

I.V.U.N. NEWS

International Ventilator Users Network

Fall 1993 ■ Volume 7, No. 2

Air Scuba ... or I Can't Walk But I Can Fly

by Randy Haims*



Vent users, I'm breaking the mold! Several months ago I was talking to Steve Kaliszewski, a friend who is a C7 quad and also a wheelchair sports specialist at Sharp Memorial Hospital in San Diego, and he told me he had just had an experience of a lifetime. "I went skydiving," he said. He went on to explain how it was done, and as he did light bulbs started flashing in my head. A quad sky diving is an accomplishment, but a quad on a vent sky diving is astounding, bordering on stupidity, but well-calculated stupidity.

After talking with Steve, I started brainstorming to figure out how I could jump. I thought I could take a small scuba tank and diving regulator and use that to help me frogbreathe, but after almost a month of making different adjustments on the regulator, I was very disheartened. I could not breathe with it, but I was not ready to give up yet. I put the equipment aside and waited for another good idea to come along.

A month later, another light bulb went off, and I knew I had the solution. I took the mouthpiece off of the regulator, added a piece of flex hose, and connected it directly to my trach. Now I just needed to go back to the dive shop, have them set the regulator on a constant air flow, and I would have more than enough air until I reached the ground. I felt I had brought the risk factor down to a minimum.

Ready to go, I called Jim Wallace of Wally World, an expert sky diver with almost 11,000 jumps to his credit, including numerous tandem jumps. I told him to set a date. When the big day came, I suited up,

velcro-strapped and duct-taped the air cylinder to my stomach and the regulator near my shoulder, strapped my ankles and knees together, and strapped my arms across my chest. To get into the airplane, I was turned slightly sideways so Jim could attach the hooks from his harness to mine. Then five of us, plus the ventilator, loaded ourselves into the four-person Cessna. We were just ready to take off when the internal battery on my vent died, but we quickly exchanged it with my wheelchair vent, and sailed off into the wide blue yonder.

It took us a half an hour to reach 12,500 feet, our jump altitude, and then things started moving very quickly. I was transferred to my air scuba tank, Jim and I sat upright, the door opened with a chilling rush of air and an unbelievable sight of the ground below (we were over Murrieta Hot Springs). The camera man stepped out, barely clinging to the plane, then Jim and I stepped out, and we were falling at a speed of 120 mph. We freefell for almost a minute, and then Jim pulled the ripcord. My legs jackknifed almost to my face, and my head was thrown around a bit, but then things settled down and we were able to converse until we landed. As we approached the landing site, we were blown off course about 50 feet, so the people who were supposed to catch my legs were not there. We still managed a perfect landing on our feet. The jump had lasted five to six minutes, and after we landed — to the cheers of my nursing staff who had come to watch — I still had 13 minutes of reserve air in the scuba tank.

A message to quads and quads on vents: don't let society, family, doctors, or anybody set limits on your life. Life is short enough; be adventurous, yet careful, and, above all, be limitless.

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*Readers of *I.V.U.N. News* first met Randy, a C2 quad and ventilator user (trach positive pressure), in the Fall 1992 issue. Randy is looking forward to his next skydive soon.

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Ventilator Reimbursement Issues

by Judith R. Fischer and Joan L. Headley

The Health Care Financing Administration (HCFA), the agency administering Medicare, is admirably trying to streamline paperwork and cut costs, but in so doing, HCFA is revising and rewriting many policies. Ventilator users whose ventilatory equipment is paid for through Medicare have been advised that changes in policy may affect their reimbursement for more than one ventilator. HCFA has already reduced the number of codes for ventilators to two: one code for positive pressure ventilators and one code for negative pressure ventilators. This could cause problems for ventilator users who may use multiple ventilators for different purposes, including backup, during a 24-hour period. These ventilator users may be disallowed, because, on paper, Medicare is being billed several times under two codes or twice under one code, etc.

Another change affecting ventilator users is in Medicare's insurance carriers. Currently, each carrier has its own policy regarding multiple ventilator reimbursement. On October 1, 1993, HCFA is scheduled to reduce the number of insurance carriers that handles its claims from 33 to only four, consolidating the country into four regions. These carriers are known as Durable Medical Equipment Regional Carriers (DMERCs). We have been advised that HCFA will not be issuing a national policy for ventilator reimbursement by October 1, 1993. This is worryingly ambiguous, because no one knows how the new DMERCs will act come October 1. If there is no national policy, what policy will they follow?

Longtime ventilator users realize that a change in the policy to allow payment for multiple ventilators could ultimately result in the institutionalization of some people, which we all know is astronomically more expensive, with an additional cost to the health care system estimated at nearly one billion dollars.

Many *I.V.U.N. News* readers, ventilator users as well as medical professionals, have written to officials at HCFA and to the medical directors of the new DMERCs expressing their support for a national policy that allows reimbursement for multiple ventilators. (Longtime ventilator users will remember that HCFA attempted to disallow payment for multiple ventilators in 1984, and it was consumer protest, led by Gini Laurie and the *Rehabilitation Gazette*, that convinced them to rescind that policy.) We hope that as this issue of *I.V.U.N. News* reaches you, the new DMERCs will let the reimbursement status quo continue, until a new national policy can be established.

