

# INTERNATIONAL VENTILATOR USERS NETWORK I.V.U.N. NEWS

Spring 1994 ■ Volume 8, No. 1

## OTHER ADVICE FOR VENTILATOR USERS

by John R. Bach, MD

Letters such as that by Jim Gassen, a ventilator user with Duchenne muscular dystrophy (DMD), and a personal story and advice by another ventilator user with muscular dystrophy, Tedde Scharf, (appearing in *I.V.U.N. News*, Fall 1993) are helpful and inspiring to individuals who are using or considering the use of mechanical ventilation. However, it is disconcerting to me to see such active, productive individuals as Jim and Tedde shackled with a tracheostomy tube. Virtually no one with muscular dystrophy requires an indwelling tracheostomy even after 24-hr ventilator use for 20 years or more.

In a study of 168 ventilator users (*Chest*, December 1993, 1702-1706), I found that the overwhelming majority of ventilator users with experience using both tracheostomy and noninvasive methods of ventilatory assistance preferred the latter for comfort, safety, swallowing, speech, sleep, appearance, convenience, and overall. Noninvasive intermittent positive pressure ventilation (IPPV) methods can also greatly decrease cost.

In another study, individuals using noninvasive methods of ventilatory assistance over 20 hours per day had a significantly lower risk of respiratory complications and respiratory-related hospitalizations than those using tracheostomy IPPV. Indeed, very few individuals with spinal cord injury, post-polio sequelae, DMD, spinal muscular atrophy, or most other neuromuscular conditions should ever require intubation or a tracheostomy for ventilatory support even when there is no measurable vital capacity or ventilator-free time. With sound medical management and access to mouthpiece/nasal IPPV, an adequate variety of nasal/oral interfaces, and effective manual or mechanically assisted coughing (In-Exsufflator, JH Emerson Co., Cambridge MA), we have even been able to avoid hospitalizing and intubating individuals presenting in acute respiratory failure with severe intercurrent respiratory tract infections.

Unfortunately, the great majority of physicians are not familiar with the variety of noninvasive inspiratory and expiratory muscle aids and interfaces which are important for avoiding or elimi-

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## CONSIDERING A CHANGE TO NONINVASIVE VENTILATION

by Tedde Scharf

First, let me tell you about the circumstances which have led me to investigate noninvasive ventilation. I have used trach positive pressure ventilation for the past six years, after respiratory failure at age 46 due to limb girdle muscular dystrophy. In 1988, when respiratory failure occurred, I was married and working fulltime as the director of a large program for students with disabilities at Arizona State University.

When the initial medical crisis passed, my physician resorted to tracheostomy after other methods such as the turtle shell (which only caused bruises and contusions) failed. Although at least one rehabilitation program in the East was working with noninvasive ventilation in 1988, I could find none in Arizona or the West Coast.

For the first few years, the trach did not seem to be a bad solution, physically. I was breathing better than I had for years. Gone were the perpetual headaches, drowsiness, bloated body tissue, fatigue, and memory lapses. I had more energy and longer endurance. Personally and socially, I learned to accept the changes exacted by the medical ramifications of my situation as, suddenly, there was an increased need for personal care attendants, knowledge of medical procedures, and I found myself surrounded with tubes and machinery in a large power wheelchair. My marriage dissolved and I threw myself headlong into my career.

Then, about four years ago, I began to have pseudomonas infections around the trachea site. Antibiotics quickly killed the infection and life went on in the fast lane (I travel by plane across the country several times a year, and generally am an active university administrator). A year ago, my system became resistant to the most effective oral antibiotic which attacks pseudomonas. The

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indicated medical treatment was intravenous antibiotics which must be administered in a hospital or by home health care nurses. Both are very expensive. Hospitalization is also time consuming and would have impacted my job. I elected to let nature take its course and fight off the infections naturally.

Letting nature take its course has been a fairly successive mode of treatment. However, I have side effects which are not pleasant, such as headaches, extreme fatigue, severe coughing spasms, excessive mucus, and a bad taste. I am essentially right back where I was in 1988, except I am not in respiratory failure.

When I learned about noninvasive ventilation, I was somewhat skeptical. I was reasonably comfortable with my trach and ventilator, and, most important, I could talk as well as anyone via a Passy-Muir Tracheostomy Speaking Valve. Speech is essential to my job. However, the longterm effects of the constant infection began to concern me, as well as the expenses involved with trach care, the equipment and supplies, and the costs of extra attendant care for suctioning, etc.

In the past year, I have relentlessly prevailed upon my current physician to research techniques for transferring to noninvasive ventilation. He is supportive, but unfortunately, due to the present HMO insurance available to state employees in Arizona, it is a slow process to obtain anything but basic medical care. We are taking one step at

*I.V.U.N. News readers first met Tedde Scharf in the Fall 1993 issue with her article "Advice for the New Ventilator User."*

a time. The actual switch requires a rehabilitation team in a closely-monitored medical unit. I will probably need to use a nasal mask at night, but during the day I will use mouth positive pressure ventilation.

