

**NONINVASIVE VENTILATION: A SUCCESSFUL CHANGEOVER**

*by Tedde Scharf*

*I.V.U.N. News readers first met Tedde Scharf, who has limb girdle muscular dystrophy, through the Fall 1993 issue with her article "Advice for the new ventilator user." A trach positive ventilator user since 1988, Tedde later wrote "Considering a change to noninvasive ventilation" for the Spring 1994 issue of I.V.U.N. News.*

On March 1, 1995, I traveled from my home in Tempe, Arizona, to HealthSouth Dallas Rehabilitation Institute (DRI) in Texas to have my trach removed. The much anticipated trip had never materialized during a long three year battle with the HMO insurance system in Arizona. In early 1995, my physician, Dr. Franklin Preiser, successfully convinced the new carrier, Blue Cross/Blue Shield, of the medical necessity for pursuing non-invasive ventilation due to a chronic, intractable trach infection. Blue Cross/Blue Shield supported the well-documented noninvasive ventilation method as a viable one for me. They negotiated a cost package with DRI for all medical expenses, however, I was responsible for transportation.

The primary medical team at DRI included Randall Rosenblatt, MD, Joseph Viroslav, MD, Shelley Morris-Tomazevic, RRT, and Wilma Breau, RRT. For 14 years, this medical team has applied and improved noninvasive ventilation techniques to help more than 200 hundred individuals make successful transitions.

Upon arrival, I expected to be suctioned, but a respiratory therapist informed me, "We don't believe in suctioning at DRI." Fleetingly, a sense of panic came over me. However, the therapist quickly taught me to clear secretions. He reclined my wheelchair to elevate my feet above my head, disconnecting my trach, and used the ventilator tube with a mouthpiece to enable me to take in large volumes of air while he applied a Heimlich-type thrust up and under the diaphragm. This technique caused the mucus to shoot up and out of my lungs.

I was amazed at how quickly the secretions in my lungs dried up when the suctioning stopped. Within half a day of my arrival at DRI, I had no significant secretions, just a normal clearing of the throat in the morning. I learned to use large volumes of air to stretch and expand the lungs

which helps prevent atrophy and calcification of lung tissue. Air stacking helped me generate my own cough. Within 24 hours, I was fitted with a custom-molded Lyon nasal mask for night ventilation and a pneumobelt for day-time ventilation.

Daily I kept asking Dr. Rosenblatt when the trach would be removed. He was surprised at my eagerness to give up the security of the trach. The transition process includes careful evaluation of patient readiness before removing the trach. My blood gases were carefully monitored, as was my heart for stress. The team discussed my daily routines, caregiver system, and activities at work and home. Finally, on the third day, ahead of schedule, the trach was removed, and I relied on intermittent mouth positive pressure, the pneumobelt, and the nasal mask.

Back home in Arizona, the stoma refused to close completely, and, six months later, it was closed surgically by the same surgeon who had performed the tracheotomy eight years earlier. This certainly helped improve my speech.

The only drawback during the transition was the length of time it took to synchronize speech with breathing. While trached, I had learned to speak on inhalation and exhalation. Retraining myself to speak only on expiration was a challenge.

In October 1995, Bill Altaffer, a good friend and ventilator user, the Muscular Dystrophy Association, Carondelet St. Mary's Hospital, and I coordinated two half-day workshops in Phoenix and Tucson on "Innovative Approaches to Respiratory Health Care: Noninvasive Assisted Ventilation." The DRI team, John Bach, MD, from the University of Medicine and Dentistry of New Jersey, and local speech therapists were guest presenters. They

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provided hands-on demonstrations to Arizona health professionals and interested ventilator users and lay people on coughing techniques and the In-exsufflator machine, the Lyon mask, the pneumobelt, and frog breathing (glossopharyngeal breathing).

For years, I had tried unsuccessfully to learn frog breathing. Returning from the Phoenix workshop that evening, I met my neighbor who is a master at glossopharyngeal speech due to a laryngectomy after throat cancer. As I tried to demonstrate what I had observed at the workshop, my neighbor began to use the technique to talk to me. Suddenly, it clicked, and, Presto! I was frog breathing.

The final test of my new breathing methods would be the ability to deal with a respiratory infection. Unfortunately, I had that occasion this past winter when I contracted a serious viral infection which turned into bronchitis. Although I required several days of hospitalization, the new breathing techniques worked well. The medical staff, from the emergency room to the respiratory floor, were fascinated by noninvasive ventilation.

