

I.V.U.N. NEWS

International Ventilators Users Network

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Quality of Life Perceptions of Ventilator-Assisted Individuals

by John Bach, M.D., and George Gombas, M.D.

With the availability of portable ventilators and the variety of noninvasive methods of assisted ventilation, it is unfortunate that many people with neuromuscular conditions and chronic hypoventilation are misdiagnosed early on and never appropriately counseled.

Many health care professionals who influence these individuals on options for ventilatory support may discourage use of these aids because of misperceptions about the individual's quality of life. A review of medical literature reveals a paucity of information regarding quality of life and life satisfaction perceptions in this population.

A survey regarding various quality of life issues was undertaken of 600 ventilator-assisted individuals with neuromuscular conditions, most of whom live at home in the New York/ New Jersey area and who have an average age of 49 years, and 254 health care professionals with an average age of 33 years.

When asked, "Currently, how satisfied are you with your life as a whole?", 82% of the ventilator-assisted individuals responded that they were neutral to very satisfied (positive responses) with their lives in general. However, only 24% of the health care professionals thought that those individuals would respond in that manner.

Other aspects of the quality of life that were surveyed included satisfaction with health, social interaction, housing, transportation, education, employment, family situations, and sexual function. The percentage of ventilator-assisted individuals who responded positively to these issues follows: health-57%; social interaction-75%; housing-90%; transportation-78%; education-81%; employment-81%; family situations-87%; and sexual function-60%.

"The results of this survey may help to alter our perceptions... and discourage health care professionals from undervaluing the satisfaction with life that the majority of these individuals feels."

Most of the ventilator-assisted individuals were not dissatisfied with most aspects of their lives. When the same life satisfaction issues were asked of the health care professionals, the same number of subjects had positive responses to within +10% as did the ventilator-assisted individuals. In only three categories were there more positive responses from the health care professionals. They were in the areas of health, social satisfaction, and sexual function.

The results of this survey may help to alter our perceptions of how ventilator-assisted individuals view their lives. The results should discourage health care professionals from undervaluing the satisfaction with life that the majority of these individuals feels.

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Whatever Happened to Katie Beckett?

by Julie Beckett

In 1981, former President Ronald Reagan brought national attention to the case of Katie Beckett, a ventilator-dependent three and one half-year-old, who had had viral encephalitis at age five and one half months. Katie had incurred huge hospital bills because of Medicaid regulations which would not permit reimbursement for more desirable and less costly home care. Reagan waived the Medicaid rules in Katie's case. Later known as the Katie Beckett waiver, it gave the states the option of extending coverage to children with disabilities who live at home or in the community provided that the cost of the care does not exceed the cost of institutional care.

The beginning of this decade is a new beginning for Katie and me. Many changes have occurred, some of them pleasant, some of them not so pleasant, but mother and daughter have endured to take on new challenges and face new obstacles with a greater feeling of hope and satisfaction.

Katie is now a 12-year old young lady who is actively involved in sixth grade, extremely curious about space and space travel, but also curious about her new interests (music, movies, and boys - in that order!), new changes in herself, and her future. She faces her challenges with a positive attitude. She accepts that there are no easy answers but that does not inhibit her from looking for what is truly right in the world.

The most wonderful thing about all we have been through is that Katie is just naturally herself. She is confident and intuitive. She appreciates my work. She has travelled with me to conferences. She has even talked about counseling other children with disabilities and their siblings.

Her care is still time consuming, with chest percussion treatments twice a day, ventilator support at night, and trach care. However, preadolescence sometimes disrupts the routine. She has needed more suctioning at various times, but she has preferred to cough instead of suctioning. Her biological changes have brought on new problems with the absorption of her medication. She has required medications for so long I am concerned that she may be faced with some chemical adaptation to those medications.

Katie has also had problems with swallowing. She still must have a high calorie formula four times a day. She is able to eat blended foods and soft foods such as scrambled eggs, Spaghetios, puddings, and ice cream. But if I don't push her to eat, she probably would never feel the urge to eat on her own.

To help her breathing and stamina we have joined a health club. We both work out on the treadmill and Katie will soon be in an aerobics class. She is really looking forward to joining kids her own age working out. This has definitely helped her activity level in school gym class.

In October 1989, all my work on behalf of Katie and as Associate Director of the National Maternal and Child Health Resource Center seemed to have come to fruition when a story broke in Omaha about twin girls who had been born and suddenly developed central hypoventilation syndrome, requiring ventilators and 24-hour intensive care. The parents were both so involved in the initial crisis that the cost of the care was far from their minds.

Both had very good jobs and good insurance coverage, but not until one of the twins died did reality set in. The bill that came the day she was buried totaled \$450,000 for less than 6 months of care. Should the other twin survive, the parents would be faced with no health insurance coverage in a very short time.

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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The parents called me and I explained that Nebraska had a good waiver program and told them what resources to investigate. Benefits from the comprehensive high risk pool available to the uninsured in Nebraska were good, and the parents felt they could pay their share as long as they could afford to without having to go on Medicaid. But the six-month waiting period might put them into bankruptcy if the surviving twin needed hospitalization. I advised the parents to find a good state legislator to introduce a bill to waive that waiting period for those who already had reached the limit on their insurance policy. The parents were successful and I, along with Katie, was interviewed about my role in helping the parents.

Since Katie was in the hospital with double pneumonia at the time, we were interviewed in the hospital lounge. The reporter asked Katie how she felt about my work. She responded in her most self-assured manner, "What my mother does is the most important thing any mother could do for children. If it weren't for my mother, kids like me would have to live away from their homes and their families and be left without an opportunity to know what that love really means. They couldn't go to school with their brothers or sisters. They couldn't have their moms sing them to sleep every night. My mom's work helps people to understand how important kids like me are to the world around us."

The reporter continued, "What would you have missed most if you hadn't been able to come home?" Katie said, "Christmas, because Christmas is a time to show people how much you really care about them. I don't think I could have lived without being able to spend Christmas at home with my mom and dad."

The interview continued with Katie responding to a few more questions, but she was getting tired so she went back to her room. The reporter was impressed with Katie's composure on camera and her ability to articulate her feelings. I had to agree, because I have always protected Katie from having to respond to questions that might make her sad. I found out that day just what being a mother was all about: nurturing your children to take care of themselves and the world around them.

Address: Julie Beckett, National Maternal and Child Health Resource Center, College of Law Building, University of Iowa, Iowa City, IA 52242.

Editor's Note: An excellent discussion and explanation of the waiver in its various forms can be found in an article entitled, "Payment Mechanisms for Pediatric Home Care," by James Murray that appeared in *Caring*, October 1989.