Thanks, Scott Cameron

by Jim Gassen

A friend told me about I.V.U.N.'s newsletter. I was looking for other people like me with Duchenne muscular dystrophy (DMD) who had chosen to be ventilator users. The first issue I received in spring 1990 had a story written by Scott Cameron, who had DMD and who had used a ventilator for several years. The story inspired me, and it reaffirmed my decision to be a ventilator user when the time came. I wrote Scott a letter after reading his article and we kept in touch.

In March 1993, right before my own tracheostomy, I received a FAX from Scott. He stated, "Almost all the time I know I made the right decision 13 years ago. If you have a zest for life and feel that you have lots more to do, then go for it! Do you have family and friends who will support you with this tough decision? Whatever decision you make is the right one. Best regards, Scott Cameron." I am now a ventilator user, and I am glad. I am grateful to my family, to my doctor, and to Scott for the encouragement.

Scott Cameron died in May 1993, but gave to the very end. I am proud to be following in his footsteps. I never had the pleasure of meeting Scott, but he is loved and respected by many. I will always remember Scott.

ADDRESS: Jim Gassen, 907 N. Hayes, Oak Park IL 60302. 708/386-3878. Jim encourages other individuals with DMD to communicate with him.

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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Advice for the New Ventilator User

by Tedde Scharf

Generally, the new ventilator user has already dealt with a disabling condition and has either accepted it or is struggling with some phase of the process. The continuing process is the positive evolution of a new value system which allows the individual to accept him/herself as a capable, functioning being, despite the loss of additional physical ability.

There are three primary keys to success for us as ventilator users: creative thinking, organization, and persistence.

Creative thinking. When, as newly ventilated and perhaps trached individuals, we find ourselves lying in some hospital bed facing extreme, frightening changes in our lives, we must challenge ourselves to begin developing ways to cope with this new life situation. We must:

- Set daily goals;
- Involve ourselves intensely in the rehabilitation process;
- Start an exercise program, e.g. range of motion, passive resistance, etc., while still hospitalized;
- Take an interest in the equipment, find out how it works, what happens when it does not, how to fix it or find someone who can;
- Demand information on tracheostomy speaking valves, such as the Passy-Muir, because communication is critical to both the rehab process and life itself;
- Involve ourselves in the functional use of the ventilator with a wheelchair and other existing equipment, focusing on the adaptations that enable us to function most effectively;
- Research good nutritional habits for keeping the digestive system well-balanced despite frequent use of antibiotics for respiratory infections;
- Problem-solve for creative approaches to modifying personal care needs, reevaluating the work setting and transportation needs, resolving financial/insurance issues, coping with social interactions, and understanding our new medical needs;
- And most important, take responsibility for our own survival. A busy mind does not have time to dwell on loss or diminished functioning. Active productivity facilitates a broader scope of values, better self-esteem, and ultimately, acceptance of the ventilator.

Organization and consistency are major factors in our successful rehabilitation and subsequent good health, as independent and productive ventilator users. Even before we are discharged, we need to establish daily schedules for personal care, trach care, and equipment maintenance, as well as meals, rest, exercise, and social activities. Supplies and workspace need to be well-organized, both at home and in the work setting. We should develop a preventive health maintenance program with our

Tedde Scharf is Associate Director of Disabled Student Resources at Arizona State University in Tempe. Diagnosed with limb girdle muscular dystrophy at age 6, Tedde was a commercial artist in textile design and then in oil portraiture before switching to a career in higher education. She serves on the Board of Directors of the Muscular Dystrophy Association and its National Task Force on Public Awareness. Now 51, Tedde became a ventilator user in 1988. She uses trach positive pressure with a PLV-100 ventilator, but is hoping to have her trach removed and move on to non-invasive mask ventilation. Tedde says, "I am fortunate to have family and medical professionals who support my desire to work and remain active in all ways ... Life has been good to me in so many ways. I see this daily as I watch students with all types of disabilities struggle to make a path in a world with new laws, new rights, and new barriers. The challenges will always confront humanity. Only we, as individuals, can make the choices which open doors to overcoming those challenges."



pulmonologists, respiratory therapists, and general physician. We must learn to train personal care attendants in "clean/sterile" medical procedures for trach care and suctioning. We must educate (without intimidating) coworkers and friends in the use of the suction machine and the "blue bag," how the various tubes and hoses connect to the ventilator, how the alarm sounds and why.

Persistence and motivation return us to a satisfying lifestyle. Throughout the critical care stage, we can set small daily goals for ourselves and expect results. This exercise teaches us persistence and motivates us to take responsibility for our own survival, goal-setting, and meaningful existence. We will discover the primary motivators in our lives and focus on pursuing them, without letting a trach or a ventilator interfere. We can read about successful individuals who use ventilators, and seek to meet positive role models. We should request referral to the State Rehabilitation Services or Vocational Rehabilitation for job site modification and/or retraining. If we are non-Rehab clients, we can get some assistance through the State Rehabilitation Services SIL office for home modifications and assistance with independent living. We must use all the information we can gather to rebuild our lives. We must learn to be our own best advocates, and be assertive in our dealings with

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Nasal Mask Adjustment Tips

I.V.U.N. News readers respond to the call for suggestions on adjusting to oral and nasal masks:

Barbara Carter of Granada Hills, California, writes: "Like other polios with continuously weakening breathing, I too had to adjust to a nasal mask a few years ago. Lacking LIFECARE's instruction manual, I suffered through all the problems with leaks, sore skin, etc. Then I started using nasal pillows with my ADAM CPAP circuit, and what a difference! Nasal pillows simply don't leak (if the right size is used) and care is taken to position the headgear correctly. It also must be the right size.

