

**CONSUMER-DIRECTED HOME CARE PROGRAM
SAVED FROM NEW YORK BUDGET AX AND EXPANDED**

by Ira E. Holland

With the new emphasis on cost-effectiveness, the monies that insurance companies, Medicare, Medicaid, and other third party payers are willing to spend for discharge and longterm home care have shrunk drastically. If it is determined that severely disabled people who also require ventilatory support will cost the insurance carrier more money if they are discharged to the home than if they are discharged to an institution, then serious consideration will be given to institutionalization. Most private insurance policies have a cap or limit at which point the consumer is referred to the Medicaid system.

Unfortunately, most Medicaid programs are strictly oriented toward institutionalization, because home care traditionally utilizes certified home health care agencies. These costly, usually for-profit operations, are mainly the only available option in cities and towns; alternative and more innovative programs are not yet a widespread reality. These expensive home care agencies will ultimately cause a severely disabled ventilator user to lose essential hours of service which could lead to losing their ability to maintain themselves in the home care setting. These hours will undoubtedly be curtailed by the local authorizing agency in order to cut costs and thereby expand limited services.

One alternative to the home health agency is a more cost-effective home care program. Concepts of Independence, Inc., initiated a consumer-directed Personal Assistance Program in 1980 to provide New York state and local governments just such a cost-effective home care program. It was our intention to craft a program that would permit ventilator-dependent consumers to access a community or home-based living situation, enabling them to realize significant levels of independence with the promise of becoming functional and productive. The program would provide the option of less expensive personal care services with the active participation of the consumer who would select, train, and supervise the caregiver.

In 1980, the options were few, and only home health care agencies were permitted to provide

ventilatory support services, including suctioning, dressings, enemas, range of motion exercises, etc. In 1992, after many years of discussion, the New York legislature passed Chapter 795 which modified the Nurse Practice Act, enabling a Consumer-Directed Personal Assistant to perform services that were previously limited to the licensed or certified caregivers. Thus, caregivers employed by the Consumer-Directed Personal Assistance Program, could perform duties, at \$6.35 per hour, instead of registered or licensed practical nurses at \$20-30 per hour. The home care worker now could provide ventilatory support and personal care services at a substantially reduced cost.

Then, in January 1993, New York installed its first Republican Governor in some 40 years. George Pataki, the new Governor, initially announced that he would slash enormous sums of money from the Medicaid program, proclaiming that 100 hour caps would be mandatory on all home care programs. Caps of 100 hours per month meant the elimination of home care programs for ventilator users, as this would equate to barely 3 hours of service per day.

I immediately initiated an aggressive education campaign of letters, graphics, and informational packets, delivered by overnight mail or by personal and group trips to Albany. In all, Concepts sent over 2,000 pieces of mail and made more than 20 trips to Albany. We illustrated clearly that Concepts of Independence, Inc., by utilizing the Consumer-Directed Personal Assistance Program, was saving the taxpayers of New York more than **\$10 million** annually. If the shifting of our clients to higher levels of service was implemented, New York would forego that \$10 million up front.

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THE TRACHEOTOMIZED PATIENT: TRACHEAL TOILET AND SPEECH

To the Editor ...*

As a quadriplegic and ventilator-dependent person since 1987 resulting from ALS and with a background training in general and thoracic surgery, I have become increasingly concerned with the inadequacies of suctioning techniques shown by theoretically well-trained professionals.

Training of medical, nursing, and respiratory therapy personnel in suctioning techniques has been largely on unresponsive individuals or on individuals who could not communicate or lacked definitive experience or medical knowledge sufficient to allow them to convey any perceived dissatisfaction with the methods of tracheal toilet used.

Verification of the effectiveness of suctioning via palpation, percussion, auscultation, or x-ray is infrequent, relative to the frequency of suctioning, and little feedback is available from the patient. Therefore, several questionable and probably undesirable techniques have become widely used.

The positive pressure maintenance adapter PEEP-Keep, Concord-Portex, SIMS has a capped chimney with a hollow silicone rubber plug in the chimney that fits snugly about the suction catheter, allowing maintenance of positive pressure and oxygenation while the patient is being suctioned. Use of the adapter helps obviate such traumatic practices as in-and-out suction catheter passage necessitating multiple passes, insensitive too-rapid catheter passage, and twisting of the catheter. It is more importantly comfortable, less distressing, and hence, less frightening to the patient.

