

I.V.U.N. NEWS

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

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

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\$5 for ventilator users
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ERIN'S STORY: YES, YOU CAN OUTGROW THE NEED FOR A VENTILATOR!

by Karen Shannon, SKIP Founder

How well I remember standing at Erin's crib side, stroking her head and hearing what seemed to be in the distance the beeps and alarms of the monitors of the Pediatric Intensive Care Unit (PICU). But those alarms weren't for someone else, they were Erin's monitors sounding. Erin was in a crisis again and I was whispering, "Hold on, Erin, you can make it."

As I recall the early years of Erin's life, I remember the many unexplainable episodes of respiratory arrest and the many times we felt we were losing her. Now, at age 9, I watch Erin proudly jumping off the diving board, and I know that Erin might not be alive today, let alone participating in all aspects of life, without an incredible support system. This is the story of that support system.

It all began with our family's unwillingness to accept the doom and gloom with which we were often faced. We were determined from the beginning to overcome obstacles.

Karen Shannon founded SKIP (Sick Kids [need] Involved People), and is now a consultant and training specialist in the Department of Family Support Service at The Kennedy Institute in Baltimore.

Repeated recommendations were to put Erin in an institution. We were told over and over, "Institutionalization will be better for Erin and better for your family." We could not accept that. We were optimistic as we looked at Erin, but we were realistic, too. We knew we had a very sick little girl, and we knew if Erin had a chance at all, we had to be willing to take the risks. We were only willing to make educated and informed choices, because we knew a bad choice meant Erin's life.

We had waited long to hear the good news, "You have a healthy baby girl, a little small, but she appears fine." What joy those words brought to us and her three brothers! That excitement lasted a few hours until we heard the doctor say, "I am sorry, but I feel your daughter has some very serious problems that could shorten her life significantly, along with causing severe developmental and growth problems. However, we won't know for certain until she has reached one year of age."

Erin was less than 24 hours old as I tightly held her, feeling devastation and shock that could not be measured. All I remember now is that I wanted to run away and hide and never tell anyone. I was afraid that with such a poor prognosis Erin would never have a chance for any kind of life.

Little did we know what lay ahead of us. Little did the medical personnel

Continued...

know how many times they would revise their diagnosis for Erin. All they could tell us was that Erin had tracheobronchial malacia, indicating abnormal collapse of the trachea due to abnormal softness of the tracheal cartilage. We were told that Erin needed a tracheostomy, ventilator, oxygen, and aerosol therapy to live. Today, this prescription seems straightforward and feasible, but in 1979 it was unheard of to have a child at home with these kinds of supports.

In bringing Erin home from the hospital at 5 months of age, we learned to recognize the signs and symptoms of respiratory distress. We learned to manually ventilate her with an ambu bag. We learned to administer chest compressions. Our doctors were concerned about our providing Erin's complete 24-hour care, and, fortunately, we found that our private insurance had a provision for home care which renewed our commitment to keep Erin at home.

We were also fortunate that our medical professionals were so available. We were able to call Erin's doctor at any time of day or night, even weekends, and he was always there. A commitment had been made to support Erin and our family, and a system was developed to directly admit Erin into the PICU whenever it was necessary. We built that support system on trust, respect, and faith in each other.

Ken Schuberth at Johns Hopkins, Erin's primary doctor, called all over the country to find out what others were

doing with similar cases, and helped develop a broader support network. Erin's fourth birthday celebration in 1983 included a home ventilator. It was only then that we finally had control over Erin's respiratory crises. Never again would Erin have an emergency admission into the PICU. How comfortable it felt to replace our crisis controlled system with management controlled support.



Karen and Erin Shannon

We now had new problems. The ventilator gave us stability we never had had, but brought increased lung infections. Erin would have pneumonia constantly. At this time, attention was focussed on a program at Children's Hospital of Philadelphia directed by Dr. Robert Kettrick. Dr. Kettrick, Dr. Schuberth, myself, and others from Erin's support team quickly joined to see what could be developed.

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THOUGHTS ON ALS AND VENTILATORS

by Dee Holden, R.N.

Make an informed choice about using or not using a ventilator **before** one is needed. Avoid ending up in an emergency room somewhere, intubated and attached to a ventilator, when you did not wish to be so.