In conclusion, the transition to noninvasive ventilation has meant the end of chronic infection and suctioning, decreased cost, and less dependence on constant personal care and, therefore, greater independence. For me, noninvasive ventilation has made all the difference.

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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 home mechanical ventilation.*

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## **PASSEY-MUIR VALVE HELPS WEAN FROM TRACHEOSTOMY**

*Mary Koch's husband John Andrist suffered a brain stem stroke in December 1993 which left him completely paralyzed, although he continues to recover some limited movement. Until December 1995, John had a tracheostomy tube, not because he needed a ventilator, but because of his inability to protect his airways when swallowing.*

*The Passey-Muir Tracheostomy Speaking Valve is a simple device invented by David Muir who had Duchenne muscular dystrophy and wanted to speak with a tracheostomy. The valve fits on the opening of the tracheostomy tube. One breathes in normally, then the valve closes and air is forced up through the vocal chords to create speech. It may not give stroke patients instant speech, but they can use it to begin weaning themselves from the trach.*

*Mary and John are co-publishers of The Omak-Okanogan County Chronicle in central Washington state. Since the stroke, Mary has written a weekly column, "Surviving the Stroke," about John's progress. The following is excerpted, with permission, from her column of November 1, 1995.*

"... When it comes to removing the trach, we've learned one thing for sure — nobody seems to know for sure when it should go or what the results will be. We're pretty certain John is about ready to remove the trach, but we're determined to err on the side of caution. After 22 months, the cold turkey route is too scary.

"We'd heard about the Passey-Muir valve, but didn't have a lot of information. Even so, John was certain it was the way to go. His librarian daughter, Jean, was cruising the Internet one day and came up with detailed information on it. That was all we needed.

"John first tried the valve about three weeks ago. I was hoping he'd be able to tolerate it for five minutes. He kept it on for 45 minutes. Now he wears it 10 or more hours a day.

"With air going past the vocal cords, John is able to make some sounds. For the most part, he has to evoke an emotion, such as sadness or laughter, to get a sound going. It is common for stroke patients to express emotion more readily (it's called lability), so John has ample opportunity to sound off . . .

"Thanks to the Passey-Muir valve, John has begun to work on the rudiments of making sounds. Talking is a long way off, but I agree with him that he'll get there. It is sad that when he finally does, he will not be able to say 'thank you' in person to David Muir. David died in 1990 at the age of 28. . . ."

**ADDRESS:** John Andrist & Mary Koch, P.O. Box 3346, Omak WA 98841.

## NEW DANISH CUSTOM NASAL MASK

Thomas Kaiser, of Kaiser Orthopaedi in Frederiksberg, Denmark, is both a physiotherapist and prosthetist/orthotist (CPO). Since 1989, he has developed and made nasal masks for use with PLVs, PVVs, CPAP, and BiPAP® systems in close collaboration with the Home Ventilation Centre at Copenhagen's University Hospital. Kaiser has made more than 150 masks for both children and



Figure 1

adults; his smallest mask was made for an almost-two-year-old boy with muscular dystrophy.

Kaiser works closely with ventilator users to improve the mask's function. He has recently introduced a casting kit that enables

a plaster cast to be made locally, after which the cast is sent to him for manufacturing of the mask. The prescribing physician/department orders a casting kit which includes a detailed casting manual and everything necessary for the casting procedure. The cast is sent to Kaiser who then makes the mask and sends it, with instructions and users manual, approximately 3-4 days after receipt of the cast. The price of a custom nasal mask is about \$550 (USD) with 15% discounted if more than one mask is ordered at the same time.

The mask is made of allergy-tested acrylic mate-

rial. The excellent fit of Kaiser's custom nasal masks prevents sores, and the wearer can turn freely in bed with no leakage. The wearer can also use eyeglasses, read, and watch television with the mask on. The mask lasts longer than most pre-manufactured standard masks, and a one-year guarantee against normal use breakage is offered.

Kaiser has also developed a new type of head-gear that can be seen in the accompanying photos. His masks can include special features, such as a nourishment

probe (Fig. 1.). The mask in Fig. 2. shows the tubes turned downward, a request from several users.

Bud Blitzer, long-time mask wearer who compiled *Directory of Sources for Ventilation Face Masks*, is experimenting with the Kaiser mask.

Regrettably, he reports problems with leakage and having to adjust the mask each time it is worn. However, this is the first use of the casting kit in the U.S., and Blitzer is confident the problem lies in the casting method rather than the mask itself.