Health Care Reform

by Debbie Poehlmann

A recent newspaper article reported that "Home care is among the fastest growing segments of the health care industry. . . . One attractive thing about [it] - from a profitability standpoint - is that, so far, insurance companies have been willing to pay what home health care companies charge because the savings over hospitalization is dramatic."

The article's particular focus seemed to be infusion therapy in the home, which is enjoying great success and widespread support from patients, insurers, physicians and medical groups. The inherent short-term nature of intravenous therapy and the fact that it is done usually only one to three times per day make it very manageable in the home.

What is much more difficult is managing the health care costs of those who are ready to be at home, and deserve to be at home, but who will need many hours per day of skilled nursing care, not for a two-week course of therapy, but for months and years to come. That is a completely different matter. Ventilator dependence, paralysis, and neuromuscular degeneration are only a few of the numerous and perhaps lifelong conditions that would have to be dealt with daily in the home.

The same technology that allows us to maintain quality of life comes with an exorbitant price tag. Who is going to pay? Where will the funding come from when one's resources are exhausted? What if it is *your* loved one we are talking about? Do you want to see him or her confined to an institution where a cut-rate per diem price may also reflect equally cut-rate service?

Where do we go from here? What can we do to realistically get more help? Many of us are facing very critical issues in our own families right now. We are not only trying to cope with the needs of individual family members, but also with how to pay for maintenance of quality of life. It is a very heavy load.

When we unite our voices and educate each other about our rights and options, we will be much more likely to bring about the changes we need to improve life for us all.

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Editor's Note: Debbie has a young son who uses a ventilator. Her story about him appears on page 10.

Notes from Australia

by Hugh Newton-John, M.D.

"In the Home Ventilation Program in Victoria, there are 42 adults and three or four new patients waiting for assessment. We have been using the Bennett and LP series portable ventilators, but, unfortunately, their cost here is prohibitive: at least A\$12,000 each. I have just discovered a doctor in Perth who has designed a simple machine which costs only \$3000. We are also working on such a machine and have it to the prototype stage.

"Because of the issue of professional isolation, I have decided to initiate the formation of a network in Australia. My idea is to create a network of all those people, whatever their discipline, who are involved in this field. Then I hope to have a regular newsletter.

"I have become interested in post-polio issues other than just those of respiratory failure. In our hospital we have a great opportunity to create a centre for the assessment and management of disability due to old polio. Questionnaires have been sent to members of the Australian Polio Network and the replies reflect a clear desire for more information and help from a centre of expertise. I believe we will be able to develop such a centre after we have identified the resources we will need.

"In the questionnaire I was after some clue as to the likely need in the future for ventilatory support in polio survivors in Victoria. My estimate is that we can expect between 25-40 new patients in the next 10-15 years from this group alone. Of course, our attention is not confined to polio, but this is the largest group identifiable. In the last three years, we have been accruing three to four new patients per year, about two-thirds of whom are old polio patients.

"We have adapted the design of the Lyon silicon nasal mask which Dr. Dominique Robert and colleagues invented. We found that we could make many masks from 1 kg of the silicon material for a modest price so that we can keep the total cost of a mask to under \$A75. It takes us only an hour or two to complete a mask from scratch and the fitting takes less than 20 minutes. At present we are in the process of changing most of our patients over to this mask."

Address: Hugh Newton-John, M.D., Fairfield Infectious Diseases Hospital, Yarrabend Rd., Fairfield, Victoria 3078, Australia.

Advocacy and Action By and For Ventilator Users

Advocacy and support groups for ventilator users are springing up more and more to promote home care and independent living by individuals who can direct their own care. **ALIVE** or Association for Living Independently in a Ventilator Environment has been formed in the Southern California area by parents of ventilator-assisted children. Contact either Carrie Keife, 213/696-8165, or Debra Poehlmann, 818/882-1733.

In Canada, the Committee for Independence in Living and Breathing grew out of a staff meeting at the Canadian Paraplegic Association (CPA-Ontario division). It sponsored a successful medical symposium on longterm home ventilation in October, 1989 and is planning another for Fall 1990. A subcommittee on housing and support services is working on job descriptions for attendants and assisting West Park Hospital in training attendants for home ventilator care. Contact Romeo Dicamillo, CPA, 520 Sutherland Dr., #246, Toronto, Ontario M4G 3V9. 416/422-5644.

Home care nurses with ventilator-assisted patients have formed a round table in Southern California. Organized by Barbara Beal, R.N., M.N., a clinical nurse specialist in ALS and home care, the group meets monthly with the support of the local American Lung Association Chapter. Nurses have identified problems such as difficult patients, family dynamics, lack of standardization of nursing procedures, difficulty in obtaining appropriate medical care, dying at home, etc. Call Barbara Beal, R.N., M.N., 5311 Tufton, Westminster, CA 92683. 714/895-3375.

Pediatric Users Network, sponsored by Aequitron Medical, Inc., met for the second time in Anaheim in December 1989 during the annual convention for respiratory therapists. They discussed applications of the LP6 ventilator and innovative set-ups. The next meeting of the Network is during the Region II Respiratory Meeting in Cincinnati, May 16-18. For more information, contact Kim White, Aequitron Medical, Inc., 14800 28th Ave. North, Minneapolis, MN 55447. 1-800/824-7203.

Kangaroo Kids: An Idea Whose Time Has Come

by Judith Raymond Fischer

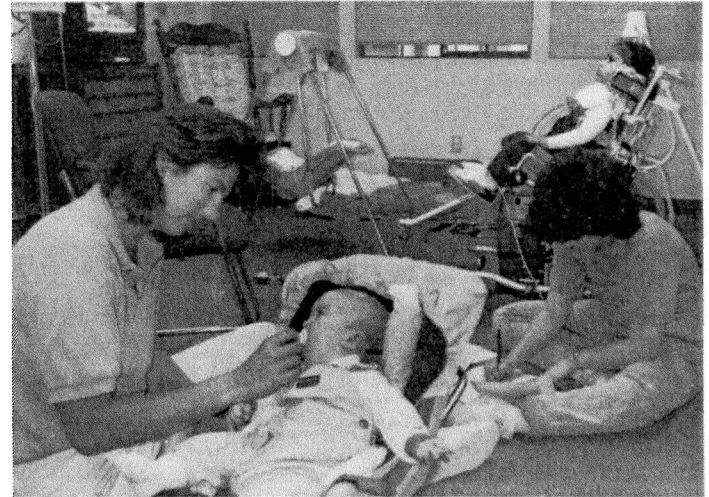
When Kangaroo Kids, the Center for Fragile Children, opened in October 1989 in Santa Ana, California, it became one of the first day care centers in the nation to provide a protected environment for children with medical problems.