Discuss the matter with everyone you feel would be influenced by your decision, i.e., spouse, children, friends, clergyman, physician, etc., about what life with a ventilator entails -- physically, emotionally, financially, intellectually. Never forget that this is **your** decision. Don't let anyone else make it for you.

Make your decision and stick with it. Make certain that your caregivers stick with it, too. Your physician must have a written statement of your wishes, signed by you and appropriately witnessed. This is **not** covered by a "Living Will" in most states. The additional measure of a "Durable Power of Attorney" for health care authorizes your selected agent, i.e., spouse, child, family member, friend, etc., to act and make your decision for you if you are unable to express your wishes yourself. Your physician must know all this and have copies in your chart. It would be wise to consult with an attorney regarding the laws in your state.

Find a physician whom you trust and who will follow your wishes when the time comes for this decision. Prefer-

ably, this should be a physician who has some knowledge of ALS. It need not be a neurologist; a family practitioner or internist will suffice.

If you make the choice of using a ventilator, use it for any length of time, and then decide that you wish to discontinue use, you must have some arrangement with your physician for allowing yourself to be legally withdrawn. This is not allowed in some states, so again it is wise to consult your attorney or your physician.

Once you do choose to use a ventilator, enjoy life to the fullest. Use the new technology of portable respiratory systems and go out with your family and friends. Learn about the equipment; don't be afraid of it. Take advantage of its versatility. A ventilator is functional, adaptable, and mobile. Use it!

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ETHICAL CHALLENGES OF CHRONIC ILLNESS

A special supplement to the *Hastings Center Report*, February/March 1988, focuses on chronic illness and disability in an aging society and the challenge to the American health care and social service systems. The 16-page supplement is available for \$4 each from The Hastings Center, 255 Elm Rd., Briarcliff Manor, NY 10510.

LONG-TERM MECHANICAL VENTILATION IN AUSTRALIA

Hugh Newton-John, M.D., heads the Home Ventilation Programme at Fairfield Hospital in Melbourne, Australia, and currently has 27 enrolled adult patients. In *The Medical Journal of Australia*, Vol. 150, January 2, 1989, pp. 3-6, Dr. Newton-John discusses his and other ventilator programs in Australia and the practical and ethical issues involved. Dr. Newton-John's usual eloquent style and calm reason are reflected in the following excerpts.

"The words 'iron lung' conjure up distressing images of monstrous, coffin-like machines from which there can be no escape. This archetypal fear of ventilators has important implications when we consider the ethics and social impact of the long-term ventilation of patients. Nowadays, the ventilator has become a powerful symbol of ambivalence (even suspicion) towards the practice of medicine. This ambivalence is exemplified by the Karen Quinlan case, about which one commentator has noted 'once turned on, the respirator seemed autonomous, its power to save life matched by its power to torment life.'

Dr. Newton-John published a story entitled "Last Rights," about one of his long-term ventilator using patients, in *Rehabilitation Gazette*, Vol. 26, 1985.

... Long-term ventilation for patients ... makes them feel better - after all, this is why it is undertaken in the first place. This simple point may be overlooked easily by those who take a moral stance about 'quality of life' and who fail to distinguish between a ventilator that is used in the acute care setting as a life-support system and that which is used in the rehabilitation setting as simply another appliance to improve well-being and mobility.

... Life 'on a ventilator' can be a liberating experience, in much the same way that an electric wheelchair can transcend the limitations on mobility that are imposed by a paralyzing disorder. To deny a drowning person a life-jacket would be unconscionable; to deny a person who is suffering from 'terminal' respiratory insufficiency a ventilator can be viewed in the same light. Once we as physicians learn to accept that a ventilator, however complex it may appear, is a pump to help our patients to breathe - no more and no less than that - we shall have come a long way towards changing the prevailing community attitudes about severe physical disability."

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

ADVOCACY GROUP FOR VENTILATOR DEPENDENT CHILDREN AND ADULTS IN SOUTHERN CALIFORNIA

Formed in January 1988, the Advocacy Group includes more than 50 nurses, physicians, discharge planners, etc., representing 9 hospitals in the Southern California area as well as the American Lung Association. The Group met with Medi-Cal representatives to endorse support for the In-Home Medical Care Program which enables individuals using ventilators to live at home with attendant care services.

