

I.V.U.N. NEWS

International Ventilator Users Network

Spring 1993 ■ Volume 7, No. 1

Communication for the Ventilator User with a Tracheostomy

by Daniel M. Goodenberger, MD

Progressive respiratory failure may occur in a variety of situations. Diseases with worsening neuromuscular weakness commonly are associated with progressive difficulty in breathing; examples include the muscular dystrophies, post-polio syndrome, and amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease). Severe deformities of the chest wall or spine, such as kyphoscoliosis or thoracoplasty, may cause progressive respiratory insufficiency.

Respiratory failure requiring mechanical support may also result from acute neurologic events, such as high spinal cord injury. In addition, marginally compensated individuals with chronic bronchitis or emphysema may deteriorate acutely, resulting in the need for mechanical ventilation; in some cases, these individuals may continue to survive only with the aid of long-term ventilatory support. In many of the above situations, chronic respiratory insufficiency may progress to the point at which ventilatory support is desirable even in the absence of any acute event.

A wide variety of methods of artificial ventilatory support, both negative and positive pressure, are available. Noninvasive positive pressure ventilation is thought of as a relatively recent development, although some variations of it have been used successfully by certain physicians for years. These noninvasive methods may forestall the need for delivering breathing assistance via an endotracheal tube or a tracheostomy tube, but, despite our best efforts, there are those for whom tracheostomy delivered positive pressure ventilation is necessary and/or desirable.

In addition to undergoing a surgical procedure, a major fear on the part of both patients and physicians has been that having a tracheostomy must necessarily interfere with the production of normal speech. It has been our observa-

tion that this may lead to the inappropriate refusal of mechanical ventilation by the affected individual, by his or her physician, or both. Unfortunately, many physicians (and many pulmonary specialists) are unaware that tracheal positive pressure ventilation does not necessarily mandate loss of vocal communication.

There are a number of options for communication for patients who require positive pressure ventilation via tracheostomy. Those who maintain muscle control may communicate by writing. This is, however, slow, cumbersome, and tends to truncate communication. Computer-generated mechanical speech has generally been reserved for those who have severely impaired speech at baseline (as in some cases of cerebral palsy), and for those who are unable to control the muscles of speech due to progressive illness, as may occur with ALS.

The Electrolarynx functions by producing vibrations which are applied to the larynx (voice-box). This generates sound in the larynx which can be formed into audible and interpretable speech by the other muscles of communication. The speech quality is somewhat tinny (sometimes likened to R2D2), but individuals' speech may be highly recognizable — we have routinely been able to identify individual patients over the phone.

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Communication for the Ventilator User

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The major disadvantage of the Electrolarynx is that it requires the use of the hands for application, and is therefore not appropriate for most patients with muscular dystrophy or spinal cord injury. Patients must also have normal function in the muscles of the mouth, lips, and tongue to produce intelligible speech. Additionally, many patients are somewhat hesitant about using this because of the feeling that it calls attention to themselves.

Some individuals who use only nocturnal tracheostomy-delivered positive pressure ventilation may revert to normal vocal speech during the daytime. During these periods, the tracheostomy tube must have the cuff deflated, or the patient must be ventilated with a cuffless tracheostomy tube. Speech may be accomplished simply by plugging the tracheostomy tube, in which case

the patient breathes through the mouth and nose with air moving around the tracheostomy tube in the trachea (windpipe). The increased resistance to breathing may be too much for some patients; for that reason a variety of valves are available which attach to the tracheostomy tube and allow air to enter via the tracheostomy tube, but leave by way of the mouth and nose. With the exception of the Passy-Muir Tracheostomy Speaking Valve, none of these valves may also be used with a ventilator.

For those patients requiring 24-h mechanical ventilation through a tracheostomy, several other communication options are available. Some patients may require mechanical ventilation with the tracheostomy tube cuff inflated. This may be necessary to prevent aspiration, although simply inflating the cuff during meals may be appropriate for those patients.

Some patients with chronic bronchitis and emphysema may be difficult to ventilate with the cuff down because their lung physiology is such that the adequacy of ventilation with an uncuffed tracheostomy tube is uncertain from hour-to-hour and day-to-day. However, it has been our experience that a substantial number of patients even with chronic bronchitis and emphysema can be ventilated with the tracheostomy tube cuff down. For those who cannot, the Electrolarynx may be used.

Another device, the Venti-Voice, is no longer available through retail sales, but a used one may be occasionally obtained. It uses switch-activated airflow to generate vibrations in the back of the nose and throat which may be transformed into speech by the muscles of vocalization. It is not generally recommended because of multiple problems, including poor voice quality.

"Talking" tracheostomy tubes are also available. These devices allow for the delivery of air into the larynx on demand from a source other than the air that the patient is breathing. Thus, the mechanisms of ventilation and voice production are completely separated. This air is delivered to the larynx by closure of a valve by the finger of a patient or caregiver. Relatively high

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

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flow rates are necessary to achieve adequate voice production. Problems with this system include plugging of the air outflow site in the throat by secretions, drying of the mouth and nose by the relatively high airflow rates required, the necessity for a compressor or other external air source, and the fact that plugging of a valve is necessary for speech production, which makes this inappropriate for the severely neurologically-impaired patient.