Unfortunately, this device is not ordered routinely and even when used, it is often not accompanied by changes in suctioning technique that would quite obviously be beneficial to the patient.

To be maximally effective, suctioning should be carried out at moderate speed continuously on the way in as well as on the way out. Good technique demands the use of the senses of touch and hearing, as well as sight. Most importantly, to be most effective, one should stop to empty collections of secretions whenever encountered before proceeding further.

For those tracheotomized quadriplegic patients who have vocal cord function and can tolerate cuff deflation, there appears to be inadequate dissemination of information about and use of devices such as the Passy-Muir Valve, a simple one-way valve that opens in inspiration and closes in expiration forcing the expired air out through the vocal cords, allowing and augmenting speech.

For the patients who cannot tolerate cuff deflation, controllable speech is of incalculable importance. With a talking tracheostomy tube (Trach-Talk, Portex) with its Christmas tree adapter attached to suction tubing, by plugging a suction machine into a standard X-10 appliance module (PowerHouse, Radio Shack), a ventilator-dependent quadriplegic with functioning vocal cords can use any switching device and remote control to turn on and off the suction and talk at will!

*Stewart A. King, MD
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The phone number (314/534-0475)
and FAX number (314/534-5070)
remain the same.

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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After six months of 18-hour days and 7-day weeks, we began to meet with key State Senators and Assemblypersons and their staffs. We had a lengthy and significant meeting with the Governor's office. In that relatively brief time, we succeeded. The New York State legislature, with the support of the Governor's office, mandated the implementation of Concepts' Consumer-Directed Personal Assistance Program statewide. Recently we signed contracts with nine counties in upstate New York. Consequently the program will enable ventilator-dependent consumers statewide to enter a program making it possible for them to live independently at home.

It should be clearly understood that while this program is not appropriate for every ventilator user, nor for every severely disabled individual, there are a significant number of these consumers currently being serviced by certified home health agencies billing in excess of \$18-20 per hour, compared with Concepts' billing of \$11.03 per hour in New York City and \$12.85 upstate.

In New York State, Concepts of Independence, Inc., was confronted with a problem which could have resulted in the elimination of the home care program for people with severe disabilities. Concepts was able to turn the drive to eliminate waste and save money to a more positive direction that has led to the expansion of the program statewide. We emphasized that our program saved money by utilizing a more cost-effective level of staff and reminded the legislators that the administrative cost of the program was only 3.8% because the consumers managed a substantial portion of the administrative responsibility.

The excessive cost of maintaining a ventilator-dependent consumer can be significantly lessened if the local districts will exploit the advantages of an approach that has worked so well and saved so many taxpayer dollars for 15 years. If there is to be a future for people who require ventilatory



Ira Holland and Concepts' staff meeting with New York legislators

support, it is imperative that we begin to familiarize governments with the proven options and solutions which may help to overcome the mounting legislative opposition to the cost of longterm care as it relates specifically to people who are severely disabled and/or ventilator-dependent.

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MORE ON ATTENDANT CARE CUTS

From Minnesota, Leah Welch of Independence Crossroads, Inc., reports changes in the personal care attendant (PCA) program. Effective July 1, 1995, PCAs must be 18 years or older and they must be able to speak and read English along with the language the client uses. Beginning January 1, 1996, initial assessment and service plans will be conducted by county public health nurses, with care plans still developed by the provider agency. On July 1, 1996, unless other proposals are enacted by the '96 legislature, the number of hours people can receive services are cut 12.5-25% and those who cannot direct their own care are transferred to waived services.

In California, Richard Daggett, Polio Survivors Association, reports that SSI benefits, relied on by many people with disabilities, have been reduced, but that the In-Home Support Services program, heavily used by ventilator users, has not. However, Los Angeles County hospitals are implementing dire and drastic cuts in outpatient clinics. Rancho Los Amigos Medical Center is one of several county hospitals facing possible closure in October unless State monies come through and a Federal waiver is approved.