In the future, the Group plans to:

- set up a database of the ventilator user population in Southern California (later the entire state),
- expand the Advocacy Group Board to include ventilator users,
- network available resources,
- establish local support groups,
- assess current standards of in-home care,
- advocate for insurance coverage,
- support available community resources,
- establish a statewide network.

Address: Irene Gilgoff, M.D., Rancho Los Amigos Medical Center, Bldg. 900, Room 81, 7601 E. Imperial Hwy., Downey, CA 90242. 213/940-7847.

FROM ROCKING BED TO NASAL MASK . . . SUCCESSFULLY!

by Willa Schuster

In September 1988, urged on by Gini Laurie, I explored positive pressure breathing with a face mask instead of my rocking bed. I was hospitalized for a 2-day introduction to the new apparatus by my pulmonologist, who had insisted that I earlier undergo a day's testing with Augusta Alba, M.D., at Goldwater Memorial Hospital in New York. The ultimate result has been my successful conversion from the rocking bed to a portable volume ventilator and nasal mask which I use for 9 hours per night.

The initial adjustment to the confinement of the mask, etc., has been more than compensated for by its positive results. I am energized, sleeping well, and generally much improved.

The one major problem was a continuously blistered spot on my forehead from the mask. After much trial and error, I have hit on a winning combination: a generous slathering of Neosporin ointment topped with a 3/4 inch square of telfa bandage held in place by surgical paper tape each night before putting on the mask.

Address: Willa Schuster, 3 Park Place, Mystic, CT 06355.

Respiratory polio survivor since 1955, Schuster described her return to the rocking bed for nocturnal ventilatory assistance in *Rehabilitation Gazette*, 1986, Vol. 27, No. 1.

Continued from P. 3...

After an extensive evaluation, Dr. Kettrick felt strongly that if Erin's lungs were ever going to be given the opportunity to strengthen, the infection would have to be controlled. Dr. Kettrick was also able to determine that Erin's lungs continually collapsed on expiration, causing increased risk for chronic lung disease. Dr. Kettrick was not overly optimistic in the beginning, but asked us if we wanted to try positive end-expiratory pressure (PEEP) with Erin. This aggressive therapy was risky, but he felt that Erin was at greater risk of succumbing to an infection.

During a routine examination more than a year later, Dr. Kettrick was able to identify such dramatic improvement in Erin's lung function that he shared his optimism that one day Erin would be free of all life supports. Dr. Kettrick also felt that we should add home antibiotic IV therapy to Erin's support in order to reverse the infection level.



On August 5, 1987, Erin was no longer supported with medical equipment. She was finally on her own. Today, Erin is in 4th grade and involved in ballet, Girl Scouts, and basketball. She has been the focus of great caring support, without which she could not have developed the inner strength and determination to survive. When you ask her what she wants to do when she grows up, she says, "I want to help kids get well, I want to be a nurse or a doctor." Erin's survival and the person she is today is truly a tribute to the support system that made it all possible.

Address: Karen Shannon, 216 Newport Dr., Severna Park, MD 21146.

Sick Kids [need] Involved People (SKIP) has the following goals:

- to advocate for individuals and their families to receive adequate and appropriate care and services in home and community based environments,
- to assist individuals to enjoy the benefits of public education/vocational training opportunities among their nondisabled peers,
- to advocate for the support services needed by individuals and families in order to participate within the community, and
- to provide information and education to policy makers to reform laws and policies.

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ON SWALLOWING AND SALIVA

by Barbara Beal, R.N., M.N.

Swallowing is a complex act, involving numerous muscles and nerves, any of which can become affected in persons with neuromuscular weakness notably bulbar polio and ALS.

Because there are so many varieties of swallowing problems, it is very helpful to know what the specific problem may be. A cine-esophagram (swallowing evaluation test) creates a video movie of the swallowing act while a person swallows a spoonful of substance that is radio-opaque. The resulting video looks like a moving X-ray that can be played back in slow motion until the swallowing problem is detected. After the test, a diet of foods with the appropriate texture can be recommended to help minimize swallowing problems.