"One should use a humidifier from day one with a face mask to avoid complaints about dry nostrils and throat. I have made my humidifier interchangeable with my PLV-100 and/or my Respironics BiPAP. My BiPAP, by the way, is paced by my rocking bed — a great combo to give me the best of both ventilatory aids. Rocking rests my tired back and alleviates swollen feet. Also it is wonderful for postural drainage, which I do daily in conjunction with using a percussor to loosen phlegm.

"One humorous note: a few weeks ago, I arrived at my lodging at Yosemite with my attendant and all my equipment, except for the nasal pillows. My ingenious attendant discovered wax ear plugs in my travel gear, however, and fashioned makeshift pillows that worked well enough through my three-day vacation."

Tina Givens, RRT, from Birmingham, Alabama sent this tip: "I would like to share a trick that I've learned in helping with pressure points at the top of the nose from nasal masks. A Dr. Scholl's corn pad was used by one of my patients who had pressure point areas, and this corrected the problem."

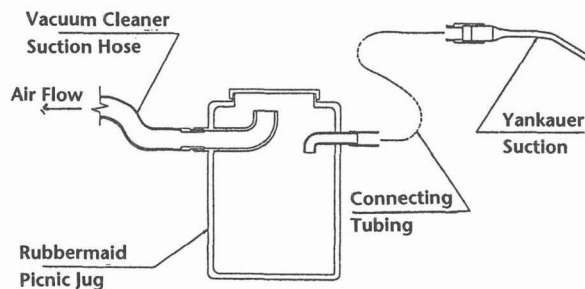
Holly Ruccia, RRT, from Medigas, Inc., Toronto, Ontario in Respironics, Inc., *InterVENTions*, June 1993, advises: "To prevent tissue breakdown on the bridge of the nose, or to prevent silicone mask irritation on sensitive-skinned people, I recommend Dr. Scholl's Moleskin®. Apply Moleskin by its adhesive backing to the nasal mask, allowing the soft, felt side to rest on the person's skin. Moleskin can be cut to any desired shape, and can be easily removed (for cleaning the mask) and replaced with a freshly cut piece. Moleskin seems to work better than other suggested tapes."

Annice Smith, of Monroe, Louisiana, wrote: "I sew a three and one-half inch side hair comb to the back of the head strap that attaches to the nasal mask. I insert the comb in my hair and it helps hold the strap secure ... For the past year, I participated in a biological engineering project by senior students to have them design a leak-free nasal mask, and they did! I would encourage others to contact their local graduate schools of dentistry and biological engineering to see if they have a need for such a project for their students."

Homemade Suction Machine

Bill Moldenhauer of Oconomowoc, Wisconsin, had ALS, complicated by very deep, thick secretions. None of the medications available to control secretions worked, and the suction machines on the market were inadequate to the task. Dr. John Scanlon, Bill's brother-in-law and a dentist, designed a more powerful and more easily portable suction machine for Bill to use. The suction tube removed secretions from Bill's throat, and the back and roof of his mouth. Bill and his wife Sylvia had decided against a tracheostomy and ventilator.

Following the schematic diagram below (drawn by Bob Strehlow of the Southeast Wisconsin Chapter of ALSA), the suctioning power is supplied by a home vacuuming system, such as a vacuum cleaner or a central system. All of the components, except the Yankauer suction tube, are available at the local hardware store. The largest component is the collection container made from a 1 gallon or 5 gallon Rubbermaid picnic jug, modified by adding standard plastic pipe fittings for attaching the hoses. The hoses are glued in place with plastic pipe cement. All sections can be easily cleaned. (The diagram does not show an air vent hole which should be added.)



Thanks to the Southeast Wisconsin Chapter of ALSA, and Sylvia Moldenhauer, 1340 N. Dousman Rd., Oconomowoc WI 53066.

Advice for the New Ventilator User

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agencies, services, and other bureaucracies.

Today, the doors to unlimited opportunities have opened through the development of modern advances in medications, portable ventilators, suction machines, exsufflation machines for coughing, new applications for noninvasive ventilation, speaking valves, accessible public/private buildings and transportation, access to jobs, and increasing public awareness of the abilities and rights of persons with disabilities. It is essential that medical professionals and families recognize the potential of persons who are ventilator users and support the development of a fully functioning independent existence. But it is even more important that we, as ventilator users, recognize our own potential to organize new lifestyles. We make the choices for success and acceptance.

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CHILDREN AS VENTILATOR USERS

OBSTACLES TO DISCHARGE FOR VENTILATOR-ASSISTED CHILDREN

by Pamela K. DeWitt, RN, MN, Mary T. Jansen, LVN, Sally L. Davidson Ward, MD, and Thomas G. Keens, MD

For many ventilator-assisted children, home care is a safe and relatively less expensive alternative to prolonged hospitalization or institutional care. Most ventilator-assisted children do quite well at home. The majority of these children attend school, and participate in regular childhood activities such as Boy Scouts or Girl Scouts, camping, vacations with families, etc. The high level of motivation of parents for the care of their children in the home results in a high quality of care.

Although home care for ventilator-assisted children improves psychosocial development and reduces medical costs compared to hospital care, many ventilator-assisted children remain hospitalized for lengthy periods of time after they become medically stable enough to go home.