Thanks to today's technology, more and more infants are surviving with longterm medical problems. The most difficult time is after the child's discharge from the hospital, a time when parents report stress and exhaustion in coping with the child's needs . . . and their own. A place like Kangaroo Kids allows parents to be free of responsibility for a period and to enjoy a more normal family life.

The for-profit Center, owned by Care Visions Corporation, is designed to accommodate 40 and serves children up to a developmental age of 5 years old who have severe lung problems, heart disease, neuromuscular disease, colic, seizure disorders, cancer, and other conditions that prevent them from being accepted in regular day care centers.

Kangaroo Kids is open 16 hours every weekday, with respite care weekends available. It provides a very home-like atmosphere and the benefit of being with other children. Parents are encouraged to participate, and many stop by on their lunch hours to feed their children. Staffed by licensed professional nurses experienced in neonatal and pediatric care, a multidisciplinary team is also available to provide any necessary physical, occupational, speech, or developmental therapies.

The cost of the care averages about \$20 per hour and is approximately 40% less than home care, and 60% less than hospital care. Insurance companies are enthusiastic about the type of alternative care the Center offers, and Medi-Cal is also, but must first find the proper bureaucratic niche for the Center.



Kangaroo Kids in action

The Center also houses a parent resource library and the Family Support Network, a support group for parents who have "graduated" from an intensive care unit or have children with special health needs.

Home nursing care is also available through Care Visions. According to President Jeffrey Gasser, it was first thought that, with Kangaroo Kids available, the demand for home nursing care would decline, but instead it is thriving. Parents have different reasons for choosing home nursing over the Center.

With a successful first venture in the Los Angeles/Orange County area, Kangaroo Kids plans its second Center in the Riverside-San Bernardino area. There are no plans yet to develop nationwide, but the meeting of such a critical need should dictate that Centers be available all over the United States.

Address: Kangaroo Kids, 1800 N. Bush St., Santa Ana, CA 92706. 714/KID-7070.



Leeda and Barbara Evans, L.V.N.

Proceedings of The Home Mechanical Ventilation Workshop.
G.I.N.I.'s Fifth International Polio & Independent Living Conference.
St. Louis, June 1989

Home Care for Ventilator-Assisted Children & Adolescents - A 15-Year Personal Perspective
by Allen Goldberg, M.D.

In 1975, I was given the challenge to create a designated special care unit and program for ventilator-assisted children at the Children's Hospital of Philadelphia (CHOP). Working with associates Bob Ketrick and Jack Downes, and with the encouragement of C. Everett Koop, Surgeon-in-Chief, we successfully demonstrated home care for ventilator-assisted children. Our accomplishment was due in large part to the respiratory rehabilitation model developed by doctors Augusta Alba and Mathew Lee at Goldwater Memorial Hospital in New York.

A few years later, as medical director of respiratory care at Children's Memorial Hospital in Chicago, I developed another home care program in collaboration with the Division of Services for Crippled Children (DSCC). Our first ventilator-assisted child was discharged in 1979.

By 1980 it became clear to me that the small but undetermined number of ventilator-assisted children from our region would be better served by the establishment of a program beyond the scope of one pediatric hospital. What they required were also the special needs of a much larger group of children who depended upon medical technology and a variety of community-based resources.

I co-founded Care for Life, a not-for-profit organization, concerned with care for ventilator users, to provide documentation, foster education, and encourage demonstration. I turned to adult ventilator users for expert advice and direction and was introduced to *Rehabilitation Gazette*, which my wife, Evi Faure, realized was the best source of information available for our purpose - it was not necessary to reinvent the wheel.

A travel fellowship in January 1980 permitted me to study international models of independent living and home respiratory care. Finally the occasion arrived for Evi and me to visit Gini and Joe Laurie, publishers of the *Rehabilitation Gazette*, for an unforgettable six-hour lunch in October 1980.

Gini and Joe raised several interrelated issues worthy of our immediate attention: independent living for individuals who are disabled; "post-polio" syndrome; a new generation of ventilator users.

To address these issues, Gini suggested that we collaborate with Dr. Henry Betts and the Rehabilitation Institute of Chicago in the sponsorship of a meeting. As a result, "Whatever Happened to the Polio Patients?", the First International Post-Polio Conference, was held in Chicago in October 1981.

Keynote speaker C. Everett Koop, Surgeon-General designate made public his commitment to children with disabilities. He agreed to sponsor, with the Division of Maternal and Child Health, the Surgeon General's Workshop for Children and Families with Handicaps: Case Example - the Ventilator-Assisted Child. As a result of this conference at CHOP in December 1982, the issues facing ventilator-assisted children were now a subject for demonstration projects and public policy debate.

In 1983, DSCC in Illinois was awarded a demonstration project to develop the Children's Home Health Network of Illinois (CHHNI). During 1983-1987, CHHNI was active throughout Illinois and St. Louis in demonstrating the home care planning process, conducting research, and developing a home care model. In those same years, I conducted several independent studies to better understand the broader issues facing the ventilator user.

Over the past 15 years, my experiences have given me a personal perspective in designing and developing integrated management systems for home respiratory care. They have also provided me the means to observe the evolution of respiratory care techniques, technologies, and practices.

During that period, major demonstration projects have been documented and national public policy studies have been commissioned and disseminated by the U.S. Congress, Office of Technology Assessment. The magnitude and complexity of the issues and workable solutions have been offered by a consensus obtained by the Task Force of the Secretary of Health and Human Services and Congress.

These recommendations are now being implemented in a multitude of settings by a variety of approaches in the private, public, and voluntary sectors. Concerns about the performance of home respiratory care equipment and services have been issues of major initiatives by federal agencies and professional organizations, guidelines for home care have been published, and device and care standards have been established.

Despite the progress to date, as we approach the next decade, I am concerned about the lack of public policy. Instead, there is a "waiver" approach with a great deal of allowable discretion. In addition, there is fragmentation of the sources of funding and service delivery, resulting in a wide variety of possibilities regarding the options available to ventilator-assisted children and their families.

Statutory and regulatory constraints have been imposed which have augmented home care costs beyond institutional alternatives. Partial regulation has fettered the marketplace. While there are some opportunities for profit, patchwork funding policy has restricted innovation due to reimbursement uncertainties and inadequacies.

As a result, some ventilator-assisted children may be denied home care because the cost will exceed an allowable limit, and service providers may become discouraged. Quality and/or safety will be compromised by efforts to develop programs within the constraints.

As personal, individualized approaches are being delegated to larger systems of care, the approaches are becoming institutionalized and bureaucratized. This reduces flexibility as well as sensitivity to individual situations.