In Illinois, Larry Biondi, Progress Center for Independent Living, writes "The Illinois Department of Rehabilitation Services (DORS) has *not* denied any new intakes into its Home Service Program. A bill which would have created a two-tier system, in effect exempting people earning above \$614 per month, was abolished. This came thanks to the efforts of Illinoisans with disabilities writing letters, staging protests to Governor Jim Edgar, and visiting state legislators. On August 17, 1995, Governor Edgar signed H.B. 1869 into law. This law increases the hourly wage for personal assistants in DORS Home Service Program to \$5.00, retroactive to July 1, 1995."

SUGGESTIONS FOR AVOIDING RESPIRATORY COMPLICATIONS

by John R. Bach, MD

The best ways to avoid respiratory complications commonly associated with having weak inspiratory and expiratory muscles are: 1) to remove airway secretions, and 2) to maintain normal ventilation around the clock.

Failure to effectively remove airway secretions is the main reason people with weak respiratory muscles develop pneumonia. People who have muscles with normal strength remove airway secretions by coughing. Those who have not destroyed the connective tissue that holds their lungs together by cigarette smoking and who, therefore, do not have irreversible obstructive lung disease, and who have sufficient throat muscle strength to fully open their vocal cords, can cough effectively either by manually assisted coughing or by mechanically assisted coughing with the In-exsufflator (now available through LIFECARE International, Westminster, Colorado).

The In-exsufflator provides mechanical insufflation-exsufflation by delivering a deep breath through a mask covering the nose and mouth. The positive pressure is followed by negative pressure for forced exhalation. This method can also be used through a tracheostomy tube, instead of tracheal suctioning, because it is more comfortable and effective than suctioning. When suctioning routinely, it is next to impossible to get the suction catheter into the left airway for anatomical reasons. Thus, most pneumonias are in the left lung. In-exsufflation does not damage airway tissues, and it is necessary for anyone with throat muscle function for whom manually assisted coughing is not very effective.

It is advisable to have your maximum cough flow measured by an Access Peak Flow Meter (HealthScan, Inc., Cedar Grove, New Jersey). This device costs about \$8. You simply cough through it and measure the flow. If your vital capacity (VC) is less than 1.5 L, cough through it after receiving a maximum deep breath (insufflation). Then cough through it after receiving a maximum insufflation and having someone give you an abdominal thrust. The latter measure is the most important. Anyone who can generate 180 L/min (3 L/s) of cough flow in this manner does not need a tracheostomy tube whether the VC is 3000 ml or nothing at all.

If maximum flows are under 4-5 L/s be certain that you obtain or have rapid access to an In-exsufflator. Do not hesitate to use it every 10-15

minutes around the clock and at pressures from +50cm H₂O to -50 cm H₂O when you have secretions. Your local home care company should be able to obtain one for you within two hours if you develop a cold, need surgery, or have airway secretions for any reason. If you have not had a deep breath in a long time, increase the positive pressure gradually or else a deep insufflation can cause a muscle pull in the chest.

The second part of avoiding respiratory complications is maintaining normal ventilation. Your oxygen saturation (SaO₂) should always be over 94%. This can be measured with an oximeter (new models cost under \$1,000).

People who have been using body ventilators are almost always underventilated, and they should consider switching to the use of nocturnal mouthpiece — lipseal — intermittent positive pressure ventilation (IPPV) or nasal IPPV. Anyone can maintain normal ventilation by properly using these techniques. It is critical, however, that normal ventilation be maintained both during the day and the night. BiPAP® systems are not usually appropriate for people with neuromuscular conditions who need or

who will need aid during the day as well as the night because you cannot take a deep breath (air stack) with a BiPAP® system.

When SaO₂ is below 95%, it means you are underventilated and should be using noninvasive IPPV, *or* you have a mucus plug which needs to be removed by manually or mechanically assisted coughing immediately, *or* you waited too long to remove the mucus plug and you now have pneumonia.

A baseline SaO₂ of 92-94% while maintaining normal ventilation and optimally removing mucus usually indicates microscopic atelectasis. The chest X-ray is usually normal, and the SaO₂ baseline returns to normal by continuing to maintain normal ventilation and by effectively removing mucus. When the baseline is below 92%, the mucus has been left too long, and you may have developed pneumonia or other serious complications which may then become an emergency.