Eliminating these delays may help decrease the costs of medical care to ventilator-assisted children. In order to identify factors which contributed to a delay in discharge, we reviewed the records of 54 ventilator-assisted children who were discharged from Childrens Hospital Los Angeles with home mechanical ventilation between 1977 and 1991.

We found that the average length of initial hospitalization was six to seven months, and lasted over two years for one child. Although it took only one to two months to achieve medical stability, nearly three-quarters of the length of this initial hospitalization occurred after the children were medically stable and otherwise ready for discharge. Thus, ventilator-assisted children spent a considerable amount of time in the hospital to resolve home care issues not directly related to the child's medical condition.

The greatest obstacle to discharge was the time spent waiting for approval of home care funding, which averaged over three months. Once home care funding was approved, children were discharged within two months. It is ironic that funding agencies delay approval for home care funding while they continue to pay relatively high inpatient costs. The charges for medical care in an intensive care unit (ICU) for a ventilator-assisted child exceed \$2,500 per day, while home care costs are approximately \$600—\$1,000 per day, even with in-home nursing care. Overall health care costs for ventilator-assisted children may be substantially decreased by expediting approval of home care funding.

The home care for ventilator-assisted children can be complex, and one might predict that training parents to provide home care would take a considerable length of time. However, we found that parent training was usually completed by the time home care

funding was approved; it was never an obstacle to discharge. Thus, parent training did not prolong the initial hospitalization for ventilator-assisted children.

Ventilator-assisted children require vigilant, consistent, and technically sophisticated care. It is often unrealistic to expect parents to provide continuous medical care for these young children without in-home nursing care or other respite care. We found that 80% of our patients used 8-24 h/d of in-home nursing care. However, the length of time to obtain home care funding approval was unnecessarily prolonged in both children with and without in-home nursing care.

Half of our patients had home care funding provided by public agencies and half by private insurance agencies. Hospitalization was longer for patients receiving public funding than those with private insurance. The time required for public agencies to resolve non-medical home care issues was nearly four times as long (six months) as that required by private insurance (one and one-half months). This was due almost entirely to time required to approve home care funding.

The magnitude of this increased cost can be estimated making the following assumptions: 1) charges for ICU hospital care are at least \$2,500 per day; 2) public agencies in California fund a maximum of 16 h/d of in-home nursing care and pay \$355 per day; 3) public agencies spend an average of six months time to approve home care funding. Thus, keeping ventilator-assisted children in the hospital for the increased time to approve home care funding cost an extra \$386,100 per patient, compared to having them at home during the same time. This amounts to **\$20,849,400** for all 54 children. Once funding was approved, the time required to discharge was similar in patients with public or private funding. These results suggest that the overall costs of home mechanical ventilation could be substantially reduced if public funding agencies improved the efficiency with which they approve home care funding.

We speculate that overcoming the obstacles to discharge of ventilator-assisted children could be facilitated in the following ways: 1) the use of experienced centers to facilitate stabilization of the patient, parent training, and arranging for in-home nursing, home respiratory care vendors, and funding; 2) provisions for home care included in public and private health insurance policies; 3) more rapid processing of applications for home care funding by third party payers. Skilled nursing facilities are not an acceptable solution to this problem, because they cannot meet

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Children as Ventilator Users

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the cognitive, developmental, and psychosocial needs of alert ventilator-assisted children.

In summary, ventilator-assisted children often remained hospitalized for prolonged periods of time to resolve non-medical issues after they became medically stable. The greatest obstacle to discharge was seeking approval for home care funding. Public funding agencies took longer to approve home care funding than private insurance. We conclude that increased costs of medical care are unnecessarily

incurred by prolonging hospitalizations for ventilator-assisted children to resolve non-medical issues. The greatest obstacles to discharge of ventilator-assisted children are related to funding; these could be improved by administrative and/or legislative action.

Adapted from "Obstacles to discharge of ventilator-assisted children from the hospital to home," by DeWitt PK, Jansen MT, Davidson Ward SL, and Keens TG, Chest 1993; 103: 1560-1565.

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CCHS NETWORKING: How It Began

by Mary Vanderlaan

I started the Congenital Central Hypoventilation Syndrome (CCHS) family support network and the *CCHS Family Newsletter* formally in 1990 out of desperation to find support — emotional, informational, etc. — given the issues we faced with our CCHS son, born in 1988. When Nicolas (Nico) was finally diagnosed at age 6 weeks, we were told that there were probably about 12 cases in the U.S. There was also little research and literature on "Ondine's Curse," the foreboding nickname of the syndrome. We felt terribly isolated, frightened about the future, and totally dependent upon the medical community, something two professional people, accustomed to being independent and in control, found even harder to accept.



The issues and constant critical concerns associated with having a small infant (Nico was six weeks premature) with a ventilator and in need of frequent suctioning, bagging, trach care, and the like, were physically and emotionally draining. To make matters worse, we came home with a six-lb. infant at nine weeks *without* nursing support.

