necessity to work out the details, but it turned out not to be a monumental task. I was directed to a ground supervisor at the airport with whom I met about a week ahead of time to show the equipment and to request permission to carry on the ventilator I use at night (cuirass with Emerson ventilator). The supervisor cautioned that decisions about onboard items are in the hands of the flight personnel, but was optimistic that I would not have any problems. Indeed I did not.

I carried on the plane my PLV-100 for inflight use (under my legs and partway under my seat), a sealed 12-volt battery with connector cables to run the PLV-100, and my cuirass and ventilator for night-time use. In the overhead compartment was a bag with a spare battery just in case. In the

\*Evergreen Travel Service, 4114 198th St., S.W., #13, Lynnwood WA 98036, 206/776-1184. Wheelchair Getaways, 800/659-1972.



baggage hold was my motorized wheelchair, which folded up simply once the power pack was detached.

No one asked for letters from a physician stating my diagnosis (polio) or for any other information. I took the precaution of finding out the location and phone number of the closest LIFECARE office to my destination.

Upon arrival at Miami, the main problem was the traffic jam that the van was in so that we had to wait about 45 minutes until it arrived. The full-size van was very quiet and comfortable (I have a mini-van and the difference was striking). While in the van I ran the PLV-100 off the car battery through the cigarette lighter outlet using the connector cable I had made in Pittsburgh before leaving.

From my point of view, the worst part of the trip was departing the plane on the return to Pittsburgh — the temperature was 25 degrees Fahrenheit!

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## Ventilator User Settles Airline Suit

Bill Tainter, respiratory polio survivor and Director of the California Department of Rehabilitation, recently settled a lawsuit with United Airlines which claimed, among other things, that United Airlines violated the law by allegedly refusing to allow Tainter to board its airplane with his ventilator and gel cell battery pack. (Tainter was on his way to Washington to attend a disability rights conference in January 1991.) In settling the case, United denied any fault or liability on its part.

Tainter stated that he was "satisfied with the settlement and pleased that United Airlines was receptive to his concerns. . . . United's reaction has been positive and constructive. I am pleased that United demonstrated its commitment to improving its services for the disabled community and correcting any problems that may have led to the incident in which I was involved."

## From the Brink *(continued from page 11)*

I could say with tears in my eyes was "Thank God." These were the first natural words that I had spoken in nearly eight months, and how wonderful it felt.

The next few months had its ups and downs as I tried to find a mask that was suitable. I now knew that I still had to be fairly reliant on a machine to keep me alive. Until now my whole existence for months had been the single-minded goal of getting the tube removed, forgetting that the basic problem of chronic respiratory failure would always require a certain amount of assisted ventilation.

The final words said to me when I was discharged after nearly 12 months were, "We have taught you how to breathe again. Now it is up to you to go out and live."

It has been three months since I left, and I have my nasal mask and ventilator almost mastered. It has not been an easy adjustment, new limitations have to be absorbed, but I am trying. I truly believe that this is my second chance. How many people get an opportunity to do the things they have put off, and most important, to say the things to friends and loved ones that have been left unsaid?

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**I.V.U.N. periodically receives requests from individuals wishing to purchase ventilators. If you have equipment available, please send the details to I.V.U.N.**

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\*Selected articles of interest on  
home mechanical ventilation  
arranged in order of most current  
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## Calendar

**Mechanical Ventilation: Principles and Practice**, September 25-27, 1992, Radisson Hotel Metrodome, Minneapolis. Contact University of Minnesota, Radisson Hotel Metrodome, Suite 107, 615 Washington Ave. SE, Minneapolis MN 55414.

**Management of Pediatric Feeding and Swallowing Difficulties**, October 16-17, 1992, Vestal Education Center, The Children's Hospital, Denver. Contact Cindy Doll, The Children's Hospital, 1056 East 19th Ave., Denver CO 80218, 303/861-6338.

**Longterm Respiratory Insufficiency, Late Effects of Poliomyelitis, and Orthopedic and Physical Therapies, International Medical Congress of the Stiftung Pfennigparade**, November 19-21, 1992, Arabella Hotel, Munich, Germany. Contact Stiftung Pfennigparade, Kongressburo, Barlachstr. 24/1, D-8000 Munchen 40.

**Pediatric Ventilator Users Network Meeting**, December 12, 1992, 5:00-7:30 pm, AARC annual meeting, Marriott River Center, San Antonio. Call Jan Nelson, Aequitron Medical, 800/497-4979, ext. 256.

**International Conference on Home Mechanical Ventilation**, March 3-5, 1993, Palais des Congres Internationaux de Lyon, Quai Achille Lignon, Lyon, France. Contact J.I.V.D., Hopital de la Croix-Rousse, Service de Reanimation et Assistance Respiratoire, 93, Grande Rue de la Croix-Rousse, 69317 Lyon Cedex 4 - France.

## WANTED!

I.V.U.N. is collecting standards and guidelines for facilities wishing to establish intermediary or transitional care for ventilator users. Health professionals and government agencies with such standards/guidelines are asked to send a copy to I.V.U.N., 5100 Oakland Ave., #206, St. Louis MO 63110.

## Best Wishes ...

... to Sue Sortor, RRT, and Patrick Leger, MD, who were married on August 1, 1992 in Dallas. Sue is well known in I.V.U.N. for her work with face mask ventilation; Patrick is a pulmonologist at Hopital de la Croix-Rousse in Lyon. Dr. and Mrs. Leger will be making their home in St. Dider Au Mt. D'or, France.

## Deadline ...

... for submission of articles, stories, information, etc., for the Spring 1993 issue of *I.V.U.N. News* is February 28, 1993.

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