Unfortunately, when one has pneumonia and the baseline SaO₂ is under 90%, oxygen therapy may be necessary, noninvasive inspiratory aids are often no longer effective, and tracheal intubation may become necessary. ***Do not let yourself get into this situation.*** If you cannot avoid being

*Only you
can prevent
your lungs
from
becoming
diseased.*

Continued on page 13

1995 I.V.U.N. DIRECTORY

Longtime ventilator users and health professionals who are experts about and advocates for home mechanical ventilation are listed below. Send additions, deletions, and corrections to I.V.U.N., 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915 USA, call 314/534-0475 or FAX 314/534-5070.

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MECHANICAL VENTILATION AND HOME CARE took root during the 1950s polio epidemics and led to the development of ventilator technology and to new ideas about health care. It was soon realized that respiratory polio survivors were unnecessarily occupying expensive hospital beds when they could live at home with attendants and other support services such as equipment maintenance for one-third of the hospital cost.

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These developments, coupled with increasing recognition of the cost benefits of home care, enable individuals with high spinal cord injuries, ALS, muscular dystrophy, cystic fibrosis, and technology-assisted infants and children to live at home in their communities, rather than in an institution.

Today, advances in positive pressure ventilation and noninvasive forms of ventilation, such as the face mask, have increased the independence and quality of life of longterm ventilator users while at the same time decreased the need for unnecessary tracheostomies.

INTERNATIONAL VENTILATOR USERS NETWORK (I.V.U.N.) is a worldwide network of ventilator users and health professionals experienced in and committed to home care and longterm mechanical ventilation.

I.V.U.N. networks through *I.V.U.N. News*, a biannual newsletter, offering articles on family adjustments, equipment and techniques, travel, ethical issues, medical topics, and resources. Contributors include health professionals and, most important, the true experts — ventilator users themselves.

I.V.U.N. is a forum for ventilator users, pulmonologists, pediatricians, respiratory therapists, ventilator manufacturers and vendors to discuss unique problems of home ventilation and to cooperatively seek solutions.

Although I.V.U.N.'s constituency includes health professionals as well as ventilator users, I.V.U.N. is the voice of the consumer. I.V.U.N.'s goals are to foster a positive image of ventilator use and to affirm the safety and cost benefits of longterm ventilator use at home.

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**SUGGESTIONS FOR AVOIDING
RESPIRATORY COMPLICATIONS** Continued from page 4

intubated, however, continue using mechanical in-exsufflation through the endotracheal tube until baseline SaO₂ goes over 92%. When the pneumonia shows signs of clearing, return to the use of noninvasive IPPV. Do not accept a tracheostomy tube unless the intubation lasts over 2-3 weeks. If you undergo tracheostomy, but still have functional throat muscles, have the tube removed and return to using noninvasive aids. If you absolutely require surgery, be certain that you are returned to your noninvasive aids as soon as you wake up (barring excessive sedative and narcotic use) whether you can breathe or not. The longer you are intubated, the greater the risk of respiratory complications. In other words, you must be prepared for emergency situations, and, if possible, you should prepare your local hospital for such emergencies so that they are familiar with you and with your equipment.

A warning about oxygen therapy: it decreases one's own ventilation, increases blood carbon dioxide (CO₂) levels, and can lead to people stopping breathing completely. It also prevents one from using an oximeter to indicate underventilation and mucus plugs. It should only be used when one requires intensive care.

Only *you* can prevent your lungs from becoming diseased. If throat muscles weaken to the point that maximum peak assisted coughing flows can not exceed 3 L/s and the upper airway is too closed for the In-exsufflator to be effective (such as in people with ALS and infantile SMA), a tracheostomy becomes the only option and invasive management routines can be followed. Polio survivors, people with Duchenne muscular dystrophy, and people with high level SCI who can swallow rarely ever need tracheostomy tubes.

ADDRESS: John R. Bach, MD, University Hospital, Department of Physical Medicine and Rehabilitation, 150 Bergen St., Room B-239, University Heights, Newark NJ 07103-2406. 201/982-4393.