Sometimes the difference between swallowing and choking lies in the consistency of the food. Sometimes it is the temperature. People with swallowing problems are aware of which foods stick and which are easier to swallow.

Individuals who have ALS find that thick liquids are usually swallowed more easily. Good thickeners are yogurt, sour cream, instant mashed potato flakes, applesauce, and gelatin. "Thick-It," an instant cornstarch product, is available commercially.

A last resort when choking is too frequent is a gastrostomy tube. With the newer fiberoptic scopes, this surgery is relatively simple. If a person can still swallow, the use of a tube can supplement the diet and help avoid weight loss.

A tracheostomy does not interfere with swallowing, although most people have to learn new swallowing techniques. A cuff around the tracheostomy tube will prevent food and secretions dripping into the trachea from the pharynx, but a cuff is not usually necessary if the epiglottis closes properly on swallowing. The cuff can be inflated just during meals and then deflated to allow speech.

People seldom think about **saliva** unless something goes wrong with it. If a person drools, it is assumed that he or she has too much saliva. Is that assumption correct or is the normal amount of saliva out of control?

It is like saying the car is running all right when no water drips out. If water spouts from under the hood, there must be too much water - better get that water removed right away. Makes sense to the nonmechanic, doesn't it?

The same thing with saliva. The fact is that a normal adult produces 1-1 & 1/2 quarts of saliva per day. We swallow almost all of it all the time. It lubricates the throat and esophagus and is reabsorbed by the body.

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What happens to saliva when one can't swallow it readily? It pools in the mouth and throat. It makes one drool. Sometimes it drips into the windpipe. Small amounts of saliva wash back and forth normally as we sleep, so small amounts inhaled are probably not harmful. Problems arise when food is mixed in saliva and it goes into the windpipe, or there is such a large pool "back there" that one chokes on it.

Saliva is rich in potassium. Chronic removal of saliva, which therefore cannot be swallowed, can lead to potassium depletion. In small amounts, this is not a problem.

Saliva can be controlled by the following methods:

- Lean forward and rinse the mouth out over a sink with a Waterpik.
- Suction the mouth with a portable suction machine by reaching the mouth tip in as far as possible to remove saliva and food particles. (Some people can suppress the gag reflex by using the voluntary muscles to hold the throat open, the throat open, then pushing the suction tip past the throat pillars to suction the throat.)
- Take medication to decrease the amount, such as bantnine, pro-bantnine, Atarax (hydroxazine), and atropine. To obtain the side effects of dry mouth, one may have to put up with the drug's bad main effects. If drooling is significant, medications are worth a try, but check with a physician first. Some people use over-the-counter anti-

histamines to dry out the mouth. But these may also cause secretions in the lungs to dry out, which is to be avoided. Chest secretions should be as watery as possible to ease their clearance.

- Use a small sponge hidden in the mouth to collect saliva and lessen drooling. Change it frequently and keep it clean. A "cigar" made of absorbent paper material and held in the mouth can also help and is not too unsightly if changed frequently.

The ALS Association (ALSA) publishes *Managing Swallowing Problems (MALS Manual IV)* which provides greater detail on swallowing, saliva, tube feedings, etc. The manual is free to individuals with ALS, but shipping charges are \$3 per manual. There is much useful information for persons with other neuromuscular disorders. Call ALSA, 800/782-4747.

Two cookbooks are also helpful:

- *Non-Chew Cookbook* by J. Randy Wilson, Wilson Publishing, Inc., P.O. Box 2190, Glenwood Springs, CO 81602. 303/945-5600.
- *Meals* by MDA/ALS Research & Clinical Care Center at Baylor College of Medicine in Houston. (Free copy from MDA, 810 7th Ave. New York, NY 10019.)

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ALS Home Care Consulting, 5311
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714/895-3375.

NON-INVASIVE ALTERNATIVES TO TRACHEOSTOMY by Sue Sortor, R.R.T.

Providing optimal ventilation without the use of tracheostomy is a challenge that many health professionals are undertaking. Many individuals with neuromuscular weakness or restrictive lung or chest wall disease may experience severe progressive cardiorespiratory insufficiency that may lead to failure after one or two years. Oxygen therapy alone may not be adequate to stabilize or reverse the progression.