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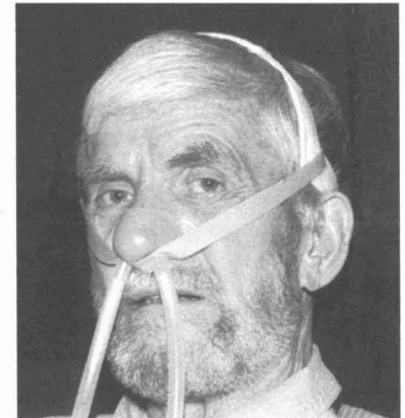


Figure 2

## TRACHEAL TOILET AND SPEECH

Stewart A. King, MD, discussed suctioning techniques and adapters in a letter to the editor of *Chest*, reprinted with permission in *I.V.U.N. News*, Fall 1995. Dr. King, a ventilator user due to ALS, had published an original article, "The tracheotomized patient: tracheal toilet and speech," in *Clinical Pulmonary Medicine*, November 1994. More on Dr. King's methods are discussed in the same journal in the March 1996 issue. Reprints of both are available by writing Dr. King in care of I.V.U.N., 4207 Lindell Blvd, #110, St. Louis MO 63108-2915 USA.

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## FROG BREATHING: STILL USEFUL, STILL LIFESAVING

by Judith R. Fischer

**F**rog breathing, the common term for glossopharyngeal breathing (GPB) because of the frog-like gulping technique, has been used for centuries by deep sea divers in order to fill their lungs with reserve air just before diving. During the polio epidemics of the 1950s, respiratory polio survivors accidentally taught themselves to use GPB, and Rancho Los Amigos Hospital under Clarence W. Dail, MD, in Downey, California, became the leading respiratory center for GPB use. GPB enabled a person to produce adequate ventilation without the use of equipment. Many polio survivors still use it during equipment emergencies, and as a way to stretch the chest and aid coughing. GPB can also be taught to individuals with spinal cord injury.

Basically, the mechanism of GPB is the same as that of a pump: the tongue and the throat act as a piston, and the mouth, soft palate, and larynx act as valves, resulting in an expansion of the lungs as air is pumped into them. Canadian polio survivor Gary McPherson describes the technique thus: "Frog breathing involves the use of the throat and posterior tongue muscles to hold the breath once you have taken it. A vital capacity three to four times the tidal volume can be achieved with frog breathing.

"You take a breath through your nose or your mouth, then hold your breath and add to it with gulps of air. I start by taking a neck breath with my accessory muscles. I get about 150 cc of air in my lungs and then I hold it. Next I open my mouth and draw my tongue and throat muscles down to allow air to enter my throat. Then I close my mouth and force the air down my throat with my tongue and throat muscles while I hold my breath. I call this inspiration of air a stroke, and I get about 50-75 cc of air into my lungs with each stroke. Since my average breath is about 800 cc and I started with 150 cc from the neck breath, I need about ten strokes per breath. Sitting and talking I need about eighty breaths per minute. . . . Only when I have taken several strokes do I release my breath. It takes a lot of practice, and your throat and tongue muscles need to be active. . . .

"Frog breathing through the nasopharyngeal airway is very similar except you draw air in

through your nose instead of your mouth. However, the stroke volume is somewhat reduced. The advantages of frog breathing through the nose are that it provides natural humidification, it eliminates the dryness of the mouth, and aesthetically it is less obvious to the people around you. The muscles used in frog breathing need to be exercised regularly to gain strength and efficiency."

Augusta Alba, MD, who has helped many people learn frog breathing at Goldwater Memorial Hospital in New York, suggests one start by saying, "gup." The "g" puts the ball of the tongue in the proper position to push a bolus of air into the pharynx. Then the "p" closes the lips while the tongue relaxes in the floor of the mouth. "gup" should be said repeatedly about 100 times per minute with a pause every 15 seconds to exhale. If there is enough air in the lungs, the air expired at the end of a series should last 15 seconds. Dr. Alba's frog breathing studies show that effective use of the technique permits a more effective cough, improves lung compliance, allows more normal speech, decreases lung infections, and, of course, reduces dependence on mechanical assistance.

Audrey King, polio survivor and frog breather, says, "Those who have reduced capacities may find it a little harder to learn glossopharyngeal breathing because they guard the air they have and don't relax their chests to allow air in. Also, if you say "gup" you need air coming out of the lungs to voice the word, and that's the opposite of what you're trying to do, so it gets a little confusing. . . . It takes about eight or so successful "gups" before you can feel your chest expanding and know that you're doing the right thing, but once you get this feedback, you really are on to it.