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Potpourri

□ **REPORT ON DOMICILIARY MECHANICAL VENTILATION IN DENMARK**, an excellent report about the status of 110 Danish ventilator users living outside of hospitals, produced by Dr. Henning Sund Kristensen, and nurses Grethe Nyholm and Tove Agertoft Nielsen. The report details the extent of ventilatory needs, level of activity, family and caregiving arrangements, housing, transportation, employment, etc. Copies of the report are available from: University Hospital, Centre for Home Ventilation, Department 7712, Tagensvej 20, DK 2200 Copenhagen N, Denmark.

□ **VENTILATOR REGISTRY PROJECT BY THE AMERICAN ASSOCIATION OF RESPIRATORY CARE (AARC)**. The AARC is seeking requests for proposals (RFP) to develop and manage a register of ventilator-assisted individuals. The registry would include simple data such as age, diagnosis, duration of ventilator use, and location. The AARC hopes to use this information to create another network of individuals and caregivers, develop standards of practice, deal with reimbursement issues, etc. Send RFPs to: Richard Branson, RRT, Department of Trauma/Critical Care, University of Cincinnati, 231 Bethesda Ave., ML 0558, Cincinnati OH 45267-0558. 513/558-5661.

□ **WHITE TRACH CAPS** are available. Amy Kamp of Missouri writes, "For about two years now, I have been wanting a white cap to replace the obnoxiously bright red decannulation plug with twist-lock connector that comes in every package of the Shiley fenestrated tracheostomy tubes. I called the Shiley manufacturer's Mallinckrodt Medical Customer Support Center (800/854-4071). I was told only my home health care provider could order the white caps for me, and that they are slightly more expensive than the red caps."

□ **ACTOR CHRISTOPHER REEVE**, who suffered a spinal cord injury after a fall from a horse in May, remains at the Kessler Institute for Rehabilitation in W. Orange, New Jersey. He is learning how to use an electric wheelchair with a sip and puff device, and getting used to tracheostomy positive pressure. Reeve was sent several issues of *I.V.U.N. News*. Ventilator users who wish to offer Reeve encouragement and support may write to him c/o Kessler Institute for Rehabilitation, 1199 Pleasant Valley Way, West Orange NJ 07052.

LIFE WITH A TRACHEOSTOMY: A PERSONAL DECISION

by Michael Lubber

Tracheostomy. Ventilator. Gastric tube. These are all words that at one point in my life brought a sinking feeling to my stomach and a tear to my eye. With time and education, however, these words have come to mean a new lease on life and a better quality of living.

Genetic testing to determine the exact type of muscular dystrophy I have was inconclusive, but suggested I have some type of either Becker's or limb girdle. In January 1992 I learned I was underventilated, and this discovery led to a long series of life-altering decisions ultimately culminating in decisions to accept a tracheostomy tube and a gastrostomy tube in March 1994.

For more than a year, I used a BiPAP system[®], and managed to put the thought of tracheostomy and full-time ventilation out of my mind. But I was not breathing well enough and I had begun to lose weight. To me, the picture of a ventilator user with a tracheostomy connoted someone unable to leave the house, unable to speak, and with a poor quality of life. I had difficulty picturing myself wheeling around with a ventilator on the chair and this big tube coming out of my neck. Also, as a psychotherapist, I have come to realize how obvious my disability is and what an important role it plays in therapy. Thus I was very concerned about how another obvious contraption would affect therapy.

Many of these fears began to shatter when I attended a muscular dystrophy telethon. I struck up a conversation with a woman about my age, and during the course of the conversation was surprised to learn that she had a tracheostomy and used a ventilator. She was far from my image of a ventilator user. She talked normally, had a scarf draped around her neck and shoulders disguising the tubing, and I did not hear or notice the ventilator on the back of her chair. As she revealed the many pitfalls and advantages of life with a tracheostomy and ventilator, I realized that here was a very independent and productive woman.