Nocturnal mechanical ventilation via mask has been shown to alter the natural evolution of cardiorespiratory insufficiency and to increase comfort without the complications of tracheostomy or of negative pressure which can be cumbersome and may increase the risk of obstructive sleep apnea.

Mask intermittent positive pressure ventilation (IPPV) has also been tried on individuals with COPD, and a percentage of those have benefited from nocturnal ventilation in conjunction with oxygen therapy.

Several configurations that can be used with mask IPPV are nasal, oral, or a combination of oral/nasal.

Excerpted from Sortor's presentation to the World Congress on Home Care in Rome in March 1989.

Nasal masks can be either premolded manufactured ones or silicone customized masks (Sefam, Lyon). For most people, these masks do not provide a sealed system of ventilation. Leaks are common, but do not necessarily indicate inadequate ventilation. Mask leaks, generally in the infraorbital area, have responded to different mask size, different position, or increased tension in the supporting head bands. Careful monitoring is imperative. Continual air leaks in this area may cause conjunctivitis. Sinusitis has been reported to be a complication.

Oral combinations include a mouthpiece with Bennett seal, scuba mouthpiece, or customized mouthpiece.

There can also be strapped oral/nasal masks and strapped or strapless customized oral/nasal masks.

A portable volume cycled ventilator should be used, preferably with both house current and battery pack power capabilities. Assist/control mode should be available with a sensitive trigger mechanism and a quick response time. Frequency and I:E ratio should be adjustable.

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MUSINGS: A CONTINUING COLUMN

by Karan McKibben, Ph.D.

Recently, the I.V.U.N. offices received a report from a high school senior in Pennsylvania who was experiencing considerable difficulty gaining admittance to college reportedly because she uses a ventilator.

This is quite puzzling, and, at first, one is ready to hurl accusations of discrimination or suspect a hardening of the public's attitude toward people who use increasingly sophisticated medical equipment. Upon analysis, however, one soon realizes that the problem illustrates the importance of clearly understanding the issues involved from the standpoint of both society and of the person with a disability seeking to live independently.

The most curious aspect to this problem is that any college should deny admittance because of the need for a ventilator. Traditionally, admittance to a university is based solely on scholastic aptitude, i.e., grade point averages, S.A.T. scores, teacher recommendations, and in general, any evidence of past scholastic performance. A student's use of a ventilator or any other medical equipment is clearly a separate issue that ought not to be the school's concern.

Dr. McKibben, respiratory polio survivor since age 8, teaches English at UC-Riverside. She recounted her own graduate school experiences in *Rehabilitation Gazette*, Vol. 27, No. 2, 1986.

The problem gets even more curious when the student reports that she was turned down by the University of Illinois, Champaign-Urbana, which has built a special residence for ventilator users. This suggests that even that accommodating school has gotten the idea that ventilator use is an issue that will affect the student's academic performance.

Perhaps the student failed to focus the schools' attention on her academic abilities rather than her physical disabilities. I know from experience that it takes a bit of strategy to keep institutions and people focussed on the right issues. For example, if the student mentioned her ventilator use at all on her application, she needed to make sure that piece of information was clearly subordinate to the more relevant facts of her previous academic performance and her potential for future performance.

If the schools raise the issue of ventilator use nonetheless, the student should find an effective way to remind the schools that the student's academic abilities are the only legitimate concern involved in the admittance procedure. An outside agency, such as a state department of rehabilitation or an independent living center, might be able to reinforce this argument by citing legal obligations and traditional admittance patterns.

Continued...

There is one point, however, when the schools can legitimately raise the issue of ventilator use. This point is when the student asks for living accommodations on campus. If, in granting admittance, the schools perceive that they are accepting responsibility for unusual medical needs and physical dependency, they understandably may be very reluctant. In the current litigious atmosphere, institutions are growing increasingly wary of even the perception of additional legal and moral responsibilities.

In this case, the student needs to assure the school that she will be fully responsible for her medical needs, her equipment, her physical well-being. That means that she should be willing to function wholly independently from the school even if it means living off campus in her own apartment, finding attendants on her own, and locating a medical support team unconnected with the school. But then living independently is presumably the whole point of leaving home and going to college.