Day after day that first summer, I cared for an intensely medically involved little boy who was hooked up to both his ventilator and his oxymeter around the clock. My husband, who wanted to stay at home to join in the care of our baby, had to keep working to maintain our medical insurance. Most days I never managed the time or energy even to get dressed, and at night we took turns sleeping on the floor by the crib in order to respond to alarms that seemed to go off every few minutes. Needless to say, while we were literally driven in this period to meet Nico's need minute by minute, we were soon clinically exhausted. Help came when we found qualified

What is CCHS?

by Mary Vanderlaan

Children born with CCHS do not breathe during sleep or when they are seriously affected with a respiratory illness. In approximately one-quarter to one-third of the cases, the child also does not have respiratory response during awake hours. Most of these children have diaphragm pacers, which allow them free time from the ventilator. The children who do have awake respiratory response do breathe shallowly and their respiratory response is easily compromised, for example, by high heat and humidity or periods of prolonged physical and mental stress or strain.

CCHS children must be clinically observed by parents or nurses at all times. Intervention by bagging or stimulation to improve O₂ saturation becomes fairly regular for children in their early years. Optimum medical maintenance for the majority of CCHS children involves trachs and ventilators, although a growing number of older children are moving to noninvasive nasal ventilation.

There is a range of outcomes for the children in cognitive and motor development. Most CCHS children, due to some hypoxia or other medical complications, manifest delayed motor development. Many experience delayed speech development and are diagnosed with learning disabilities in one or more areas once they progress through elementary school. The vast majority of CCHS lead "normal" lives and have a good prognosis for a productive and satisfying life. The oldest CCHS children are now reaching 20 years old and are graduating high school and taking jobs or planning for college. There is every reason to expect that they can be independent through their adult lives.

nursing care for some hours each day. We found and trained the nurses ourselves, after having two bad experiences with nursing agencies unaccustomed to providing care for such critical cases in the home.

Because we knew no family with a CCHS child even close to Nico in age who might be going

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I.V.U.N. DIRECTORY 1993

Longtime ventilator users and health professionals who are experts about and advocates for home mechanical ventilation are listed below. Send addition, deletions, and corrections to I.V.U.N., 5100 Oakland Ave., #206, St. Louis MO 63110 USA, or call 314/534-0475, or FAX 314/534-5070.

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Children as Ventilator Users

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through the same things we were struggling with, and because our local pediatrician — excellent and supportive as he was — was also seeing this syndrome for the first time, I began calling people and putting ads in pediatric nursing journals in efforts to find other families. Slowly at first, and then regularly, calls started coming in from families, nurses, and doctors who had or were caring for CCHS children in the U.S., Canada, the U.K., Europe, and elsewhere. Over time, I became a clearinghouse of sorts for information, exchanges of ideas on maintenance and care protocols, news about research, etc., for the children.

In mid-1990, when I sent out the first newsletter and then produced the *CCHS National Directory*, we had 40 children in our network. Today, we have 102 children and their families, and we publish three to four newsletters per year. We have just updated the directory, which now includes seven families in Canada, two in the UK, and one in New Zealand. The newsletter is now funded by voluntary donations from our families and shares family stories, research news, and reports from doctors. Happily, the *CCHS Family Newsletter* has been an important source of information for families and their doctors. It has become the information/support source we had been looking for when Nico was born.

Nico is now 5 years old and starting kindergarten. He is accompanied to school by an LPN who will act as a teacher's assistant in the classroom so that she will not be identified as "Nico's nurse." At the first student rally, Nico and I showed off his trach and ventilator, and answered questions. Nico plugs his trach during the day to minimize infections and optimize his speech, which is very clear now and which he has been working on since he was 3 years old and

could tolerate wearing the Passy-Muir speaking valve. He has some major motor delays, but is intellectually on target.

In the past few months, we have had problems with regular servicing of our ventilators and our ET CO2 monitor. One of the ventilators and the monitor were each returned after servicing, by two different companies, in inoperable condition. In each case, technicians responded to our phone calls with skepticism that our observations about their equipment were legitimate. The equipment had to be sent back again, at some cost to us.

Another constant issue is finding and keeping night nursing support, definitely a quality of life issue when both parents work. In New York, the Medicaid Waiver program pays for nursing care not covered by insurance, but the paperwork enrolling a new nurse and initiating payment can take six months, and we have lost three nurses this year because of that.

However, life does go on, during and after CCHS! I am long since back in my position as a professor of political science at Hartwick College, and recently became department chair. "Poppy" continues as a mental health counselor for New York State, working with children. Both of us, however, continue first as Nico's advocates, respiratory therapists, equipment technicians, medical supply clerks, nursing care coordinators, insurance negotiators, research cheerleaders, and all the rest that comes with being CCHS parents. And now that life has become somewhat easier as Nico ages, we have a new puppy ...

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Editor's Note: The first CCHS Family Conference is planned for October 9-11, at Camp Fowler in Mayville, Michigan. Scholarships are available. Call Nancy Stone for information, 317/299-0801.

ISSUES AND CHALLENGES OF A TECHNOLOGY-DEPENDENT CHILD

by Stephanie M. Ellenberger, RN, & Tony Hilton, RN

Jane was a term infant, but she was born with hypoplastic lungs and her entire intestinal tract and liver herniating through the wall of her unusually small abdominal cavity. The defect was so large that it could not be repaired by conventional methods, but Jane's own skin was expected to grow over the defect within three to six months. Then, if Jane survived, at the age of 1 or 2 years, the remaining hernia could be repaired.

For most of her first year of life, Jane's hospital course was unsteady. She required a tracheostomy for prolonged mechanical ventilation, and her hospitalization was further complicated by multiple episodes

of central line sepsis, patent ductus arteriosus, pulmonary edema, pneumonia, chronic lung disease with reactive airways, gastroesophageal reflux, aversion to oral feedings, and seizures.