The months rolled by and my weight continued to decrease. I noticed that I was not feeling as good as I wanted to feel. I did not have the energy that I needed to be as productive as I wanted to be. I decided that the safest medical procedure would be to have both a tracheotomy and gastrotomy performed at the same time. Because I feared the surgery, I talked with several doctors to find the best and safest use of anesthesia, and was reassured. I also feared the hospitalization, but was informed that I would be on a CCU floor, strictly monitored, with one nurse for every two patients. As for the inability to communicate, I researched some technological

devices. I was told that I would not be able to talk for the first two days after the operation, and would need some way of getting the nurses' attention. I discovered a beeper system that can be attached to one's forehead which can be triggered by a simple raising of an eyebrow. Although this was quite sensitive, it actually did a terrific job in letting my needs be known.

After the operation, I discovered that I had worried much about nothing. The operation was the easy part: I had taken a nap and awakened with two extra holes in my body. After the first two days, I was able to talk, thanks to the Passy-Muir Tracheostomy Speaking Valve.

The recovery was much more a slow and difficult process, both emotionally and physically. I and my family soon realized that we were unprepared to take care of the extra medical needs. We

needed extra nursing and support care, and it was difficult because I had several different individuals taking care of me who were all learning the procedures for what needed to be done. I was not used to the lack of privacy, and there were many times when I just wanted to be left alone. As the weeks passed, I began slowly to gain weight and to feel stronger.

I was in conflict with the doctor's urges to try to wean from the ventilator. I was able to have free time from the ventilator for a few hours, but during that period I was very tired. I found I was just sitting and watching television and not doing anything. I realized that I would rather have energy and use the ventilator longer in order to be more productive and feel good. I resolved that I was not going to be able to wean myself free of the ventilator.

For me, the advantages of tracheostomy, gastrostomy, and ventilator are: increased energy; increased appetite and weight; decrease in stomach and bowel problems; normal speech, easier swallowing, and less fear of choking, because of the Passy-Muir Speaking Valve; and normal oxygenation.

The disadvantages are: suctioning; risks of infection; round-the-clock attention in case a tube becomes disconnected (a baby intercom is helpful); trach care and cleaning.

Once I started feeling better, I was frequently asked, "Aren't you happy you had the surgery?" I did not know how to respond. Finally I found the right response: "No, I am not happy about the surgery. I do not think anyone could be happy about having surgery. I do, however, feel I made the right medical decision, and if I had to make the decision again, I would make the same choice."

ADDRESS: Michael Lubber, 6920 N. Barnett, Milwaukee WI 53219.

*After the operation,
I discovered that I
had worried much
about nothing.*

IN-HOME CARE STANDARDS FOR FREQUENCY OF VENTILATOR TUBING CHANGES

by Teri Nikolai Wilson, RRT, RPFT

The frequency of ventilator tubing change in hospital and critical care settings is a topic often discussed by respiratory therapists, because of the large cost factor. Clinical practice guidelines published in 1994 by the American Association for Respiratory Care state that ventilator tubing may be changed ≥ 5 days in the hospital setting only. As a pediatric respiratory therapist involved in discharge planning and family instruction for the past 13 years, I wanted to know if tubing in the home could be safely changed less often. When I could not locate any articles or studies that covered ventilator tubing changes in the home care setting, I began a search for information and sought out people with the most experience in this area.

First, using Aequitron's respiratory health professionals network, I surveyed other therapists and clinicians and found everyone recommended different intervals, the most common answers being weekly and every 2-3 days.

Second, I surveyed *I.V.U.N. News* readers — the real experts. Overwhelmed and delighted by your responses, I learned that despite the variety of techniques for home ventilator tubing care and frequency of changes, each individual's methods worked well for him/her. Of 143 responses, 48% of the respondents use invasive ventilation; 52% use noninvasive ventilation. Many ventilator users prefer permanent circuits, which in the long run, present a considerable cost savings compared with disposable tubing. Cleaning solutions for the permanent tubing ranged from vinegar solutions to Control 3, a commercially available disinfectant. The life of the tubing is dependent upon the lifestyle of the user. Ventilator use only during the night enables the tubing to last much longer than ventilator tubing that is "on the go." For many ventilator users with a tracheostomy, the tubing is usually changed every 2-3 days or weekly. For noninvasive ventilator users, tubing changes occurred at many different intervals, with no common practice.

The third phase of my plan is to design a clinical study to document the safety of less frequent tubing changes in the home. *I.V.U.N. News* readers will be hearing from me again. My thanks to all of you who participated in the survey.