Although a few good models have been established, now that cost containment is forcing the issue, many institutions are beginning to consider home care for technology-dependent children without an understanding of what is involved. This results in improper selection of candidates and inadequate preparation of children and families.

Ventilator-assisted individuals do not need nor want solutions imposed upon them by well-meaning professionals or government officials. They want support services to empower and enable them to take charge of their own health and well-being. Programs that promote self-help and family-centered care provide the best opportunity for wellness and guarantee individualized focus.

All the material, financial, and human resources required by the ventilator-assisted child and family are available, and they can be utilized within the constraints of even a limited payment system. A system can be put in place to satisfy the needs of all beneficiaries: providers, payors, and users.

To accomplish this, the current fragmentation of services and funding must be replaced by an integrated management system featuring individual case management, management information systems, and family self-help as the centerpiece. Such an approach will retain flexibility, assure quality, guarantee safety, and foster cost-consciousness.

We must develop:

- designated programs for home care for ventilator-assisted children and families -
- centers of excellence for initial stabilization, preparation, and home care discharge -
- home care devices based on simple technology easy to learn, maintain, and repair in emergency -
- home care managers to monitor and coordinate care and services, expert in cost and quality management -
- active participation of all health care professionals, all of whom respect the central role of the family.

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Sleep-Related Breathing Disorders

by Oscar Schwartz, M.D.

All too often individuals with sleep-related breathing disorders end up in a crisis situation. Early warning signs of nocturnal breathing disorders may be unspecific. Symptoms of hypoventilation, as reported by Dr. Spencer, include lethargy, morning headaches, claustrophobia, frequent chest infections, speech difficulties, daytime sleepiness, as well as difficulty with concentration.

Pulmonary hypertension, chronic respiratory failure, and heart failure may ensue if sleep-related breathing disorders remain untreated. Symptoms initially are secondary to nocturnal elevations in carbon dioxide and low oxygen concentrations. Later in the course of events, chronic hypoxia (respiratory failure) with carbon dioxide retention occurs.

Underventilation and sleep apnea are not the same, although they may be associated with similar symptoms. Sleep apnea is related to snoring and the inability to maintain a good airflow. A sleep evaluation is the only way to diagnose or differentiate underventilation from sleep apnea, but sleep laboratories often have difficulty with hypoventilation problems, depending on the type of monitoring used during the test. A test may easily rule out sleep apnea but not detect hypoventilation.

Underventilation can be divided into three categories: inadequate breathing control mechanism; muscle fatigue; and increased mechanical load on respiratory muscles from abnormalities of the chest wall, airway, or lungs.

I view mechanical load as a mechanical disadvantage of the muscles of respiration. Muscle fatigue is often easily spotted, except during sleep. The mechanical disadvantage of the muscles is harder to notice.

If the muscles are slightly weak, perhaps previously involved with polio or impaired from the development of scoliosis or kyphosis, they may be unable to sustain the mechanical work necessary to maintain ventilation at night. Hypoventilation or carbon dioxide buildup in the blood ensues. The mechanical advantage of muscles worsens as the vital capacity falls.

Hypoventilation can be diagnosed by a sleep study or simply by monitoring the arterial blood gases at night. A good clue to hypoventilation at night in someone with neuromuscular problems may be carbon dioxide retention during the day.

There are many considerations in the treatment of sleep-related breathing disorders. Drug therapy has not been shown to be of great benefit. Both negative and positive pressure ventilation can be used in treatment.

Negative pressure may not be used as frequently because of reports of the development of sleep apnea with its use. However, polio survivors have used these devices effectively for 30 years or more. Health professionals may not have had previous training with negative pressure systems and may be reluctant to use them. Currently, I have a child with Ondine's curse who has used a chest cuirass for about five years without problems.

Nasal positive pressure is becoming a more common treatment. As with all forms of ventilatory aids, there may be problems. Erosions, sinusitis, and leaks have been noted with masks.

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Home Ventilation in Children and Adolescents by Virginia Nelson, M.D.

From July 1981 through December 1988, 31 ventilator-assisted children and adolescents were followed by the University of Michigan Pediatric and Adolescent Ventilator Rehabilitation Service.

The ages at onset of ventilator dependence were as follows: 16 were from 0-5 years old, 3 were from 6-10 years old, and 12 were between the ages of 11-21. Initially all of our patients were adolescents, but over the past couple of years, we have seen more patients under 5 years of age.

Of the 31, 18 had spinal cord injuries (17 quadriplegic, 1 paraplegic), 6 had myopathies (3 Duchenne muscular dystrophy, 1 myotubular dystrophy, 1 mitochondrial myopathy, and 1 multicore myopathy), and the others had a variety of diagnoses including ALS, BPD, dwarfism, after-

effects of chemotherapy, heart transplant, and unknown neuromuscular disease. Two-thirds were male.

We don't allow a lot of options for dealing with "Do you want or do you not want your child on a ventilator?" In spinal cord injury, we don't discuss the options of being ventilated or not being ventilated. We don't even say that there is an option to being on or off a ventilator unless the person can be weaned.

In those children with progressive disease, my own stand has changed. I had been positive about it. I now paint a more balanced picture than "Of course you are going to choose this." We present the options to those individuals with muscular dystrophy. Unfortunately, since we do not have a muscular dystrophy clinic, we often do not see patients with Duchenne muscular dystrophy until they are acutely in need of ventilator management. Presenting options for management at that time is not optimal.

In the case of the dwarf baby, we couldn't find anyone who had ever ventilated one. We don't know if her lungs are going to grow with her, but she is doing well at home and is beginning to wean herself.

All but one of our 31 children have gone home, and that one went to foster parents. How can we send ventilator-assisted children home? In Michigan we have no other choice, since state law prohibits children from going to nursing homes. (One must obtain special permission from the state Department of Mental Health in order to send a child to a nursing home.)

There is no group home option for ventilator-assisted children at this time in Michigan. A group home would be legal, but no one has stepped forward to form one. Patients stay in the hospital until their families are ready to take them home or unless their families voluntarily release them to foster care, and most families are unwilling to do that.

We do have some options in Michigan that other states do not have, such as a no-fault automobile insurance law. Those involved in an auto accident, whether as pedestrians or passengers, are covered by no-fault insurance, which pays all medical expenses for the rest of their lives. If they need 24-hour nursing care at home, they get 24-hour nursing care at home. There is no financial cap.

Michigan also has had the Medicaid waiver since 1983. This allows funding under Medicaid for those not otherwise eligible for Medicaid if it can be shown that care at home is less expensive than institutional care. The waiver is administered through the Crippled Children's Agency and includes

Continued on p. 9...