"I think the best way to teach somebody is by having that person imitate the cluck sound that you make in the back of your throat. Then once you're copying the cluck sound, if you form the word "gup," but don't actually voice it so that you have the lip and mouth movement, you can feel the air going in fairly quickly. Frog breathing can be done anywhere, anytime. It is great for fatigue, for coughing, and for getting a deep breath."

Randy Haims, C-2 quad, learned frog breathing from a polio survivor while he was in a rehabilitation hospital following his accident. He did not use it consciously until about eight months later when he suddenly found himself doing it automatically. Haims asked his attendant to plug his trach, and frog breathed for about 25 minutes. He

"Frog Breathing with Gary McPherson," a 12-minute video, is still available from University of Alberta, Health Science Media Service, OJ1 Mackenzie Health Science Center, Edmonton Alberta T6G 2R7 Canada. 403/492-6560 or FAX 402/492-7303. Cost is \$50 Canadian.

eventually worked his way up to almost two hours of frog breathing time. For Haims, the disadvantages are dry mouth and fatigue; he prefers to neck breathe.

Frog breathing is not easy to learn for some people; perhaps the best way is to watch another person "frogging." John R. Bach, MD, of the University of Medicine and Dentistry of New Jersey, who also helps people learn to frog breathe, advises, "Frog breathing should be monitored by regular measuring of the volume of air per gulp and the number of gulps per breath. Many people are successful at it, but do not realize it."

Once learned, frog breathing can provide valuable minutes of air during ventilator breakdowns or other emergencies. Gary McPherson states, "a person can rest comfortably knowing that he is ultimately dependent on himself, not on a machine."

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### **PULMONARY REHABILITATION: THE OBSTRUCTIVE AND PARALYTIC CONDITIONS**

*Edited by John R. Bach, MD*

Of primary interest to *I.V.U.N. News* readers is the second half of *Pulmonary Rehabilitation: The Obstructive and Paralytic Conditions* (Hanley & Belfus, Inc., 1996, \$69.95). "The Paralytic/Restrictive Conditions" by John R. Bach, MD, Vice Chairman of the Department of Physical Medicine and Rehabilitation, the University of Medicine and Dentistry of New Jersey, covers conditions seldom discussed in other medical texts. Dr. Bach is to be commended for his thorough and comprehensive treatment of neuromuscular ventilatory failure and its medical management. A compelling feature of the book is the numerous photographs of ventilator users and their panoply of masks, mouthpieces, and adaptations. Dr. Bach concludes appropriately with a discussion of quality of life and ethical issues. An excellent resource for pulmonary rehabilitation health professionals and anyone else interested in longterm mechanical ventilation.

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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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## DANISH OBSERVATIONS ABOUT AMERICAN VENTILATOR USERS

by Grethe Nyholm, RNP, and Henning Sund Kristensen, MD

*Goldwater Memorial Hospital on Roosevelt Island in New York City and Rancho Los Amigos Medical Center in Downey, California, were visited in September 1995. Both have a long and reputable history, and are highly esteemed in respiratory rehabilitation circles around the world. Augusta Alba, MD, in New York and Judith Raymond Fischer in Los Angeles had made excellent preparation for our visits, and gave valuable help during the stay to ensure the collection of extremely useful information.*

Some American ventilator users have been hospitalized for several years, undoubtedly due to shortage of funds in the social system. The conditions for these users are not much different from conditions of Danish ventilator-assisted patients who were hospitalized at Blegdam Hospital in Copenhagen in the late '50s. For obvious reasons, continuous hospitalization is not the optimal solution, though it might be accepted eventually by the users.

To us, the size of the nursing staffs of the patient wards in the U.S. seemed small, but the number of different specialties seemed high. One example of a group not seen in Scandinavia is respiratory therapists; their functions are carried out by others.

The level of noise in the wards, for instance, by ventilator alarms seemed loud to our Scandinavian ears, especially in New York, but it did not seem to bother anyone else. Personal alarms activated by the ventilator users are less frequent in America than in Denmark where they often replace the automatic alarm devices.

We were much impressed by the families of the ventilator users we met. They were ready and prepared to carry heavy burdens to support a disabled member. That was true especially for the mothers fighting with so much energy for their children. It is not hard to realize that such burdens might destroy or damage family structures and understandable that many families cannot even consider living with a family member using a ventilator. The alternative: to establish an existence independent of the family and the nursing home or the hospital is natural for adult persons but most often completely out of the question, especially for persons without means.