I have found only three rehabilitation centers in the country who are routinely switching people from invasive to noninvasive ventilation: John R. Bach, MD, Department of Rehabilitation Medicine, University Hospital, Newark, New Jersey; Nicholas S. Hill, MD, Rhode Island Hospital in Providence; and Randall L. Rosenblatt, MD, Health South-Dallas Rehabilitation Institute in Dallas, Texas.

Ultimately, noninvasive ventilation can improve the overall quality of life. It is not necessarily the right change for everyone with a trach to make, but, for me, it is an option worth investigating. I certainly plan to continue my pursuit of another choice in ventilation and improved ability to work, socialize, contribute, and live. Stay tuned ...

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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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### **Deadline ...**

for submission of articles, stories, information, etc., for the Fall 1994 issue of *I.V.U.N. News* is August 1, 1994.

Please mail or fax to:

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Please send both your old and new addresses to:

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## OTHER ADVICE FOR VENTILATOR USERS

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nating the need for intubation or a tracheostomy. The use of noninvasive aids is also initially time consuming for the physician and respiratory therapist. Further, intubation, tracheostomy placement, and hospitalization for ventilatory insufficiency are paid for by third party payers, whereas tracheostomy removal and steps taken to avoid or eliminate these invasive methods with noninvasive alternatives are less lucrative. It is not surprising, therefore, that physicians resort so readily to intubation and tracheostomy. The problems and possible complications of longterm tracheostomy are usually dealt with later on and often by some other physician.

In 1955, an international symposium defined the indications for tracheostomy as the combination of respiratory insufficiency with swallowing insufficiency and disturbance in consciousness or vascular disturbances. "If a patient is going to be left a respirator cripple with a very low vital capacity, a tracheotomy may be a great disadvantage. It is very difficult to get rid of a tracheotomy tube when the vital capacity is only 500 or 600cc and there is no power of coughing, whereas, as we all know, a patient who has been treated in a respirator (noninvasively) from the first can survive and get out of all mechanical devices with a vital capacity of that figure."

(Hodes HL. "Treatment of respiratory difficulty in poliomyelitis." In: Poliomyelitis: papers and discussions presented at the Third International Poliomyelitis Conference. Philadelphia: Lippincott, 1955; 91-113.)

The same is true today except that now we have access to much more effective means of inspiratory (noninvasive IPPV) and expiratory muscle (mechanical insufflation-exsufflation, pressure biased oscillatory mucociliary transport aids, etc. ) aids than were the body ventilators and manual coughing aids of the 1950s. The only individuals who should ever require oxygen therapy or a tracheostomy are those who:

- are comatose or otherwise uncooperative;
- have severe lung disease, usually obstructive in nature, due to longterm cigarette smoking or severe acute respiratory complications;

- have respiratory failure and such bulbar muscle weakness that nutrition cannot be taken by mouth and a gastrostomy tube is necessary;
- have respiratory failure and an uncontrolled seizure disorder.

Indeed, we have even succeeded in providing adequate ventilatory assistance and airway secretion management for up to two years for individuals with amyotrophic lateral sclerosis with severe bulbar muscle impairment and indwelling gastrostomy tubes. Ventilator use, even in the presence of an unmeasurable vital capacity and no ventilator-free time, not only does not indicate the need for a tracheostomy; but resort to a tracheostomy all but eliminates the security and benefit which could be derived by learning and using glossopharyngeal breathing for ventilator-free time and assisting cough.

The majority of people with spinal cord injuries and post-polio sequelae who use ventilators, as well as individuals with neuromuscular disease, including some ventilator users with DMD, can use glossopharyngeal breathing for hours of ventilator free-time. (Your physician is unlikely to be familiar with these alternatives, and I recommend that he or she be asked to obtain a series of journal articles discussing noninvasive ventilation. A bibliography may be obtained from my office.)

If you already have a tracheostomy tube and wish to have it removed, you should be able to swallow adequately and be capable of generating at least 4-5 liters/second of airflow during manually assisted coughing following a deep insufflation (assisted breath to over 1000 ml). You can measure this with a Health Scan Peak Flow Meter (Cedar Grove, NJ), a device

which costs less than \$20. You must find an interested physician and respiratory therapist who will permit you to learn how to use nasal/mouthpiece IPPV with the tracheostomy tube or, preferably a trach button in place, and progress from there.

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▲  
"Do you suffer from intubation and tracheostomy paradigm paralysis?" Dr. Bach asks, referring to J.L. Barker's definition of paradigm paralysis as "... the failure to learn new and superior approaches because they differ radically from the generally employed methods in which one has invested time and energy. It is the terminal disease of misplaced certainty."  
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## POSITIVE PRESSURE BY TRACH: MY CHOICE

by Jerry Daniel

The decision to use a nasal/face mask with positive pressure when a person finds her/himself in need of a volume ventilator at night during sleep and maybe rest periods during the day may be the best decision for a new part-time ventilator user. Sometimes, however, the mask cannot be tolerated, whether for feelings of claustrophobia, skin breakdowns, facial pains from the mask, etc., and may lead to dental problems as one gets older. Then a decision about a tracheostomy needs serious consideration.