Although they lived an hour away from the hospital, Jane's parents visited regularly and were eager to participate in her care. Moreover, they wanted to take Jane home, despite her need for 24-hour mechanical ventilation and other complex medical care.

The hospital's interdisciplinary team, directed by a pulmonary rehabilitation clinical nurse specialist, assessed Jane's medical and rehabilitation needs and

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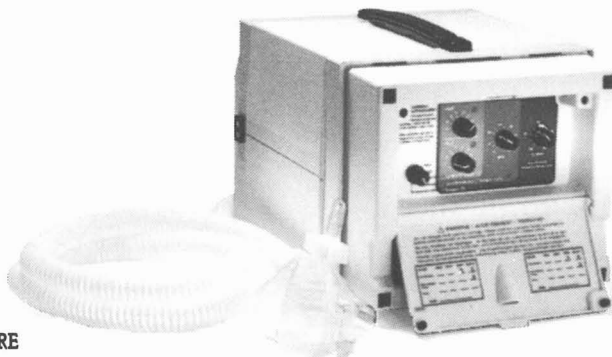


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Children as Ventilator Users

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prognosis for discharge. Jane's parents had to consent to participate in a training program and to sign an agreement committing themselves to the plan. The family's financial resources were considered, and a home evaluation was conducted to determine the suitability of the family's home for supporting Jane safely. The team also ensured that the family had access to community resources which would provide services after discharge.

Benefit coverage for home care was determined through Jane's health maintenance organization (HMO), and arrangements were made for developing a discharge plan collaboratively with the HMO providers. Recommendations from the hospital team for outpatient services, included equipment, supplies, home nursing, and followup care. The family's transportation system was assessed during the home evaluation and recommendations for home and vehicle alterations were given to Jane's family and the HMO. Based on these suggestions, a schedule for making adaptations was developed with Jane's parents.

The HMO selected the home care nursing agency, but the agency's ability to manage Jane's nursing care was verified by the hospital team, who scheduled training for the home nurses.

The HMO also selected the equipment and supply agencies, but again these were verified by the hospital team. Equipment was ordered and delivered to Jane's hospital room for use during the training program.

The essential part of Jane's discharge was family education and training — teaching Jane's parents to perform her care and monitoring that care. Training was documented carefully. The training program for the home care nurses was specifically tailored to Jane's physical and emotional needs; it also was monitored and documented.

The outpatient service providers were identified and included in the final team conference. Jane's parents were given a complete list of telephone numbers for contacting both inpatient and outpatient team members; the family was also given instructions

regarding which health care providers to use for specific care.

Several challenges arose during the discharge process. Jane's family lived a significant distance from the hospital. Barriers to communication existed between the hospital and community teams. A ventilator-assisted patient was a new experience for most of the people involved in Jane's care. Although the HMO had limited practice with home ventilation, it was responsible for providing primary care and case management after discharge. Other challenges included working with multiple outpatient service providers, financial constraints, time limitations, and Jane's medical fragility.

Based on the experiences encountered during Jane's transfer, several recommendations can be made: 1) collaborate early with the community team to develop a plan for transferring care; 2) design a time-line for implementation of the discharge plan; 3) identify an individual in charge of outpatient clinical case management, such as someone with the knowledge and background to integrate managed care and case management of a medically fragile patient; and 4) urge everyone's participation in routinely scheduled discharge planning conferences. When multiple groups are cooperating on the discharge of a complex patient, it cannot be overemphasized that teamwork is essential. The interest of the child is foremost.

Jane has been home for over a year and soon will celebrate her second birthday. In May 1993, her hernia was completely repaired, and in July 1993, she was weaned from mechanical ventilation. Her parents are pleased with her accomplishments and believe that Jane's quality of life has far exceeded their hopes and expectations. Jane's progress can be attributed to the cooperation of her parents, the hospital team, the HMO, and the community team.

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PAMELA WOLFE

by Judith R. Fischer

Pamela Wolfe, now 6 years old, seems to have defied the odds. She was born with prune belly syndrome,* a congenital abnormality with one or more layers of the abdominal musculature absent. The syndrome usually affects males and the poor prognosis is often associated with heart and kidney problems. Pamela's medical problems were exacerbated by a case of pneumonia at age 2, and she has been a ventilator user (LP6) ever since, undergoing four lung surgeries along the way.



Pamela's physician was reluctant to let her come home with her ventilator, and, according to David Wolfe, her father, the insurance company was even more reluctant. (A new insurance company now pays 80% of the expenses.) The family, which is a strong unit with wonderful friends, relies on 18 hours of nursing care, assuming the remaining hours of Pamela's care. Her mother Robin is a nurse's aide. Her grandmother, affectionately known as "Mawmaw" also helps with Pamela's care, caring for her one week every month. Pamela even nominated her grandmother as Miami Valley Mother of the Year, with the words "My mawmaw should be mother of the year. She loves me. She gives me hugs." Her mawmaw won.

Pamela is ready to attend kindergarten this year, after attending a local preschool. Pamela's world is unlimited and she goes everywhere: in the pool, out to eat in restaurants, on family reunions, even to Disneyworld. The family simply plugs Pamela's ventilator into the van using an adapter, and packs a back-up ventilator, suction machine, and battery.