Extremely admirable efforts are taken by the different supporting groups and networks. Their goal is to help the users and their families, whereas the activity of corresponding Danish groups

is more directed towards influencing public opinion, legislation, and administration of the social system.

The independent living concept we encountered in New York stresses that the user should be responsible for attendant care. We do not quite understand why the attendants are not allowed to work outside the borough, to drive the car of the user, or to sleep at night provided adequate security measures can be taken. In our opinion, the Danish helper system meets the needs of people who are severely disabled, including ventilator users, in a better and simpler way. However, the provision of attendants as an isolated measure is rarely enough to make independent living possible for ventilator users.

It was most interesting for us coming from a country almost without private hospitals to meet E.A. Oppenheimer, MD, an outstanding specialist



**Dr. Kristensen, Nurse Nyholm, ventilator user Todd Tostado and his mother Karen, in Los Angeles**

in respiratory rehabilitation who works at Kaiser Permanente in Southern California. Many ventilator users might benefit from a short and effective period of hospitalization with examinations and treatment as practised at private hospitals. But the most important factor for ventilator users is the daily existence outside the hospital depending

mostly on the public social system, at least if the user has no or few means. The Danish social system is better fit to meet the needs of the ventilator user than the American, but it is sometimes a bit slow and possibly could be improved if it engaged itself earlier and more completely in the specific problems of ventilator users. Maybe it would be wise to send people from the Danish social service abroad, too, to obtain new inspiration about domiciliary mechanical ventilation. From what we saw and heard, we do not feel tempted to recommend the introduction of a private insurance system in Denmark instead of or even as a supplement to the present system.

There is one specialized nursing home in Denmark for the very few ventilator users who are unable to manage an independent household, or who do not want to do so. The institution was established in the late '50s and is no longer up to modern standards. Irene Gilgoff, MD, chief of pediatrics at Rancho Los Amigos Medical Center, mentioned group homes in the greater Los Angeles area, each with 4-5 young ventilator-

assisted adults living together without their families. They might be a model for us when our old institution must be updated.

About 60% of all ventilator users in Denmark over 20 years old are living alone in their own households. This is maybe not the very best option for all of them; neither is it the least expensive solution for the community. Therefore, other options might be considered, perhaps also a kind of group home, remembering that the needs and wishes of ventilator users are not more uniform than those of the rest of the population.

We learned a great deal, most of all about the American openness and readiness to share experiences with foreigners. It is really, as many other things in America, worthy of imitation.

**ADDRESS:** Grethe Nyholm, Head Nurse, Center for Home Ventilation, Dept. 7712, University Hospital, Tagensvej 20, DK-2200 Copenhagen N, Denmark. (Dr. Kristensen and Nurse Nyholm, along with Nurse Tove Agerskov Nielsen, authored *Report on Domiciliary Mechanical Ventilation* in Denmark, published by Muskelsvindfonden, in 1995. The report is available on request.)

## I.V.U.N. DIRECTORY UPDATE

*This update is a companion to the Directory published in I.V.U.N. News, Fall 1995, Vol. 9, No. 1. Corrections and changes are underlined.*

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## ON HOLIDAY AT NETLEY WATERSIDE HOUSE

by Anne Isberg

The Kevin Black Centre at Netley Waterside House is in Southampton, on Southampton Water. The building itself is 20 years old, and four large flats have been prepared for people with severe disabilities, especially ventilator users with extensive respiratory equipment. The brain-child of Dr. Geoffrey Spencer, O.B.E., who recently retired as head of the Lane-Fox Unit at St. Thomas' Hospital in London, The Centre is operated by REFRESH (Resort For Responaut's Seaside Holiday), a registered charity which subsidizes the cost and plans activities. The cost is about \$1,000-2,500USD per week depending on one's financial situation; REFRESH does subsidize some of the cost.

The Centre is an essential link in the care chain of hospital, convalescence, home care, and respite care for ventilator users and their families in the United Kingdom and Europe. Its close connection with Lane-Fox enables it to borrow equipment at three hours notice. Because many of the guests are physically disabled, they have access to the use of a POSSUM unit, a computer which switches facilities on and off, so the telephone, television, radio, and other devices can be operated independently.