The most revealing history of people undergoing tracheostomies for positive pressure ventilation can be found with those polio survivors who went to Rancho Los Amigos Hospital in Downey, California, during the polio epidemics of the 1950s. A large number of polio survivors needed complex spinal fusions and other corrective orthopedic surgeries that were pioneered by Jacquelin Perry, MD, and Vernon Nickel, MD. One of the first procedures the patient had to consent to was a tracheostomy before any surgery or body cast could be done. The tracheostomy made surgery and longterm recovery with positive pressure much more manageable. When all the surgeries had been completed, the patient usually had the choice of either keeping the trach and continuing to use a portable positive pressure ventilator which was in the development stages at the time or returning to the iron lung, the rocking bed, the cuirass, etc. Many polio survivors became experts at frog-breathing for ventilator-free time.

Jerry Daniel has had a tracheostomy for 38 years.

I was one of those patients, and I and most of the people I knew chose to keep the trach. One advantage was that a ventilator user with little use of the hands could hook up to the vent in a minute or two and use the ventilator sitting up or lying down on the back or either side. I and my friends learned that once the stoma healed with healthy scar tissue, we could touch the trach with no feeling or irritation, and those of us with functional hands learned to do their own trach care.

Most of us did, and still do, have uncuffed trach tubes. During sleep, there is a tendency for some air leaking out of the mouth, but that can be compensated for by slightly increasing the ventilator volume. Some of us need suctioning more than others and some of us get bronchitis more often, but we like the convenience of using

trach positive pressure. The uncuffed trach tube also lets us talk during the ventilator's inspiratory cycle. Eating is more enjoyable with trach positive pressure, too, especially at dinnertime, because breathing gets to be hard work toward the end of the day.

I use a wheelchair and I have limited use of my hands. I do not use the ventilator while working or when going outside the home, but I do use it when sitting around the house and feel I get better rest using it then. Not being able to wear a dress shirt and tie is somewhat of a disadvantage, but turtlenecks and crewneck sweaters can cover up the plugged trach when I go out in public. I find trach positive pressure to be comfortable and conducive to my active lifestyle.

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### UPDATE: HCFA VENTILATOR POLICY

In *I.V.U.N. News*, Fall 1993, readers were advised that the Health Care Financing Administration (HCFA) was in the process of revising and rewriting many policies, some of which might affect reimbursement for multiple ventilators. A possible deadline for this action was October 1, 1993, however, that action was delayed. In late November 1993, Bob Wren, the Policy Director of HCFA, issued the following assurances:

- multiple ventilator users are grandfathered into the Medicare system, and thus will retain their benefits,
- the medical directors of the Durable Medical Equipment Regional Carriers (DMERCs) will be advised that there is no national policy to prohibit the benefit of multiple ventilators,
- a group will be convened to create a national policy under which multiple ventilators will be available, rather than relying on regional guidelines.

As this issue of *I.V.U.N. News* goes to press, HCFA officials are meeting to further discuss reimbursement for multiple ventilators, and no date has been set to convene a group (which is hoped to include an I.V.U.N. representative) to create a national policy. I.V.U.N. thanks its readers for the many letters and comments they sent in support of the multiple ventilator issue.

## VENTILATOR-ASSISTED INFANTS WITH BRONCHOPULMONARY DYSPLASIA

by Catherine Hermabessiere, MD, Brigitte Monier, MD, and Liliane Cathelineau, MD

**B**ronchopulmonary dysplasia (BPD) is a chronic lung disease that usually follows early pulmonary injuries. Careful use of artificial ventilatory supports has much improved the prognosis of the more severe forms of the disease, allowing healing between the ages of 2 and 4. Mechanical ventilation produces two results. It ensures survival at a moment in the disease when respiratory insufficiency is so severe that use of spontaneous ventilation could lead to a fatal outcome of acute respiratory failure. It also promotes gradual improvement of pulmonary function by reducing ventilatory work and by allowing maximum use of gas exchanges.

Depending on the infant's condition, the alternatives of care are prolonged hospitalization, institutional care, and home care. In order to return these children to family life, the therapeutic center, with its multidisciplinary team of doctors, nurses, psychologists, and psychomotricians, assumes their care, not only on a respiratory level, but more so on nutritional and emotional levels. The high level of motivation of parents for their children results in a high quality of care.

Respiratory supervision is important on a daily basis, under spontaneous ventilation, in order to estimate respiratory frequency, to watch for tegument coloring, to examine by auscultation, to note signs of fatigue in the respiratory muscles. On a weekly basis, supervision estimates growth and also gas exchanges via oxygen saturation measurements. On a monthly basis, direct PaO<sub>2</sub> and PaCO<sub>2</sub> measurements by a capillary gas sample are obtained. Every six months, pulmonary function and ventilatory mechanics are studied during sleep. Possible repercussions on the right side of the heart are assessed by Doppler echocardiography. Daily sessions of respiratory physical therapy (clapping), repeated endotracheal suctioning, and if necessary, aerosol therapy, are performed. Ventilator use occurs for long spans of time during a 24-hr period. Therapeutic adjustments are of course constantly made for each child depending on clinical and paraclinical surveys.

Nutritional surveillance is necessary for these infants with respiratory insufficiency. Because of their increased ventilatory work, they have an increased energetic demand. They sometimes have to catch up on growth and do not feed well due to over-tiredness. For most of the children, it is necessary to supplement the orally fractionated caloric supply, which is usually deficient, by nasogastric tube feeding during sleep.