ADDRESS: Teri Nikolai Wilson, RRT, RPFT, The Children's Medical Center, 1 Children's Plaza, Dayton OH 45404-1815. 513/226-8300, pager #508.

VENTILATOR USERS NEEDED FOR TRANSITION STUDY

The Beach Center on Families and Disability* at the University of Kansas is conducting a study of the transition experiences of adolescents between 14-21 years of age who rely on medical technology (ventilators, feeding tubes, etc.). The goals of the study include recommendations for policy change and creation of a service delivery model designed to better meet the needs of adolescents as they make the transition from school to higher education or the community.

The first phase of the study is underway and consists of personal interviews with students using medical technology. Interviews will continue two to three times annually for the next two years. These interviews focus on health care and life planning issues, needs, barriers, supports, and roles of advocates and supporters. Transcripts of these interviews will be analyzed to identify common issues faced by these individuals.

Young men and women between the ages of 14 and 21 are needed for completion of the second phase of the study which is a survey that will be prepared based on the information received from the interviews in the first phase. The surveys will be mailed in 1996.

If you are interested in participating in this study, please contact Rebecca Moberly by telephone, 913/864-7602, or by e-mail at Rebecca@dole.lsi.ukans.edu.

**The Beach Center on Families and Disability is funded by the University of Kansas, private donations, and the National Institute on Disability and Rehabilitation Research to serve as a Rehabilitation Research and Training Center.*

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**Recent professional articles of interest to I.V.U.N. News readers, arranged in order of most current publication date.*

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A SUMMER PLAGUE: POLIO AND ITS SURVIVORS

by Tony Gould
Reviewed by Judith R. Fischer

British journalist Tony Gould contracted polio in 1959 at the age of 20, and, in *A Summer Plague: Polio and Its Survivors* (Yale University Press, 1995, \$30), tells the fascinating and often compelling story of polio. This eminently readable book is a wonderful blend of the medical, social, and political history of poliomyelitis as it occurred in the 19th and 20th centuries in Europe and North America.

Gould does an excellent job of pulling it all together. We read about the early epidemics in New York City, about the early theories of how the poliovirus was spread. We read about FDR, and Warm Springs, and the evolution of the National Foundation for Infantile Paralysis into the March of Dimes. We read about the race for a vaccine and the rivalry not only between Drs. Salk and Sabin, but between other scientists as well. We read about the controversial Sister Kenny in her "Lord Nelson hat." We read how Gini Laurie alerted the world to the late effects of polio (and for this reader who worked with her, it was most gratifying to find her accurately portrayed and given due credit for her achievements). We read poignant personal accounts of British and American polio survivors. A number of rare photographs that are most intriguing further complement the book.

A Summer Plague is well worth the price, and I would urge every polio survivor to read it; it places each survivor's story within a larger con-

text. As Tony Gould says, "I have learned that however impressive a recovery you make, you don't 'conquer' or 'overcome' polio. You merely adapt to the limitations it imposes and — if you're fortunate — discover within yourself resources you might not otherwise have found."

Calendar

FROM SNORING TO SLEEP APNEA SYNDROME: THERAPEUTIC APPROACH, November 9-10, 1995, Eurexpo, Lyon, France. Contact A.D.T.S.A.S., S.R.M.R./ Hopital de la Croix Rousse, 93, Grand Rue de la Croix Rousse, 69317 Lyon Cedex 04, France.



VENTILATOR ASSISTED CHILDREN'S CENTER (VACC) CAMP, April 9-15, 1996, Miami, FL. Contact: Cathy Klein, VACC Coordinator, Miami Children's Hospital, 3200 S.W. 60th Court, Suite 203, Miami FL 33155-4076. 305/662-8222 or FAX 305/663-8417.



EXPLORING BREATHING SUPPORT OPTIONS: CHOICES — TECHNOLOGY — INDEPENDENCE, April 23-24, 1996, Toronto Congress Centre, Toronto, Ontario, Canada. Contact: Citizens for Independence in Living and Breathing (CILB), 78 Golfwood Heights, Toronto, Ontario M9P 3M2. 416/244-2248.