I had learned of The Centre during previous visits to London, and at this stage of my life, I wanted to try to be entirely on my own. REFRESH agreed to accommodate me for two weeks in the Fall of 1995, after my needs (as a respiratory polio survivor and ventilator user) were evaluated and after recommendations from my physician. The drive from London took approximately two hours, and I was delivered and then abandoned as I wished to be.

The REFRESH staff consists of nurses, trained caregivers, and domestic personnel. Mrs. Cecilia Connolly, formerly with Lane-Fox, is operations manager. The staff is experienced, motivated, and willing to fulfill each guest's individual needs. Many had worked at Netley for several years. The general attitude was very kind and friendly. Several of the Trustees from REFRESH came to The Centre while I was there. They took great interest in every concept for the place and made great effort keeping the place running according to the guests' satisfaction.

My flat was one of the smaller ones but still well above 50 square meters. It had a bathroom big enough for a wheelchair, and a ceiling hoist that went from my wheelchair to the bed to the tub and ended over the lavatory. There was a bed with a mattress according to my wishes with an electric headrest. In addition, there was a tea kettle, china, refrigerator, television, telephone, intercom, alarm, POSSUM, couch, table, chairs, and plenty of extra space. There were double doors out to the garden that were wide enough to wheel the bed through.

My windows were facing the garden and the water, and I could watch the ship traffic to the busy Southampton water.

I was served tea at around 8 a.m., then had breakfast in bed at nine or had my breakfast kept aside. Most days I was ready to face the world by 11 a.m. This could vary according to available staff. Several staff members were on sick leave when I was there, but because the remaining staff was overworked at times, the guests took turns getting up either earlier or later. On the whole, the staff was large and when I was being assisted in the morning, I had eight different people helping me. I had to be very alert all the time to remember everything. There never was any routine.

One can choose to stay in one's flat or to socialize. My days were spent reading and writing. I went for "walks" on my own wheels, shopping in the village of Netley. Many friends and acquaintances visited. I never found time to join any of the offered excursions in the afternoon, but I did manage a visit to the theatre in Southampton. I also joined the entertainment in the evenings.

Meals can be served in the flats or in the common facilities where staff is available to cut food or help feed people. I ate dinner in the dining room. Everything was served for me and, when needed, my food was cut for me. I usually went to bed at 9 p.m. so the evening staff could help me, and then watched television. The evening shift was larger than the night shift (only two persons on duty).

I made a few contacts with other guests, but it was the beautiful nature and garden with its flower beds and trees, not to mention all the birds, that I enjoyed the most. The paths in the garden were paved and a small platform was constructed close to the water.

After almost two weeks, I left. It was nice to return to my daily routine, but with new inspirations and "charged" for the oncoming winter. In the future, I plan to use Netley as a backup for care, if I would suddenly get a vital shortage of attendants or if I am temporarily down. For Americans where it so often is a spouse that is providing the attendant care, I think it would be ideal either for them to enjoy a relaxed time together or where the partner who is disabled could stay while the spouse enjoys a break.

**ADDRESS:** Anne Isberg, Castbergsvej 20-b, DK-2500 Copenhagen Valby, Denmark.

**Ed. Note:** For complete information about holidays at The Kevin Black Centre, write Netley Waterside House, Victoria Rd., Netley Abbey, Southampton SO3 5FA England.



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## NEW YORK'S CONSUMER-DIRECTED HOME CARE PROGRAM: CHAPTER 2

by Ira E. Holland

*President of Concepts of Independence, Inc., a provider of consumer-managed home care programs in New York City, Ira E. Holland wrote about Concepts' successful efforts to persuade the legislature to save and expand its programs in I.V.U.N. News, Fall 1995, Vol. 9, No. 2. Concepts worked with the Department of Social Services to develop regulations enabling a promotion of the program's expansion, and entered into negotiations with ten counties to initiate Consumer-Directed Personal Assistance Programs. The following is the latest chapter in Concepts' battle with the bureaucracy.*

As with life, nothing in politics travels in a straight line. While we were busily implementing the positive and hard-fought changes of 1995, the 1996 New York State budget was introduced, confronting us with a multitude of new challenges.

Among the new threats to our program are Task-Based and Fiscal Assessments. Task-Based Assessment is a new method of assessing service needs which considers only the specific "nursing" tasks a ventilator user/consumer may require, without considering those service needs which enable people with a severe disability to live with dignity in their own homes. Fiscal Assessment is more serious. It is a financial comparison of a ventilator user's home care program to the community's average nursing home expense. Last year, Concepts' clearly demonstrated the savings gained from home care. From our perspective, the consumer's direct management of their own home care environment creates a unique dimension in their activities of daily living, which cannot be duplicated in an institutional setting that relegates the consumer to the position of a passive (mindless) recipient of service.