Don't Get Caught With Your Battery Down!

by Jerry Daniel

If the "Big One" were to roar out of the bowels of beautiful Southern California or if tornadoes whirled up in the Midwest or if hurricanes blew into the Southeast, would you be able to breathe on your usual ventilator schedule? Or would you be trying frantically to find a ventilator external battery cable with a charged battery at the end of it?

In the 1970s I lived on the south coast of Oregon in a rural setting where every Fall there were unbelievably strong winds. One night a power failure occurred. I got a little nervous because my wet cell battery was dead and the 170C ventilator I was using at the time didn't work very well, or long, on battery operation. The report from the power company was that they would not be able to get linemen to my area for several hours, but fortunately power was restored before midnight.

Today I always have a fully charged and tested gel cell battery on hand. The system works well on all of the modern piston pump ventilators, which draw about three amps at 12 volts D.C. By dividing three amps into the 36 amp/hr battery, a theoretical time of 12 hours appears. Since most power failures occur at night, it is nice to be able to get a night's sleep and then get on the phone in the morning to deal with the problem.

In the event of a widespread and lengthy power outage, the battery supply needed to keep ventilator users at home would likely be more than home care dealers can handle. Community agencies would then be called upon to bring in car and RV batteries.

For this, a special cable system can be constructed. Large battery clamps would be needed to attach to any battery that might come along, with short electrical leads with clips to attach to the ventilator external battery cable (after it has been removed from the dead gel cell). The different sized clips are available at stores such as Radio Shack. This clip lead setup would be for emergency use only. Care must be taken to insulate the clips and leads so they cannot touch. A heavily shorted gel or wet cell battery can be a fire bomb.

Excerpted with permission from *The Polio Survivors News-Letter*, March/April 1990, published by the Polio Survivors Association, 12720 La Reina, Downey, CA 90242. Editor Richard Daggett, also a respiratory polio survivor, added some additional advice: "I have a battery setup similar to Jerry's, but as an additional safety margin, I also have a small, portable electrical generator. It has enough capacity to operate my ventilator plus a little extra for a

few lights. It also has the ability to charge my auxiliary battery. Now, if the power is out for longer than the battery's amp/hr rating, I switch to the generator. While I use the generator I also recharge my battery. These generators are inexpensive and available at most RV stores."

Editor's Note Jerry Daniel, a respiratory polio survivor since 1948, is a home ventilator repair vendor of the LP3, LP4, LP5, and LP6 in Washington. His address is 4604 Plomondon, Vancouver, WA 98661.

Home Ventilation in Children & Adolescents

Continued from p. 8...

a case manager and regional nurses who cover large areas but are quite available to families. Generally a maximum of 12-14 hours per day of nursing care is available under the waiver.

Blue Cross in Michigan also has a case management plan. They look at how many days of hospitalization are included in the policy (typical Michigan policies cover 365 days of hospitalization) and they figure the average cost for the days of hospitalization. They then say, "You have X dollars to spend on a home care plan and that has to cover it." So nursing hours are traded for therapy or equipment and therapy are traded for nursing hours, whatever is needed.

Generally, people can get by for about two years before the funds run out. The patient is then off Blue Cross for six months before being reinstated. It is scary to parents. Some parents refuse it because of what might happen during those six months. Many families use the Medicaid waiver during the six months if the child needs to be hospitalized or needs nursing care, etc.

Once the child turns 18, "chore provider" funds are available from the Department of Social Services. These funds pay for attendants. One of our teenagers who is now over 18 is getting his 24-hour attendant this way. They can't pay attendants as much as the \$7.75 per hour rate in Massachusetts, and attendants are paid less per hour if they are needed for 24 hours.

Part of the challenge of discharging ventilator-assisted children and successfully working with them is figuring out all of these options for the best possible care and lobbying the system to be responsive, to provide what people really need.

Address: Virginia Nelson, M.D., Chief of Pediatric Physical Medicine & Rehabilitation, University of Michigan Hospital 1D204F, Ann Arbor, MI 48109-0042.

One Person's Perspective

by Debbie Poehlmann

Two years ago, our son Matthew, who was three and one half years old at the time, became quadriplegic as a result of spinal cord trauma. Due to the severe cervical spinal column defect he had been born with, we had known for a good portion of his life that we might one day face such a possibility.

Yet when the paralysis did occur, it was still a terrible shock. After many weeks, we received yet another blow. Our son, it was explained to us, was suffering from chronic respiratory failure and would require continued mechanical ventilation, possibly for the rest of his life.

I had been counting the days until he could be weaned from the ventilator as some kind of sign that the end was in sight. I felt that everything would be normal again if we could only be back home together as a family.

I didn't realize it then, but our lives were just beginning again. It goes without saying that this new lifestyle is one that I never would have freely chosen. Nonetheless, after this much time has passed, I can honestly say it is one for which I am extremely grateful. Life is different than I had once envisioned it, but it is still good, it is still worth living for all of us.

Matthew's tracheostomy and home ventilator have made it possible for us to share the past two years together and to watch Matthew continue to grow only more delightful each and every month. He has managed to keep his sparkling personality and seems to savor each day's experiences. He is constantly showing us all how to get more out of life.

Although he is at times momentarily distressed because he cannot do all that his older brothers do, he is quick to adjust and adapt. Best of all, his paralysis was not permanent, as we had been told. He still has a great deal of weakness, but is now able to move all of his extremities. He has been able to achieve a small measure of independence.

The other great reward we have gained through the events of the past two years is that Matt has slowly developed the ability to verbally communicate with us. Very early in his life it was noted that he had some brain damage as well as other serious problems. He didn't begin to speak any words until he was three, and then was only able to say one word at a time, with the exception of "Yo, yo, yo, pira life for me" (Disneyland and the Pirates had made a great impression on him!). He knew about 25 words and 15 signs in American Sign Language when he became paralyzed.

After weeks of intubation, followed by the tracheostomy, I thought he had lost the ability to speak. In Matthew's case, the Passey-Muir speaking valve was a great help in allowing him to speak normally again. I was startled by the num-

ber of words he had learned during the many weeks of enforced silence. Although he still doesn't talk quite like an average child his age, he is able to tell us his wants, needs, and feelings in full sentences.

Recently we had the opportunity to babysit for some friends and Matthew was enchanted by their toddler and kept calling the baby over to play with him. The baby started to wander off and Matthew said, "Baby, come play with me. I not a monster. Mama, the baby scared with me. Baby, I just a little boy." That was really a mouthful for Matthew.



I've often thought about what I would have liked to know before coming home with a ventilator-dependent child, something beyond the techniques of suctioning, maintaining the equipment, managing 16 hours a day nursing care, juggling endless appointments, and still finding time for myself and my family.

I guess what I really wanted was an assurance that there was a life - a good life - after all of those things. There is! I take life in much smaller chunks now, but I feel I enjoy it more because I don't take so much for granted any more.