Neurological and psychological supervision are also essential. These children have many reasons to show psychological problems, such as prolonged hospitalization in intensive care units, separation from their parents, and major prematurity. Special equipment may be necessary for a neuro-orthopedic disability, and also for a visual or auditory one. Neurological disabilities are treated by a physical therapist.

Emotional followup is equally indispensable. It bears on the assessment of the child's corporal and emotional experiences and on the quality of the child's relationships. There is a constant risk of rupture in social communication in these infants who have used assisted ventilation since birth. Indeed, standardized breathing, lack of voice, and limited mobility are all sources of difficulty towards the child's contact with his or her own body, surroundings, and parents.

During the course of normal infant development, we do not usually notice the connections between early emotional life and motor development, and spatial relationships. An infant's self-awareness comes from visual and vocal exchanges, and from postural rhythms. The child with assisted ventilation has reduced abilities whether they are postural, self-exploratory, or spatial, and experiences difficulty interacting with a human partner. There is a risk that the infant will prefer to build around individual interests of a mainly sensory type. These points of interest correspond to pleasant or unpleasant sensations that the child has easy access to: the beeping noise of the monitoring apparatus (auditory), the beam of light rays (visual), bed contact (tactile), and the perceptions which come back regularly like the pressures and respiratory frequencies that are constant and rhythmical. These sensations can be compared to other reassuring fetal sensations already known to the infant, such as: periodic rocking motions, uterine contact, etc. We can see that a vicious circle could result from the difficulty of first human interactions and reasserted attachment to fetal sensations, because of all the sensory experiences provided by the respiratory pathology itself.

To break this circle, it is most important to give the child free time. This is done by making each space significant: separate places for medical care and normal life; also by maintaining family ties, and by encouraging interactions through speech. These tracheotomized children cannot communicate with their voices, but, by talking to them,

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## CCHS CONFERENCE *by Nancy Stone*

In October 1993, at Camp Fowler in Mayville, Michigan, a dream was realized. Sixteen families participated in the first Congenital Central Hypoventilation Syndrome (CCHS) Family Conference. Since CCHS is rare, it was the first time many families had the opportunity to meet another family coping with the same condition. Families attended from as near as Pontiac, Michigan, and as far away as Scotland (two families represented), as well as Canada and all across the U.S. The children with CCHS and their siblings had a marvelous time. Fortunately there were no crises — a miracle considering the parents were intensely involved in discussions for the entire weekend.

Our conference speakers included both professionals and parents, and the wide range of subjects discussed combined with the informal sharing of experiences and hope made the conference invaluable. Of particular interest to us was (and is) the subject of alternative modes of ventilation. Three of the children with CCHS were using nasal

mask ventilation, one had a diaphragmatic pacer, and the remainder used mechanical ventilation via tracheostomy. The firsthand experience of witnessing these different methods of ventilation was immeasurable.

Our plans resulting from the conference include another conference in late 1994 or early 1995 in Ft. Myers, Florida; production and dissemination of a CCHS Family Support Network brochure to better communicate our existence; and of course, fundraising, fundraising, fundraising.

The speakers, sponsors, and facilitators renewed my faith in the dedication and compassion of health care professionals and providers, especially Joyce Stein, RN, who provided unlimited time and talent. Our thanks to Respironics, Inc., Aequitron Medical, Nellcor, Puritan-Bennett, University of Michigan, Passy-Muir, Inc., Neo-Fight, and Ohmeda.

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## VENTILATOR-ASSISTED INFANTS *Cont. from page 5*

carrying them, and opening up to them all the usual activities given to children their age, such as kindergarten, walks, family exchanges, etc., they are thus allowed to grasp the beginnings of speech and social relationships. Therapists, psychomotricians, and nurses tend to each patient. They help each infant organize sensations into differentiated perceptions so as to enrich the infant's interests. And when the periods of spontaneous ventilation are too short, the child is mobilized, without hesitation, will full ventilatory assistance.

The child's family is scrupulously educated in the child's care and needs. They are regularly informed of any therapeutic evolution that could

lead to a return home. The return home is done gradually — at first, one day, then a weekend, then several consecutive days.

In conclusion, the data from the medical literature and from experience show the positive effects of taking total charge of the infants. This must be done most rigorously and precisely in all its forms and applications: respiratory, nutritional, neurological, and emotional for these children whose pathology starts in the first days of life. This complete taking charge promotes the child's stabilization, and also permits their parents' education and support.

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

Use this update as a companion to the Directory published in *I.V.U.N. News*, Fall, 1993, Vol. 7, No. 2. Corrections and changes are underlined.

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\*ventilator user  
\*\*pediatric interest

## G.I.N.I.'s SIXTH INTERNATIONAL POST-POLIO & INDEPENDENT LIVING CONFERENCE

June 16-19, 1994 • St. Louis Marriott  
Pavilion, St. Louis Missouri



### *Special ventilator sessions include:*

**Friday, June 17, 10:15-11:30 a.m.**

Facing surgery when breathing is a problem • New breathing and swallowing problems in aging polio survivors.