Also in the 1996 budget, Governor George Pataki has proposed the exclusive use of block grants to fund the Medicaid home care system. This proposal would give the local counties full and autonomous control over the home care program, without the protection of centralized state standards.

Finally, the budget would enable the state to automatically cut Concepts' operating budget by 20%, a cut Concepts could not possibly absorb given Concepts' significantly cost-effective 3.8% administrative overhead, and would permit the counties to utilize the funds they save to fund unrelated county programs.

Obviously we will continue our struggle to maintain the viability of Concepts' 1996 program by recommending that the Consumer-Directed Personal Assistance Program be exempt from Task Based and Fiscal Assessments because they are inconsistent with the objectives of the program which is to empower consumers to live independent dignified lives. We are also informing the State of our concerns regarding the block grant

proposals, by advocating the protection of the mandate to expand the Consumer-Directed Personal Assistance Program, by opposing the proposed 20% cut, and by recommending that savings be applied to the expansion of our program's initiatives.

At this writing, I am uncertain about the outcome of our legislative recommendations, but there is no doubt that Concepts will pursue the resolution of any assaults or confrontations that would compromise or destroy our programs. I strongly believe that the state, and indeed the whole country, will benefit from the maximization of self-directed home care programs for people with severe disabilities. Our statistics clearly illustrate that the cost of institutionalization far exceeds the cost-effectiveness of Concepts' programs. The economic realities must prevail.

ADDRESS: Ira E. Holland, President, Concepts of Independence, Inc., 120 Wall St., Suite 1010, New York NY 10005. 212/293-9999.

### **UPDATE: HCFA VENTILATOR POLICY**

In *I.V.U.N. News*, Fall 1993, readers were advised that the Health Care Financing Administration (HCFA), the agency charged with administering Medicare and Medicaid, was in the process of revising and rewriting many policies, some of which might affect reimbursement for multiple ventilators. A group was convened to create a national policy under which multiple ventilators would be reimbursed. Now, almost three years later, the group is still at work on a national policy statement for the insurance carriers to follow to replace the current regional guidelines. Once again, *I.V.U.N.* thanks its readers for their comments about the multiple ventilator reimbursement issue.

## Creative Writing Guides ...

*Write Now: Maintaining a Creative Spirit While Homebound and Ill* by Susan Dion, PhD, is a 90-page guide on the many benefits of writing when one has a longterm illness or disability. Numerous exercises and ideas are suggested to nudge a beginning writer along. To obtain a copy, send a self-addressed, stamped (one 32¢ and four 23¢ stamps) 6 X 9 envelope to: Susan Dion, PhD, 432 Ives Ave., Carneys Point NJ 08069.

A very funny book for aspiring authors is *Bird by Bird: Some Instructions on Writing and Life* by Anne Lamott, 1994, New York, Pantheon Books. It is available now in paperback at bookstores or in public libraries.

*Blue Pastures* by Mary Oliver, 1995, New York, Harcourt Brace, is sublime. Oliver, a Pulitzer Prize-winning poet, offers essays on writing, on nature, on herself. Also available in paperback at bookstores or in public libraries.



**EZ Keys for Windows** for use with Windows 3.1 is now available from Words+. A Windows '95 version is still being developed. EZ Keys for Windows provides all of the access methods in a single program, mouse operations are fast and convenient, there is no limit on Instant Phrases plus a new Instant Phrase Editor, and there is a free upgrade. Contact Words+, 40015 Sierra Highway, Building B-145, Palmdale CA 93550. 800/869-8521. FAX 805/266-8969.



**Christopher Reeve** reported in a recent interview with Larry King that he has worked up to 90 minutes ventilator-free time. In other Reeve news, The Reeve-Irvine Research Center, part of UC Irvine's School of Medicine, is scheduled to open within two years, and will concentrate on treatments to repair and regenerate neurological function in spinal cord injured individuals. An annual prize of \$50,000 will be awarded to the scientist who advances spinal cord research the most in a single year.

## SWIMMING IN LAKE SHASTA

Ventilator user Stephanie Stratford spent an idyllic summer vacation in 1995 aboard a houseboat on California's Lake Shasta, swimming and enjoying other water sports with her family. Stephanie, 15 years old and ventilator-assisted since a spinal cord injury at 14 months, uses trach positive pressure with a Companion 2800 ventilator. She has about two hours ventilator-free time.