David Wolfe says, "It's like being on call 24 hours per day, 365 days per year." Then he adds, "But I wouldn't have done anything differently. Pamela is a joy."

ADDRESS: The Wolfe Family, 525 Unger Ave., Englewood OH 45322.

**For more information, contact the Prune Belly Syndrome Network, c/o Barbara Hopkins, 1005 E. Carver Rd., Tempe AZ 85284. 602/838-9006.*

The Perfect Portable Ventilator

by Jerry Daniel

Ask most ventilator users and their caregivers and they will tell you that the newer state-of-the-art portable volume ventilators are heavy to lift (between 26-35 lbs.) and somewhat large to mount on the back of a power wheelchair. Could a smaller, lighter, ventilator be produced? I think so. After servicing these machines for 15 years and using them myself for many more years, I have made some observations of ventilator designs that I think could be implemented to trim size and weight. An inch of downsizing in one or two of the dimensions could make a particular unit more popular for wheelchair use, as well as enabling placement on a nightstand easier. Reducing the machine weight will be harder because it will involve less use of the heavier metals — iron, lead, and steel — all required for the power transformers, motors, gearboxes, and internal batteries. Here are my suggestions for a "dream machine."

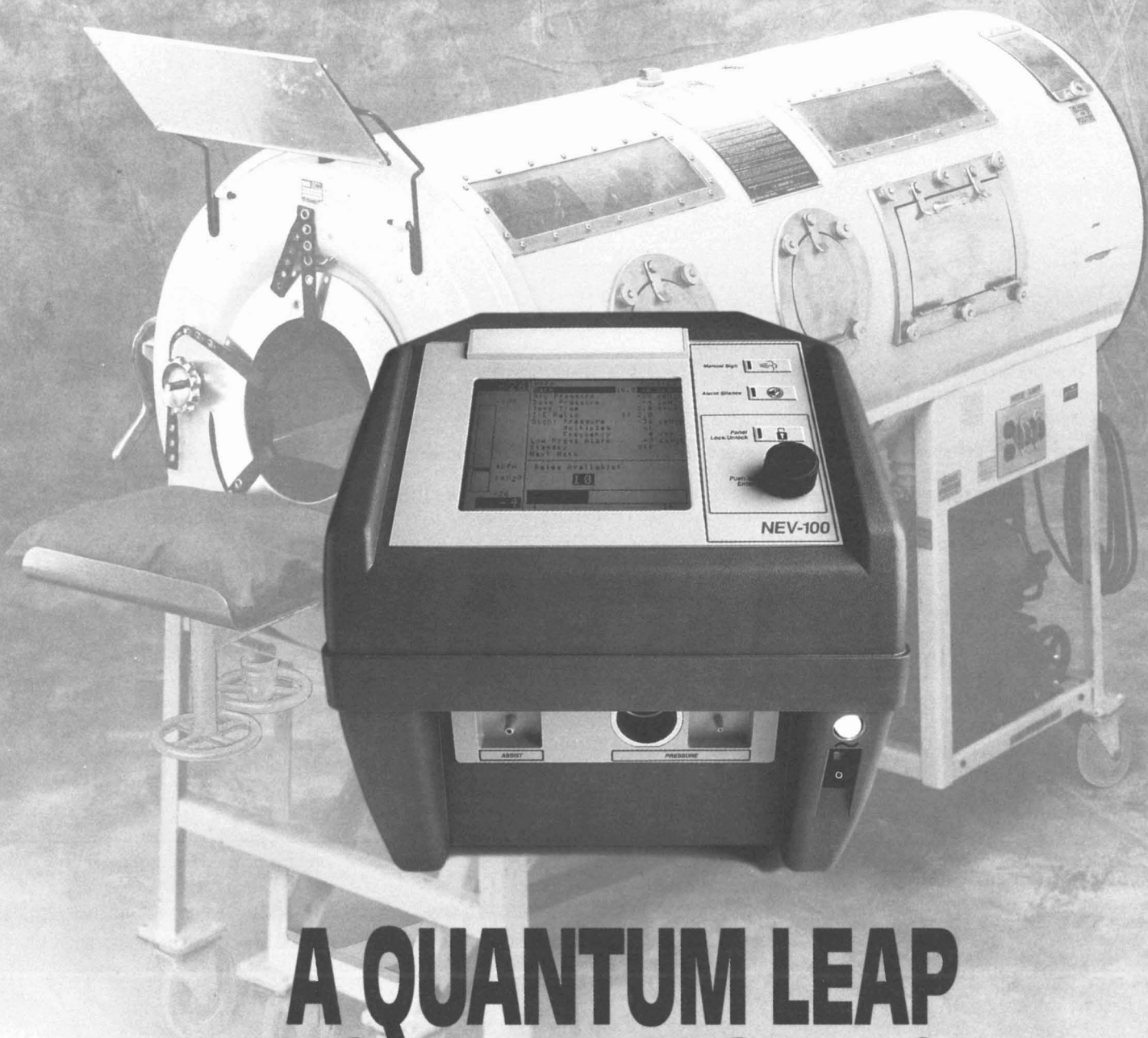
MAKE THE VENTILATOR SMALLER. Trim the width and/or height an inch or so. Crowd electrical and mechanical parts closer together. Consider simplifying large circuit boards to make them smaller, but just as efficient. Large boards could be divided into separate modules and placed in empty spaces. A trick used in the LP3 and PVV was to mount the heat emitting output transistor on the outside of the aluminum cylinder, using the density of the aluminum to dissipate the heat.