PANELISTS: Augusta Alba, MD, Goldwater Memorial Hospital, New York NY; Carl Coelho, PhD, Gaylord Hospital, Wallingford CT; Kathleen Navarre, PhD, Delta College, University Center MI; Ann Romaker, MD, Kansas City MO; Oscar Schwartz, MD, St. Louis MO.

**Friday, June 17, 1:30-3:00 p.m.**

Improving cough and decreasing infection • Changing equipment as diagnoses change in muscular dystrophy, SCI, and CCHS • Diaphragmatic pacer: what, who, and when.

PANELISTS: Augusta Alba, MD, Goldwater Memorial Hospital, New York NY; John Bach, MD, University Hospital, Newark NJ; William Dobelle, PhD, The Dobelle Institute, Glen Cove NY; Daniel Goodenberger, MD, Washington University, St. Louis MO; Sue Sortor Leger, RRT, Lyon, France; Joseph Viroslav, MD, Dallas Rehabilitation Institute, Dallas TX.

**Friday, June 17, 3:30-5:00 p.m.**

Living at home: overcoming obstacles.

PANELISTS: Patrick Leger, MD, Hopital de la Croix Rouse, Lyon, France; George Mallory, MD, Washington University, St. Louis MO; Mickie McGraw, Cleveland, Ohio; Deborah Givan, MD, Riley Hospital for Children, Indianapolis IN; Margaret Nosek, PhD, Baylor College, Houston TX; Edward Oppenheimer, MD, Permanente Medical Group, Los Angeles CA; Mary Ann Sevick, ScD, RN, Pittsburgh PA.

**Saturday, June 18, 9:00-10:00 a.m.**

Face masks show and tell • Frogbreathing lessons • Care and maintenance of your ventilator.

PANELISTS: Augusta Alba, MD, Goldwater Memorial Hospital, New York NY; John Bach, MD, University Hospital, Newark NJ; Nancy Nicoll, Respironics, Inc., Murrysville PA; Shelley Morris-Tomazevic, RRT, Dallas Rehabilitation Institute, Dallas TX; Vera Overholt, Minerva OH; Wilma Pierce, RRT, Dallas Rehabilitation Institute, Dallas TX; Oscar Schwartz, MD, St. Louis MO; Jerry Daniel, VENTEK, Vancouver WA.

Register now for the full conference or just for the ventilator sessions on Friday and Saturday. Preregistration by April 25 saves \$20. For a complete registration form and hotel registration information, contact G.I.N.I., 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 USA. 314/534-0475 or FAX 314/534-5070.

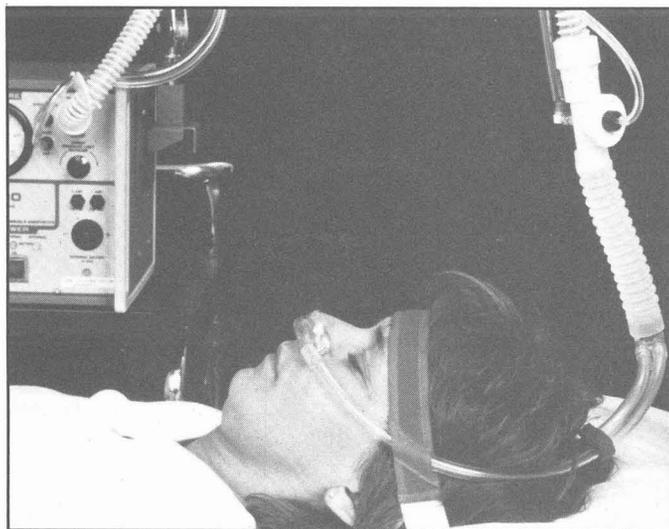
Ventilator users attending who want to rent ventilator equipment can make arrangements with Jeff Davis, LIFECARE, 110 Northwest Parkway, Riverside, MO 64150. 800/669-9234, 816/741-7667 or FAX 816/741-4853.

## THE INDIVIDUAL REMMER NASAL MASK

by Lennart J. Remmer

There are now several reports of good results with assisted, noninvasive intermittent positive pressure ventilation (NIPPV) with a nasal mask in people with respiratory failure in neuromuscular disorders. A comfortable mask permitting minimal leakage without causing tissue damage is critical for treatment success. This is not always achieved with commercially available nasal masks. The Remmer nasal mask has been in use since 1989, and more than 200 people have been equipped with it.

The mask is made by first taking an alginate impression of the nose. A high-quality impression is desirable but this is not always easy because the individual being fitted often has a reduced breathing capacity. He or she may be unable or unwilling to lie down, and the technician must accept



a more upright position. To achieve a good result, the individual should be calm and well-informed of the procedure. Facial movements during the making of the impression should of course be avoided, especially movement of the nose, because this will affect the fit of the mask.

The impression mold is made of PVC and is available in different sizes. The alginate is a superb material for impressions and can be mixed so that it has a fairly liquid consistency. The first layer of material can be spread out around the nostril openings with a finger. The remaining material is applied thickly and air bubbles should be avoided. The mold does not normally need to be sealed if the impression material has the correct consistency. It is also important that the mold is not moved during the setting period; the resultant impression may be incorrect. Sometimes the impression material can run toward the individ-

ual's eyes, but if the eyes are closed there is no discomfort.