It is an impulse that millions of young people, with or without disabilities, follow every year. It is an impulse that soon forces the individual to confront the complex relationship between the separate but related responsibilities of independent individuals and an effective society. In entering a university, the student is soon faced with the startling fact that academic

success, like success in society at large, requires self-reliance and self-discipline.

Universities no longer view themselves as acting *in loco parentis*, but as institutions providing opportunities for intellectual and moral development. Their responsibility lies in opening their doors to those with enough self-reliance and self-discipline to take advantage of that opportunity. The student's responsibility lies in establishing an independent lifestyle so that he or she can take advantage of the opened door.

For the student with a disability whose goal is also to be self-reliant and accepted by society on the basis of abilities, not disabilities, the question becomes one of determining how much special accommodation to ask of society and its institutions.

For society and its institutions, the question becomes one of how best to accommodate special needs without undermining the development of self-reliance and self-discipline. On both parts the problem requires a strong commitment: a commitment from the individual to manage disability so that ability is what society perceives, and a commitment from society to open its doors so that disability is no longer perceived as a more important issue than ability.

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

BLITZER REPORT NO. 4: NOSE NEWS by Bud Blitzer

Work on the development of more comfortable, workable, and available nose masks continues apace. I am aware of eight groups around the world who have developed their own custom-fitted nose masks with varying degrees of success. (Write me at the address below for the one closest to you that is best suited to meeting your needs.) One manufacturer is devoting serious R & D time to finding a mass production solution.

This is a far cry from the early '80s when Dr. Augusta Alba was a lonely voice extolling the virtues of nasal ventilation. It is one measure of the acceptance nasal ventilation has gained among health professionals and it is most encouraging.

Some of you must be wondering why all this takes so long. The chief problem is comfort. As the air blows into the mask, it tends to lift the mask off the face. To prevent leaks, the mask must be held tightly to the face. This causes discomfort and, in some cases, breakdown of facial tissue at pressure points. However, the outlook is not as dismal as it may sound.

In the next issue of *I.V.U.N. News*, I will report on the face mask workshop at G.I.N.I.'s Fifth International Polio and Independent Living Conference on Saturday afternoon, June 3.

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

VENTILATORS AND MUSCULAR DYSTROPHY HANDBOOK

Recent mention in the magazine of the Muscular Dystrophy Association has spurred sales of *Ventilators and Muscular Dystrophy* by Nancy Schock and Agatha Colbert, M.D.

The 36-page handbook, published in 1987 by Gazette International Networking Institute (G.I.N.I.), discusses the alternatives for individuals with Duchenne muscular dystrophy (DMD) should they choose to extend their lives by using a ventilator.

The authors have included information on the basic pathophysiology of respiratory failure, methods of respiratory care, the advantages and disadvantages of negative and positive pressure ventilators, decision making, and quality of life issues.

Medical and health professionals involved in the care and support of a person with (DMD) reaching the point of respiratory distress describe their roles. An excellent appendix includes a bibliography, glossary, resources, and related publications.

Ventilators and Muscular Dystrophy is still available for \$6.75 postpaid. Prepaid bulk orders are offered at a discount. Write or call G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108. 314/361-0475.

RESPIRATORY POLIO SURVIVORS

by D. Armin Fischer, M.D.

In late fall of 1988, the Polio Survivors Association in Downey, California, led by President Richard Daggett, circulated questionnaires on swallowing problems (dysphagia) and sleep disordered breathing to its membership of 950 people.

112 (12 %) questionnaires were returned from all across the U.S. and even Canada. However, over half (67 or 60%) of the responses came from California. The earliest onset of the acute polio stage was 1912; the latest onset reported was 1959.

Seventy-six (68%) females answered the questionnaire with the remaining 32% of the questionnaires answered by males. The oldest respondent was 85 years old; the youngest was 37 years old.

At onset, 80% had breathing problems, 56% used a ventilator, and 41% experienced swallowing problems.

Currently, 59% are experiencing breathing problems, 36% use a ventilator, and 33% are having swallowing problems.

Dr. Fischer, coeditor of the *Handbook on the Late Effects of Polio...*, recently retired as chief of the pulmonary service at Rancho Los Amigos Medical Center in Downey.