Place the motor as close to the cylinder as possible and look closely at piston driving mechanisms to see if they can be made more compact. An electronic bar graph pressure indicator on the front panel would take up less space than a pressure gauge. Try to reduce the number of knobs and switches on the front panel which also take up space.

MAKE IT LIGHTER. The cylinder, motor, and gearbox need to be a strong metal unit, and such a unit is the heart of the ventilator. The internal battery and power transformer are heavy components that cannot be reduced in weight, but the power transformer and its AC cord could be made into an external module that drops into a slot on the back of the ventilator, thus saving about six lbs.

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Jerry Daniel owns and uses two LP4s, and keeps one in the bedroom and one in the living room. He services the complete line of LP ventilators under the business name of VENTEK. Jerry cautions: "I often see battery acid damage on the aluminum case, which I assume happens accidentally when checking the wet cells of the wheelchair battery as the hydrometer drips the sulfuric acid while it passes over the ventilator. Charging of the wheelchair and external ventilator batteries emits sulfuric acid fumes. Small amounts of vapor can get inside the ventilator case and even in the patient air inlet in some cases. Wet cell batteries can emit relatively large amounts of vapor during heavy charging. Gel cells produce less. A barrier between the vent and batteries can reduce the potential for damage."



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The Perfect Ventilator Cont. from page 14

Typical usage of the removable AC module can be imagined with the ventilator on the wheelchair during the day, with the external battery as primary power source and internal battery as backup. When the machine is removed from the chair at night, the AC module is dropped into place for night-time charging of the batteries and ventilator operation. The ventilator is much easier to move with the AC module removed. If the caregiver or ventilator user feels more secure with the AC power supply in place all the time, he or she could lock it into the slot.

The ventilator weight could be further reduced by housing it in a molded plastic case rather than heavy gauge aluminum. The high impact plastic case would have to be carefully developed to give priority to structural strength and lighter weight. The CPAP manufacturer is putting its units in plastic with success, but the units are not as heavy or as large as volume ventilators.

MAKE THE PORTABLE VENTILATOR EASIER AND SIMPLER TO OPERATE. Place the control panel at a 45-degree angle so the person working with it won't need to bend way over to see the settings clearly. Touch pads in all electronic equipment have become much more popular than banks of knobs. Provide a dial light on a 60-second switch. Ventilator users should not have to turn the lights on at night just to check the settings.

The ventilator should be totally accessible from the front. Place the external battery socket on the front down at the bottom at the same level as the patient air port to allow quick and easy connect and disconnect of the battery. Locate the patient air inlet filter on the right end panel near the front for easy viewing of the filter. The filter should be easily viewed in its housing to know when to change it. I have observed that if the filter is difficult to see and change, it is not changed as often as it should be. This filter housing location also puts the air inlet farther from the battery fumes on the wheelchair mounted ventilator.

Most ventilator users use the same settings daily and many use control mode only, which means that they do not trigger ventilator breaths by their inspiratory efforts. For them, the proximal pressure tubing going to the exhalation valve could be eliminated, leaving one less tube to get in the way. All that is needed is the correct

connector at the output port on the ventilator. The exhalation valve tube is also a nuisance. It is not uncommon for the whole hose assembly to be run over by a wheelchair, or to have the small tubings snag on something and disconnect. The early LP3s had the exhalation valve tubing inside the patient hose on its way to the exhalation valve — a good idea then and a good idea now.

The ventilator manufacturers, Aequitron Medical, LIFECARE International, and Puritan-Bennett, have been working with the same basic mechanical unit and electronic package for about eight years. They have made minor upgrades, but now it may be time for them to seriously consider making a "dream machine."

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Calendar

- ♦ **Congenital Central Hypoventilation Syndrome (CCHS) Family Conference**, Camp Fowler, Mayville, Michigan, October 9-11, 1993. Scholarships available. Contact Nancy Stone, 4616 Melbourne Rd., Indianapolis IN 46208. 317/299-0801.
- ♦ **Pediatric Ventilator Users Network Meeting**, December 12, 1993, during the AARC Annual Convention, Opryland Hotel & Convention Center, Nashville, Tennessee. For confirmation and time, contact Jan Nelson, Aequitron Medical, 800/497-4979, ext. 256.
- ♦ **Respiratory Nursing Society Annual Educational Conference**, March 10-12, 1994, Stouffer Concourse Hotel, Arlington, Virginia. Contact Respiratory Nursing Society, 5700 Old Orchard Rd., 1st Floor, Skokie IL 60077-1024. 708/966-8673.
- ♦ **VACC Camp 1994**. Miami Children's Hospital's Ventilator Assisted Children's Center (VACC) announces its free VACC camp will be held in Miami, April 2-8, 1994. Applications are due by January 15, 1994. Contact Cathy Klein, VACC, Miami Children's Hospital, 3200 S.W. 60th Court, Suite 203, Miami FL 33155-4076. 305/662-VACC.
- ♦ **G.I.N.I.'s Sixth International Post-Polio and Independent Living Conference**, June 16-19, 1994, Marriott Pavilion Hotel, St. Louis MO. Special sessions for ventilator users on face masks, equipment, frogbreathing, etc. Contact Joan Headley, G.I.N.I., 5100 Oakland Ave., #206, St. Louis MO 63110. 314/534-0475.