The accessible houseboat (thanks to Seven Crown Resorts) was large enough to accommodate Stephanie, her family, and her ventilator and wheelchair. The boat's generator had enough power to charge her ventilator and wheelchair batteries overnight. To swim, Stephanie and her mother Nancy fitted her trach with a 5/8" rubber chair tip cover, just the right size. Stephanie and her ventilator also rode in the waterski boat. Taking advantage of her free time, Stephanie and her mother were towed in a two-person inner tube behind the boat.

Currently an eighth-grader active in drama and a talented mouthstick painter, Stephanie looks forward to high school next fall, but before that, to another summer vacation swimming in Lake Shasta.

**ADDRESS:** Stephanie Stratford, #4 Hillside Lane, Rolling Hills Estates CA 90274.

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## BACK ISSUES

Back issues of *I.V.U.N. News*, 1987-1995, are still available. Complete sets are \$25 (non-USA: \$30).

Single issues are \$5 each (non-USA: \$6). Send check or money order payable to G.I.N.I., 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915 USA. Issues are broadly indexed below:

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Ventilator users, new — Fall 1993  
Ventilators: lease vs. purchase — Fall 1991, Spring 1992

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## VENTILATOR CAMPS 1996

**April 9-15, Ventilator-Assisted Children's Center (VACC) Camp**, Miami FL. Contact Cathy Klein, VACC, 3200 S.W. 60th Ct., Suite 203, Miami FL 33155-4076. 305/662-VACC.



**June 2-7, Trail's Edge Camp**, Michigan. Contact Mary Dekeon, RRT, C.S. Mott Children's Hospital, University of Michigan, 200 E. Hospital Dr., F3064, Box 0208, Ann Arbor MI 48109. 313/763-2420.



**June 23-28, Camp Harmony Hall**, Middletown PA. Contact Pam Smith, CRTT, Pennsylvania Vent Camp, P.O. Box 60443, Harrisburg PA 17106-0443. 717/671-0226.



**June 23-28, Camp Inspiration**, Rocky Mountain Village, Empire CO. Contact Monte Leidholm, RRT, The Children's Hospital, 1056 E. 19th Ave., Denver CO 80218. 303/837-2502.



**August 18-24, CHAMP Camp**, Recreation Unlimited, Ashley OH. Contact David Carter, RRT, CHAMP Camp, P.O. Box 40404, Indianapolis IN 46246. 317/872-0555.



**August 29-September 1, SKIP Camp**, Seashore United Methodist Assembly, Biloxi MS. Contact Judy Abney, SKIP of Louisiana, 118 Ned Ave., Slidell LA 70460. 504/649-0882.

## calendar

... 1996 ...

**Exploring Breathing Support Options: Choices — Technology — Independence**, APRIL 23-24, 1996, Toronto Congress Centre, Toronto, Ontario, Canada. Contact: Marg Wagner, Citizens for Independence in Living and Breathing, 78 Golfwood Heights, Toronto, Ontario M9P 3M2 Canada. 416/244-2248.

**CCHS Symposium**, MAY 11, 1996, New Orleans Marriott, New Orleans, Louisiana. Sponsored by Tulane University School of Medicine and Aequitron Medical. Contact: David Gozal, MD, Dept. of Pediatrics SL-37, Tulane University School of Medicine, 1430 Tulane Ave., New Orleans LA 70112. 504/588-5601 or FAX 504/588-5490.

**European Respiratory Society**, Annual Congress, SEPTEMBER 7-11, 1996, Stockholm, Sweden. Contact: European Respiratory Society, 60 rue de Vaugirard, F-75006 Paris, France.

... 1997 ...

**Sixth International Conference on Home Mechanical Ventilation**, MARCH 5-7, 1997, Lyon, France. Contact: J.I.V.D., Hopital de la Croix-Rousse, Service de Reanimation et Assistance Respiratoire, 93, Grande rue de la Croix-Rousse, 69317 Lyon Cedex 4, France.

**G.I.N.I.'s Seventh International Post-Polio & Independent Living Conference**, MAY 28-31, 1997, Marriott Pavillion Downtown, St. Louis MO. Contact: G.I.N.I., 4207 Lindell Blvd., #110, St. Louis MO 63108-2915. 314/534-0475, FAX: 314/534-5070, or E-mail: gini\_intl@msn.com.