Our family has had so much help to make it this far during the past two years. I am so grateful to the dedicated and skilled professionals who saw us through our hospital stays and to those who help us stay at home. I am also as thankful to the many other parents and families and friends of ventilator-dependent people I have met who have helped me so much. I am glad I am not alone, that I have resources.

Address: Debbie Poehlmann, 21027 Roscoe Blvd., #2, Canoga Park, CA 91304.

Editor's Note: Debbie and her husband Tom helped found ALIVE, Association for Living Independently in a Ventilator Environment, a support/advocacy group in Southern California for parents with technologically dependent children.

Musings: The Need for a Cat on Every Home Ventilator

by Karan McKibben, Ph.D.

Occasionally, when people first learn that I often hire untrained college students as live-in attendants, they seem to question my judgment in asking inexperienced strangers to be responsible for maintaining a ventilator. Their doubts most probably stem from the only image of a ventilator they have ever seen, the ICU image flashed on the TV screen everytime someone wants to make a point about the wonders and/or horrors of modern medical technology.

Obviously, for home ventilator use, this image is inappropriate not simply because it is about fighting illness and death, but more importantly because it dramatizes the absolute dependency of the ventilator user and the mysterious complexity of the equipment involved. Dependency and complexity are, of course, just exactly what living with a home ventilator is not about.

When prospective attendants first enter my home and learn that some of the duties involve a ventilator, they do not see an intimidating array of medical equipment or hear an overwhelming list of responsibilities. Rather, they encounter a rather mundane home where a few pieces of medical equipment are almost lost in the clutter of books, plants, decorative and not so decorative knickknacks - the usual debris of daily living found in homes that have not been groomed for presentation in Better Homes and Gardens.

The explanation of ventilator duties is presented along with the explanation of household duties so that maintaining a ventilator appears no more mysterious than running a dish washer or more demanding than dressing someone everyday. And, invariably, just when a prospective attendant begins to conceive of the job as working with "life support" equipment, the cat leaps onto the ventilator, thoroughly demystifying the job and putting everything in its proper perspective: the perspective of an eminently do-able life. This perspective is important because it allows an uninitiated young person to begin working and to learn from experience that living with a ventilator is in fact as uncomplicated and manageable as living with a cat.

What also allows young, untrained students to begin working is the clear perception that, while they need to be responsible to me, they are by no means responsible for me. All of the various college students who have worked for me have understood that they would be the sole person upon whom I relied for essential services, yet all have realized that I, not they, would make sure that the equipment was running well and that they were doing all the right things.

Seeing from the beginning that they could depend on me for understandable instructions and appropriate decisions, students with varying degrees of resourcefulness and self-

confidence have been able to remain calm and responsive when strange equipment malfunctions occurred or when those inevitable, unanticipated crises shattered the household routine.

But while it is unnecessary, even undesirable, for attendants to feel responsible for me, it is essential that they possess a wholesome sense of responsibility and that they be capable of carrying out that sense of responsibility.

Sometimes, however, an overactive libido overrules a good sense of responsibility as happened one dark night when a usually responsive young woman failed to respond to a call for assistance because she was in the upstairs apartment "visiting" a would-be rock singer.

Sometimes too, the recreational use of drugs undermines a decent sense of responsibility as I learned one other dark night when I found myself trying to communicate a disconnect to an ordinarily intelligent chemistry major whose drugged mind could not comprehend why the alarms were ringing and I was not talking.

And sometimes what appears to be an ordinary sense of responsibility is in reality unwholesome and even dangerous as I discovered with a sociology major whose need to accept responsibility turned out to be the pathological legacy of child abuse and whose own abusive tendencies were barely limited to verbal assaults.

It is fortunate that most college students who respond to ads for live-in attendants screen themselves and rarely place me in predicaments that cannot be tolerated. Indeed, most students come with a healthy mixture of economic self-interest and the altruistic desire to help someone who is disabled. They are well suited for a relationship of carefully circumscribed symbiosis - the kind of relationship cats have historically established with their live-in attendants.

Although initially these students may experience some anxiety over learning about strange medical equipment and over being the only person in the house able to provide essential services, they soon experience a certain amount of pride in doing tasks usually done by health professionals and helping a ventilator user live like a cat - with uncomplicated independence.

Address: Karan McKibben, Ph.D., 800 Daffodil Dr.,
Riverside CA 92507.



Blitzer Report No. 6: Nose News

by Bud Blitzer

I have been trying for several years to find and/or develop a workable and affordable mask. The following is a list of face mask sources:

Australia -

Hugh Newton-John, M.D.
Fairfield Infectious Diseases Hospital
Yarrabend Rd.
Fairfield, Victoria 3078

France -

SEFAM (Societe Etude et de Fabrication
d'Appareillage Medical)
Pierrick Haan
Rue de Bois de la Sivrite
F-54500 Vandoeuvre-Les-Nancy

Germany -

Bur. Fur Techn. Entwicklung
Ernst Hormann
Langenstegham 25
8261 Mettenheim

Peter Peschel
Ochtumstrasse 30
Postfach 12-24
2806 Oyten

Sweden -

Remmers Dentallaboratorium
Lennart Remmer, A.I.M.F.T.
Fredriksbergsvagen 6
144 00 Ronninge

United States -

Colorado -

LIFECARE
Geoff Waters
655 Aspen Ridge Dr.
Lafayette, CO 80026

Barry Make, M.D.
National Jewish Center for Immun. & Resp. Med.
1400 Jackson St.
Denver, CO 80206

Kansas -

Puritan-Bennett
10800 Pflumm Rd.
Lenexa, KS 66215

New Jersey -

John Bach, M.D.
University of Med. & Dentistry of New Jersey
Dept. of Rehabilitation, B-239
150 Bergen St.
Newark, NJ 07103

Healthdyne
10 Bloomfield Ave.
Pine Brook, NJ 07058

Pennsylvania -

Respironics, Inc.
Pat Handke
530 Seco Rd.
Monroeville, PA 15146

Texas -

Dallas Rehabilitation Institute
Susan Sortor, R.R.T.
9713 Harry Hines Blvd.
Dallas, TX 75220

Address: Bud Blitzer, 400 S. Saltair, Los Angeles, CA 90049.

Palo Alto VA's SCI Service

Dr. Steven Linder writes, "In October 1989, we opened our ventilator equipped ICU and for the first time treated ventilator-dependent quadriplegics. At present, we have only one high (C2) quad who lives at home with a portable positive pressure ventilator. Currently, he is improving his use of a Macintosh computer.