Sixty-five percent (65%) of those who reported breathing problems at onset also reported breathing problems now. Sixty percent (60%) of those who used a ventilator at onset reported using a ventilator now. And 59% of those who had swallowing problems at onset are also experiencing swallowing problems now.

Of those who reported sleep disordered breathing problems, 57% reported awakening frequently during the night and 54% reported daytime sleepiness.

Polio survivors start out with diminished respiratory reserve, and, as they age, lose vital capacity at the normal rate of about 1% per year. It would appear, however, that sleep and swallowing problems are more prevalent than previously reported.

Polio survivors with swallowing problems should take care in eating to avoid aspirating. Swallowing clinics are becoming more common (Gaylord Hospital in Connecticut, Johns Hopkins in Baltimore, to name a few), and physical therapists can also provide suggestions for alleviating swallowing difficulties.

Sleep disorders in polio survivors should be confirmed by a sleep study, and appropriate treatment with some form of mechanical ventilation begun.

Address: D. Armin Fischer, M.D., 4635 Larwin Ave., Cypress, CA 90630.

Time to renew your I.V.U.N. membership!

YES, please renew my membership in the International Ventilator Users Network (I.V.U.N.) for another year.

- | | U.S./Canada | Overseas |
|--------------------------|--|--|
| Individual Membership | <input type="checkbox"/> \$ 5 per year | <input type="checkbox"/> \$ 8 per year |
| Institutional Membership | <input type="checkbox"/> \$15 per year | <input type="checkbox"/> \$18 per year |
- I enclose an additional donation \$ _____ to support I.V.U.N.'s work.
(Donations are tax deductible.)
- Enclosed is a check in the amount of \$ _____
- Bill my institution.
Please enclose purchase order.

Make checks payable to I.V.U.N. and mail to: I.V.U.N.,
4502 Maryland Ave., St. Louis, MO 63108 U.S.A.

POTPOURRI . . .

Gini Laurie, founder and chairperson of Gazette International Networking Institute (G.I.N.I.) and I.V.U.N., is recovering from major surgery to remove a cancerous tumor from her esophagus. She is at home: 4502 Maryland Ave., St. Louis, MO 63108. Gini greatly appreciates the many thoughtful cards and flowers she continues to receive.

Summer camp and family learning retreat at Vinland (outside of Minneapolis), July 2-7, 1989, in connection with **SKIP**, will provide traditional summer camp activities plus some unique opportunities for sharing among families with children who are technologically dependent or medically fragile.

Staffed by physicians, nurses, respiratory and recreational therapists, and psychologists, there is room for 20 sleep-over families and 10 day families. Vigorous fundraising efforts have provided transportation stipends as well as covered all expenses for the week.

There may still be space available. Contact **SKIP**, Barbara Donaghy, 6829 Thomas Ave., So., Minneapolis, MN 55423. 612/861-2544.

Wanted: Articles, stories, information for the next issue of *I.V.U.N. News*, such as stories of SCI quads living at home with a ventilator; nutrition for individuals who use a ventilator; creative financial funding for home ventilator use; children who use ventilators, *etc.* Please send an outline by September 1 to Judith Raymond Fischer, c/o I.V.U.N., 4502 Maryland Ave., St. Louis, MO 63108.

Flying Wheels Travel, specialists in travel planning for people with disabilities for more than 20 years, is getting more experienced in travel arrangements for ventilator users. Ask for Edna Cook, 800/657-4446 or write Flying Wheels Travel, P.O. Box 382, Owatonna, MN 55060.

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

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St. Louis, Missouri 63108 U.S.A.

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Ever since this unique international journal was founded at a respiratory polio rehabilitation center in 1958, it has been publishing articles by health professionals and ventilator users with all types of disabilities who live at home.

These life experiences of ventilator users are an invaluable source of ideas, inventions, and motivation for other ventilator users, their families, and health professionals.

The *Rehabilitation Gazette* covers every phase of living productively and independently in the community, as well as specialized information such as camping, foot-controlled steering, education by telephone, home based businesses, mouthsticks, and ventilator-related information, including underventilation, glossopharyngeal breathing (GPB), positive pressure by face and nose masks, tracheostomy speaking valve, portable iron lungs, rocking beds, and adapting to new forms of ventilation.

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