After the impression material has set, the mold is removed from the face. The impression is examined and if of the desired quality, the mask is then completed. The mask material is presently a light curing resin. Recently, I tried to make the nasal openings using a soft curing resin for increased comfort and minimal leakage, but it did not work. After 20 masks were in use for more than three months, I could see the soft material had delaminated and had also shrunk, and people were complaining of more leakage and sores, so I went back to the original method.

The mask and headgear are then tried on and adjustments are made. The individual comes to the outpatient unit for training in the use of the mask, and then continues use at home. Individually adapted equipment significantly increases the quality of life, enables the individual to function better socially, and results in fewer hospitalizations. Rhinitis or drying out of the nose is the most common problem, but the use of simple unheated humidifiers integrated into the tubing can solve that.

My associate Hanna Laine and I followed 67 people using the Remmer mask at home. Of these, 40 had symptoms of night-time hypoventilation. Of these 40, 33 people could sleep more than 6 hr per night with the nasal mask. A reduction in symptoms was observed in morning headaches (86%); daytime drowsiness (82%); chronic fatigue (72%); sleep disturbance (63%); and depression/irritation (55%). More than 90% of the individuals are satisfied with the fit and handiness of the mask.

NIPPV with a Remmer nasal mask in people with moderate respiratory insufficiency can be successful with appropriate technical and medical assistance. Reduction in symptoms of alveolar hypoventilation and improvement in blood gases can be expected after six months of treatment.

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Lennart Remmer is Maxillofacial Technologist in the Department of Anaesthesia and Intensive Care, Danderyds Hospital, Danderyd, Sweden.



## MEET TOBY TRACHEASAURUS

Capitalizing on the current dinosaur craze, Mary Mason, a speech pathologist and president of Voicing!, in Newport Beach, California, created Toby Tracheasaurus, a purple and green 12" plush dinosaur complete with a tracheostomy tube and Passy-Muir Tracheostomy Speaking Valve. Toby is available as either a toy (\$25) or a hand puppet (\$35). There is also a Toby Tote (\$12), an exhalation kit that includes therapeutic breathing aids such as a dinosaur whistle, a dinosaur bubble blower, pinwheels, and blow horns. By playing with these aids, the children can learn how to direct their breaths and reinforce good breathing habits to promote voicing. The Tammy and Toby Tracheasaurus coloring books (\$3 each) offer a fun learning experience about the tracheostomy procedure and help the child explore anxieties and fears about tracheostomies. A complete price list is available from Voicing!, 3857 Birch, Suite 194, Newport Beach CA 92660, 714/833-2710 or FAX 714/833-1005.

## PURITAN-BENNETT DISCONTINUES VENTILATORS

Puritan-Bennett recently announced it was halting production of its Companion 2800, Companion 2801, and Maxivent portable ventilators, although it will continue to service them for the next five years. LIFECARE is currently offering credits (through July 31, 1994) for Puritan-Bennett ventilators traded in for the purchase of LIFECARE's PLV-100, PLV-102, or NEV-100 ventilators. For the nearest LIFECARE office, call 800/669-9234.

## I.V.U.N. BIBLIOGRAPHY\*

- Hill NS. Noninvasive positive pressure ventilation in neuromuscular disease: enough is enough! *Chest* 1994; 105: 337-338
- Piper AJ, Sullivan CE. Effects of short-term NIPPV in the treatment of patients with severe obstructive sleep apnea and hypercapnia. *Chest* 1994; 105: 434-440
- Pennock B, Crawshaw L, Kaplan PD. Noninvasive nasal mask ventilation for acute respiratory failure. *Chest* 1994; 105: 441-444
- Vianello A, Bevilacqua M, Salvador V, Cardaioli C, Vincenti E. Long-term nasal intermittent positive pressure ventilation in advanced Duchenne's muscular dystrophy. *Chest* 1994; 105: 445-448
- Elpern EH, Scott MG, Petro L, Ries MH. Pulmonary aspiration in mechanically ventilated patients with tracheostomies. *Chest* 1994; 105: 563-566
- Goldberg AI. High-technology home care: the need for a creative management approach. *Chest* 1994; 105: 4-5
- Leger P, Bedicam JM, Cornette A, Reybet-Degat O, Langevin B, Polu JM, Jeannin L, Robert D. Nasal intermittent positive pressure ventilation: long-term follow-up in patients with severe chronic respiratory insufficiency. *Chest* 1994; 105:100-105
- Bach JR. A comparison of long-term ventilatory support alternatives from the perspective of the patient and caregiver. *Chest* 1993; 104: 1702-1706
- Moxham J, Shneerson JM. Diaphragmatic pacing. *Am Rev Respir Dis* 1993; 148: 533-536
- Scharf T. Yes, there is life after ventilation. *Chest* 1993; 103: 1319
- Goldberg AI. Long-term ventilatory support in the community. *Chest* 1993; 103: 1315
- Adams AB, Whitman J, Marcy T. Surveys of long-term ventilatory support in Minnesota: 1986 and 1992. *Chest* 1993; 103: 1463-1469
- DeWitt PK, Jansen MT, Davidson Ward SL, Keens TG. Obstacles to discharge of ventilator-assisted children from the hospital to the home. *Chest* 1993; 103: 1560-1565
- Chetty KG, McDonald RL, Berry RB, Mahutte CK. Chronic respiratory failure due to bilateral vocal cord paralysis managed with nocturnal nasal positive pressure ventilation. *Chest* 1993; 103: 1270-1271
- Hill NS. Noninvasive ventilation: does it work, for whom, and how? *Am Rev Respir Dis* 1993; 147: 1050-1055
- Linder SH. Functional electrical stimulation to enhance cough in quadriplegia. *Chest* 1993; 103: 166-169
- Donner CF, Howard P, Robert D. Patient selection and techniques for home mechanical ventilation. *Monaldi Arch Chest Dis* 1993; 48: 40-47