"Respiratory problems can be a major cause of death in the acute and chronic phases of traumatic quadriplegia. Part of our program includes respiratory muscle training through exercise, conducted by physical therapists. There are general body conditioning exercises as well as specific respiratory muscle strengthening of the diaphragm, neck, and shoulder girdle. Chest wall mobility exercises help prevent intercostal spasticity and contractures which lead to thoracic restriction and decreased vital capacity.

"I am very interested in researching how quadriplegia compromises the respiratory system."

Address: Steven Linder, M.D., Veterans Administration Medical Center, 128 Spinal Cord Injury, 3801 Miranda Ave., Palo Alto, CA 94304.

I.V.U.N. Directory: Update, Spring 1990

This directory update is to be used in conjunction with the directory published in *I.V.U.N. News, Fall 1989, Vol. 3, No. 2*. It is an attempt to compile the names of longtime ventilator users and health professionals who are experts about and advocates for home mechanical ventilation. As with any such attempt, omissions are inevitable. Please send additions and corrections to Judith Raymond Fischer, c/o I.V.U.N., 4635 Larwin Ave., Cypress, CA 90630. Thank you.

Alabama

Post-Polio/Ventilator Users Network
Lilly Henderson
P.O. Box 11586
Montgomery, AL 36111
205/281-2276

Frank Sutton, M.D.
Briarcliff Nursing Center
850 Northwest Ninth St.
Alabaster, AL 35007
205/663-3859

Arizona

Sue Kirchof, R.R.T.**
Western Med. Resp. Services, Inc.
2040 N. 16th St.
Phoenix, AZ 85006
602/257-9347

California

ALIVE** (Assoc. for Living Independently in a Ventilator Environment)
Debra Poehlmann
21027 Roscoe Blvd., #2
Canoga Park, CA 91304
818/882-1733

Rose Anne Baxter, R.R.T.**
Children's Hospital
8001 Frost St.
San Diego, Ca 92123
619/576-5982

Addition: Children's Hosp. of L.A.**
Mary Jansen, L.V.N.
Pamela DeWitt, R.N., M.N.

Family Support Network**
1800 N. Bush St.
Santa Ana, Ca 92706
714/836-5511

Philip Gold, M.D., Richard Sheldon, M.D.
Tony Hilton, R.N., M.P.H., C.R.R.N.
Loma Linda University Med. Ctr.
11234 Anderson St.
Loma Linda, CA 92354
714/824-0800

Kangaroo Kids**
Elizabeth Ciaccio
1800 N. Bush St.
Santa Ana, CA 92706
714/543-7070

*denotes ventilator user

**denotes pediatric interest

Steven Linder, M.D.
V.A. Med. Ctr., 128 SCI
3801 Miranda Ave.
Palo Alto, CA 94304
415/493-5000, ext.5872

Charles McIntyre, C.R.T.T.**
Pediatric Professionals
8001 Laurel Canyon Blvd., #E
North Hollywood, CA 91605
818/767-5787

Colorado

The Children's Hospital**
Monte Leidholm, R.R.T.
1056 E. 19th Ave.
Denver, CO 80218
303/861-6240

Patty Koff, R.R.T.
University Hospital
4200 E. 9th Ave., C-271
Denver, CO 80920
303/270-8116

District of Columbia

Richard Waldhorn, M.D.
Georgetown University Med. Ctr.
Washington, DC 20007
202/625-3684

Indiana

David Carter, R.R.T.**
Lifelines of Indianapolis
1707 W. 86th St.
Indianapolis, IN 46240
317/872-0555, ext. 114

Michigan

C.S. Mott Children's Hospital**
Mary Dekeon, R.R.T.
F1421 Box 0208
Ann Arbor, MI 48109
313/763-2420

I.U.U.N. Directory: Update, Spring 1990

Correction: Virginia Nelson, M.D. **
313/936-7200

Missouri

Sheldon Braun, M.D.
University of Missouri-Columbia
One Hospital Dr.
Columbia, MO 65212
314/882-3350

New York

Norma Braun, M.D.
St. Luke's-Roosevelt Hospital Med. Ctr.
1090 Amsterdam Hosp. Ctr.
New York, NY 10025
212/870-1939

Moved: SKIP **

990 Second Ave., 2nd Floor
New York, NY 10022
212/421-9160

Pennsylvania

Charles Boig **
Children's Hospital of Pittsburgh
3705 Fifth Ave.
Pittsburgh, PA 15213
412/692-6479

Allan Freedman, M.D.
Presbyterian Med. Ctr. of Philadelphia
39th & Market Sts.
Philadelphia, PA 19104
215/662-8060

Texas

Dennis Schellhase, M.D. **
Texas A & M University
2401 South 31st St.
Temple, TX 76508
817/774-2111, ext. 2006

Utah

Primary Children's Medical Ctr. **
Joanna Lynch, R.R.T.
Shari vanBeuzekom, R.R.T.
100 N. Medical Dr.
Salt Lake City, UT 84113
801/588-3070

Virginia

Tim Sharkey, R.R.T. **
Children's Hosp. of King's Daughters
800 W. Olney Rd.
Norfolk, VA 23507
804/628-7323

Washington

Linda Donnelly, R.C.P., R.R.T. **
Lincare
1535 4th Ave., S., #1
Seattle, WA 98134
206/623-2880

*denotes ventilator user

**denotes pediatric interest

International:

Canada-Ontario

Committee for Independence in
Living & Breathing
Romeo Dicamillo
Canadian Paraplegic Association
520 Sutherland Dr., #246
Toronto, Ontario M4G 3Y9
416/422-5644

Judith Durance, M.D., F.R.C.P.
Kingston General Hospital
82 Ontario St.
Kingston, Ontario K7L 2V7
613/546-6012

Respirecare
Beverly Brown, R.R.T. **
1719 St. Laurent Blvd.
Ottawa, Ontario K1G 3Y4
613/748-1011

Jeffrey Simons, M.B., F.R.C.P. **
Children's Hospital of Eastern Ontario
401 Smyth St.
Ottawa, Ontario K1H 8L1
613/737-7600

England

John Shneerson, M.A., D.M., F.R.C.P.
Newmarket General Hospital
Exning Rd.
Newmarket, Suffolk CB8 7JG

Custom-Built Mask

by Marsha Ballard

As a respiratory polio survivor who has used an iron lung for 15 years, I am once more in control of my own life with the use of a positive pressure mask. If my husband and I want to spend the night in a motel, we can do so. We can visit my daughter in Virginia with my new positive pressure ventilator as an inconspicuous piece of carry-on luggage. No longer must someone be there while I sleep and disorient me when I wake. My husband can get up early to go jogging or go on overnight fishing trips. I feel like an adult again!

I had heard about positive pressure ventilation, but the reports admitted that the various masks and the Bennett lipseal had problems and only worked on certain people. When I heard that Susan Sortor, R.R.T., cardiopulmonary director at Dallas Rehabilitation Institute (DRI), had developed effective customized nasal masks, I contacted her.

I stayed at DRI for four days while I was tested for various masks and equipment. For those needing less ventilatory support than I need, Ms. Sortor has developed a soft, custom fitted nasal mask which is held in place by elastic straps. A respiratory therapist makes one of these in about an hour. I spent the first two nights using this while therapists monitored my heartbeat, blood oxygen, and carbon dioxide. (I now keep this mask as a back-up.)

Meanwhile, Dr. Carolyn Parker, a Dallas prosthodontist, painstakingly constructed my custom-fitted acrylic mask. It is attached to retainer-like teeth plates and has no straps. The teeth-plates hold the mask firmly in place and I can easily put it on and remove it by myself, using mainly my jaw and facial muscles.

For the first three nights, I used LIFECARE's PLV-100, a sophisticated and versatile machine, but, for me, this equipment had two disadvantages. First, it had an alarm that went off at the most trivial provocation. Second, it seemed that everytime I started to go to sleep, the machine would suddenly blast me with a giant breath of air. The respiratory therapist adjusted it, but the machine was convinced it knew better than I did what was good for me.

The fourth night, wearing the second of my new masks, I tried a different ventilatory support system, Repironics' BiPAP S/T-D. This model is still in the preliminary stage, but will be on the market in May 1990. I found it much more comfortable to sleep with and definitely user-friendly. Although its wheeze is slightly louder than the PLV-100, it never whops me with air or shatters the night with alarms.

I am delighted to be out of the lung and in the big warm bed with my husband, and Ms. Sortor assures me positive pressure ventilation is more efficient for me now. As my throat muscles weaken and chest wall becomes more rigid with age the vacuum method of the lung becomes progressively less efficient. I had to increase my negative pressure to 30 cm. of water or more and in addition had to use C-PAP at 10 cm. of water. This was the maximum adjustment on the iron lung, and it was hardly enough. I'm glad mask technology was there when I needed it.

Address: Marsha Ballard, Route 5, Box 450, 11621 C.R. 461, Tyler, TX 75706.

Ventilator User? Ventilator-Assisted? Ventilator-Dependent?

Readers of *I.V.U.N. News* will probably have noticed several similar terms that are used by the various contributors in the newsletter to describe individuals who need ventilators to help them breathe.

Some people prefer "ventilator user" because the term empowers the individual and connotes more independence in much the same way that the term "wheelchair user" does. However, the term, when it refers to infants and children, does not sound quite right and "ventilator-assisted" sounds better.

Low on the list of preferences is "ventilator-dependent" because of all the negative connotations associated with "dependent." (Notice that the phrase "on a ventilator" does not even enter the debate, except possibly in discussing individuals in an ICU.)

Your comments on appropriate terminology are invited! Please respond to Judith Raymond Fischer, c/o I.V.U.N., 4635 Larwin Ave., Cypress, CA 90630.

Deadline for submission of articles, stories, information, etc., for the Fall issue of *I.V.U.N. News* is August 25, 1990 and should be sent to Judith Raymond Fischer, c/o I.V.U.N., 4635 Larwin Ave., Cypress, CA 90630. Thank you!

I.U.U.N. Potpourri . . .

Ventilator-assisted children's camps:

June 3-8, 1990, sponsored by C.S. Mott Children's Hospital at Trail's Edge Camp in Maryville, Michigan. Parents do not stay at this camp; it is for technology-dependent children only. The camp is free, but there is no transportation stipend. Limited to 20 children. (24 hour service from health professionals.) Write Mary Dekeon, R.R.T., C.S. Mott Children's Hospital, F1421 Box 0208, Ann Arbor, MI 48109. 313/763-2420.

June 24-29, 1990, sponsored by the Miami Children's Hospital and the American Lung Association of Dade & Monroe Counties. The one-week camp is free, but families must provide their own transportation. Children are selected from applicants throughout the United States; there is space for 10 families. A team of health professionals from Miami Children's Hospital (2 miles away) staffs the camp round the clock. To apply, write or call Zoe Arauz, Miami Children's Hospital, 6125 S.W. 31st St., Miami FL 33155. 305/662-8222.

August 19-24, 1990, sponsored by SKIP at Camp Courage in Maple Lake, Minnesota. The camp, with space for 20 families, is free, and there is a transportation stipend. Health professionals and emergency services are available around the clock. Families must submit an application to Barbara Donaghy, SKIP, 11208 Minnetonka Mills Rd., Minnetonka, MN 55343. 612/861-2544.

"The Ventilator: Psychosocial and Medical Aspects Muscular Dystrophy, Amyotrophic Lateral Sclerosis, and Other Diseases: The Patient, The Family, The Staff, and the Community - The Present and the Future" is the title of a symposium coordinated by the Foundation of Thanatology, April 26-28, 1990 at the New York State Psychiatric Institute in New York City. For information, contact Dr. Austin Kutscher, Columbia-Presbyterian Medical Center, 630 W. 168th, New York, NY 10032. 212/928-2066.

Home care and ventilator videos about discharge planning and the transition to home care for ventilator users are available from two sources:

"Getting It Started and Keeping It Going - a Video and Workbook" from Children's Hospital of New Orleans is more suited to families with a ventilator-assisted child. Topics include trach care and changing, suctioning and monitoring, emergency procedures, etc. Purchase of the 60-minute video and two workbooks is \$195. A five-day video rental is \$50.00. Contact: Darlene Cimo, B.S., R.R.T., Children's Hospital, 200 Henry Clay Ave., New Orleans, LA 70118. 504/896-9437.

"The Ventilator-Assisted Patient: Preparing for Home" is for health professionals and describes a comprehensive, multidisciplinary program for the transition from hospital to home care. Cost of the 25-minute video and 400-page manual is \$350. Contact: Loma Linda University Medical Center, Pulmonary Rehabilitation, 25455 Barton Rd., Suite 207A, Loma Linda CA 92354. 714/824-4495.

Breathing Easy: A Guide for Ventilator Dependent Individuals Moving into the Community is an excellent publication from a Canadian independent living center. All about getting help in deciding to move from an institution to home, finding funds, hiring and training attendants, budgets and contracts, etc. The ventilator users (polio survivors, high spinal cord injured quadriplegics, people with spinal muscular atrophy, muscular dystrophy, etc.) who are profiled from present a fascinating combination of ventilator technologies. Also detailed are the support programs available in each province. Send \$13 (postpaid) to Independent Living Resource Centre, Inc., 207-294 Portage Ave., Winnipeg, Manitoba R3C 0B9, Canada.