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

## **MASK PROGRAM HELPS HEALTH CARE PROFESSIONALS WITH PATIENT COMPLIANCE AND COMFORT**

Respironics has recently finished production of a new educational video package designed to help health care professionals properly fit patients with nasal masks. "Masks and Accessories: An Examination of Size, Fit, and Adjustments," offers guidelines on selecting the correct size Nasal Mask and Spacer using Respironics' Nasal Mask Sizing Gauge; attaching and adjusting headgear to ensure proper patient fit; and attaching mask accessories, including the Comfort Flap™ and Chin Strap. It also discusses how to recognize signs of properly and poorly fit masks, and provides suggestions for solving common mask problems.

The format of the videotape (approximately 25 minutes) includes a pause after each instructional section so that viewers can stop the tape and participate in fitting exercises. It should be viewed with at least one other person: hands-on experience fitting another person and being fit with a mask is an important element of the training.

Included with each video are five copies of a companion workbook, allowing viewers to follow along as they watch the program, or use later as a reference. If additional workbooks are needed to accommodate training sessions, they can be ordered separately, free of charge. The instructional nature of this videotape is appropriate for use in the home, hospital, or sleep lab.

A well-fit mask can have a major impact on patient compliance and comfort. Mask-supplied ventilation and nasal CPAP therapy are on the rise, and proper mask-fitting techniques are essential in ensuring successful use.

To order "Mask and Accessories: An Examination of Size, Fit, and Adjustments," call Respironics Customer Service Department, 800/345-6443, and ask for part number 989062.

### **IN MEMORIAM BILL TAITER**

Ventilator user Bill Tainter died suddenly on August 23, 1993 at the age of 51. At the time of his death, Bill, a pioneer in the independent living movement, was director of the California Department of Rehabilitation. I.V.U.N. extends sympathy to Bill's family and his many friends in the disability community.

## **CAMPS FOR VENTILATOR-ASSISTED CHILDREN**

**April 5-11, 1994. Ventilator-Assisted Children's Center (VACC) Camp, Florida.** Contact Cathy Klein, VACC, 3200 S.W. 60th Ct., Suite 203, Miami FL 33155-4076. 305/662-8222.

**June 11-17, 1994. Trail's Edge Camp, Camp Fowler, Mayville MI.** Contact Mary Dekeon, RRT, C.S. Mott Children's Hospital, University of Michigan, 200 E. Hospital Dr., F3064, Box 0208, Ann Arbor MI 48109. 313/936-7339.

**June 26-July 1, 1994. Camp Harmony Hall, Middletown PA.** Contact Pam Smith, CRTT, PA Vent Camp, P.O. Box 60443, Harrisburg, PA 17106-0443. 717/671-0226.

**August 12-14, 1994. Colorado Camp, Rocky Mountain Village, Empire, Colorado.** Contact Monte Leidholm, RRT, The Children's Hospital, 1056 E. 19th Ave., Denver CO 80218. 303/837-2502.

**August 14-20, 1994. CHAMP Camp, Recreation Unlimited, Ashley OH.** Contact David Carter, RRT, CHAMP Camp, P.O. Box 40404, Indianapolis IN 46240. 317/875-9496.

**September 1-4, 1994. SKIP of Louisiana Camp.** Contact Judy Abney, SKIP of Louisiana, 118 Ned Ave., Slidell LA 70460. 504/649-0882.

As this issue went to press, no dates had been set yet for the SKIP Camp, Camp Courage, Minnesota. Contact Kevin O'Malley or Barbara Donaghy, SKIP Camp, 11208 Minnetonka Mills Rd., Minnetonka MN 55343. 612/935-5581.

## *Calendar*

**Making a World of Difference: Independent Living and Ventilation, May 19-21, 1994, Victoria Conference Centre, British Columbia.** Contact Queen Alexandria Centre for Children's Health, Amanda Maier, 2400 Arbutus Rd., Victoria B.C. V8N 1V7 Canada. 604/477-1826.

**G.I.N.I.'s Sixth International Post-Polio and Independent Living Conference, June 16-19, 1994, Marriott Pavilion Hotel, St. Louis MO.** Special ventilator sessions. Contact Joan Headley, G.I.N.I., 5100 Oakland Ave., #206, St. Louis MO 63110-1406. 314/534-0475.

**European Respiratory Society (ERS) Annual Congress, October 1-5, 1994, Nice, France.** Contact ERS, 60 rue de Vaugirard, F-75006 Paris France.

**Fifth International Conference on Pulmonary Rehabilitation and Home Ventilation, March 12-15, 1995, Hyatt Regency Hotel, Denver CO.** Deadline for abstracts: November 1, 1994. Program Chairman: Barry Make, MD. Contact National Jewish Center for Immunology & Respiratory Medicine, Office of Professional Education, 1400 Jackson St., Room M/222, Denver CO 80206. 303/398-1359.

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## I.V.U.N. QUESTIONNAIRE

Ventilator users live at home successfully with a wide range of caregivers and services. Many have trained personal assistants or family members to aid them; others use different levels of nursing care for several hours or round-the-clock. As health care reform continues, and services and costs for ventilator users become a subject of debate, I.V.U.N. News would like to know from its readers how they are coping with ventilator care. Who performs it? How was that person trained? Who pays for the services? And finally, how is the system working? Please complete the following questionnaire and return to: I.V.U.N., 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 USA. Thank you.

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### QUESTIONNAIRE

I use mechanical ventilation:     tracheostomy     noninvasive

0 to 6 hours     7 to 12 hours     13 to 18 hours     19 to 24 hours a day

The care associated with the use of my ventilator is done by:  
(please check all that apply)

myself — I was trained by \_\_\_\_\_

a live-in family member or friend,  
who was trained by \_\_\_\_\_

a stop-in family member or friend,  
who was trained by \_\_\_\_\_

a licensed RN at \$ \_\_\_\_\_ per hour, paid for by \_\_\_\_\_  
and trained by \_\_\_\_\_

a licensed LPN at \$ \_\_\_\_\_ per hour, paid for by \_\_\_\_\_  
and trained by \_\_\_\_\_

a licensed RT at \$ \_\_\_\_\_ per hour, paid for by \_\_\_\_\_  
and trained by \_\_\_\_\_

a personal attendant at \$ \_\_\_\_\_ per hour, paid for by \_\_\_\_\_  
and trained by \_\_\_\_\_

On a scale of 1 to 5 (1 = lowest or least desirable, and 5 = the best), please rank the following regarding the individual(s) listed above:

\_\_\_\_\_ my feeling of confidence                      \_\_\_\_\_ my feeling of personal control

\_\_\_\_\_ my assessment of quality of the care    \_\_\_\_\_ my assessment of independent living

What I like most about my current system: \_\_\_\_\_

What I dislike most about my current system: \_\_\_\_\_

My advice to professionals writing guidelines for ventilator use in the home would be: \_\_\_\_\_

My age is: \_\_\_\_\_

The state where I live is: \_\_\_\_\_



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## Potpourri

### **ECRI Report Evaluates Breathing**

**Circuits.** The July 1993 issue of *Health Devices* from ECRI focuses on disposable breathing circuits for portable ventilators. The evaluation discusses disconnection, misassembly, tubing kinking and crushing, and ease of use. ECRI distributes *Health Devices* to members of its Health Devices System; the report is also available to non-members for \$95. Contact ECRI, 5200 Butler Pike, Plymouth Meeting PA 19462. 215/825-6000.

### **Standards of Care for the Ventilator Assisted Individual: A Comprehensive Management Plan**

by Adrienne Baldwin-Myers, MSN, RN, et al., is now available. Composed by a committee of nursing and respiratory care professionals from five medical centers and two home health agencies in Southern California, the document thoroughly examines the discharge plan, physical environment, safety, equipment, roles and responsibilities of caregivers, vendors, health professionals, and legal issues. To obtain a copy, contact Adrienne Baldwin-Myers, MSN, RN, Kaiser Permanente, 393 Walnut St., Pasadena CA 91188. 818/405-6053.

### **Enhanced Cough in Spinal Cord Injury.**

Steven H. Linder, MD, at Veterans Administration Medical Center (VAMC) in Palo Alto, reports that he has developed a specially constructed abdomi-

nal corset which produces an improved cough in individuals with high spinal cord injuries. Functional electrical stimulation (FES) is applied to the abdominal wall muscles causes them to contract, thus compressing the air in the lungs enough to generate a cough. Wearing such a binder that delivers abdominal muscle FES lessens the dependence of a quadriplegic person upon an attendant to assist with producing a cough. This FES device also appears to effectively stimulate cough in non-spinal cord injured people. Dr. Linder reported his investigation in "Functional Electrical Stimulation to Enhance Cough in Quadriplegia" in *Chest* 1993; 103: 166-169. For more information write: Steven H. Linder, MD, VAMC, 128 Spinal Cord Injury, 3801 Miranda Ave., Palo Alto CA 94304. 415/493-5000, ext 5872.

### **West Virginia Support Group for Ventilator Dependent Individuals and Families**

in its mission statement "believes that individuals requiring longterm or permanent assistance of mechanical ventilation should be afforded every opportunity to improve their quality of life ... and is further committed to the purposeful acquisition of knowledge which leads to improvement in the delivery of health care to this unique population." Address is 6810 MacCorkle Ave., SE, Charleston WV 25304. 304/925-6675.