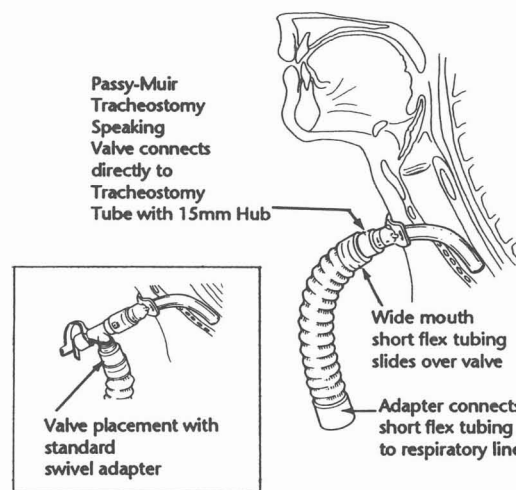
The best alternative for communication for most patients using mechanical ventilation via tracheostomy is with the cuff down or absent. As noted above, this requires that the patient has no trouble with chronic aspiration of food or fluids, that the vocal cord mechanism be intact, that the windpipe itself be clear above the tracheostomy tube, and that the patient has the ability to form intelligible speech (which may be absent in the later stages of ALS).

With this method of speech production, air enters via the tracheostomy from the mechanical ventilator, and exits (at least in part) through the mouth. As noted above, the tracheostomy tube must be cuffless or have the cuff deflated, and the tracheostomy tube must be of the appropriate size for the individual's trachea in order to allow adequate egress of air during exhalation.

Occasionally this may require direct inspection of the interior of the windpipe for adequate sizing. Most patients can produce adequate speech in the absence of any additional valves. However, because the air for speech production enters during inhalation, the affected individual must learn to produce speech during inhalation, which is counter-intuitive for many, but essentially all patients master this. Because speech occurs during inhalation, sentence structure tends to be somewhat choppy. With experience, many patients learn to develop relatively natural patterns of speech geared to their ventilatory cycle.

Currently, there is only a single one-way valve, the Passy-Muir Tracheostomy Speaking Valve, available for use with the ventilator. This device, manufactured by Passy-Muir, Inc., allows air to enter the lungs through the tracheostomy tube, but it must leave by way of the mouth and throat. As a result, speech patterns can be more normal, with speech occurring appropriately during expiration, allowing for variation in phrase length. As an example, one of our patients runs a business requiring extensive phone contact. Most individuals speaking with her are unaware that she requires mechanical ventilation, and many of her casual acquaintances do not know of

Valve Placement for Use with Ventilator Users



Reprinted with permission of Passy-Muir, Inc.

her mechanical ventilation, even while in her presence.

This form of speech during mechanical ventilation is best for patients with chronic respiratory failure due to neuromuscular disease. It is less appropriate and often more difficult in patients with chronic bronchitis or emphysema, for the reasons noted above. In addition, a significant amount of education may be necessary for both the patient and caregiver, although virtually all patients with a normal mental status and normal muscles of vocalization will be able to generate speech successfully.

In summary, tracheostomy positive pressure ventilation may be life-saving, and the prospect for excellent speech is quite good. In some individuals it may be even better than before, because breathing larger volumes may allow a stronger voice. Patients with substantial disability due to neuromuscular disease may find that mechanical ventilation with a tracheostomy changes their level of function very little. Many continue to lead a full life, which may even include international travel (see "Travel by Air 'With Air' is Possible" by Lori Hinderer, *I.V.U.N. News*, Spring 1992).

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Editor's Note: The Passy-Muir Tracheostomy Speaking Valve was invented in 1985 by David Muir, quadriplegic due to Duchenne muscular dystrophy, and has now been used by more than 100,000 people worldwide. The low cost of the valve is covered by Medicare and Medicaid. Contact Passy-Muir, Inc., 4521 Campus Dr., Suite 273, Irvine CA 92715. 714/833-TALK; outside California, 800/634-5397.

The Cof-flator Revisited

by Judith R. Fischer

Originally produced by the O.E.M. Corporation, the Cof-flator was a wonderful device used by many respiratory polio survivors in the late 1950s and 1960s to help them produce a good cough and clear secretions. Unfortunately, the Cof-flator became an endangered species, protected largely by polio survivors who diligently maintained their machines. Now, however, the J.H. Emerson Co. is offering the Emerson In-Exsufflator to help individuals without tracheostomies clear secretions. The equipment gradually applies a positive pressure to the airway, then rapidly shifts to negative pressure. The rapid shift in pressure, via a face mask, produces a high expiratory flow rate from the lungs, simulating a cough. This technique is referred to as "exsufflation with negative pressure."

People who might benefit from the use of the In-Exsufflator include anyone with an ineffective cough due to muscular dystrophy, ALS, myasthenia gravis, high level SCI, post-polio, etc. The In-Exsufflator may also treat ineffective cough due to emphysema, cystic fibrosis, bronchial asthma, and bronchiectasis.

Cost of the machine is \$2,500, and an individual must have a physician's prescription to order one. Equipment specifications can be obtained from J.H. Emerson Co., 22 Cottage Park Ave., Cambridge MA 02140, 800/252-1414.

The following excerpt from "Intermittent positive pressure ventilation via the mouth as an alternative to tracheostomy for 257 ventilator users" by John R. Bach, MD, Augusta Alba, MD, and Louis Saporito, RRT, emphasizes the efficacy of mechanical exsufflation. The article appeared in *Chest*, January 1993, pp. 174-182, and is reprinted with permission of *Chest*.

... Airway secretion management, particularly during respiratory tract infections (RTIs), is the most frequent reason that patients with chronic alveolar hypoventilation are hospitalized or intubated. This is particularly true for patients receiving no or only part-time ventilatory aid. Individuals receiving ventilation either intubated or with indwelling tracheostomies, however, have increased risk of nosocomial morbidity and mortality. This study implies that individuals using noninvasive methods of ventilatory support may also experience increased risk of nosocomial morbidity and mortality, particularly when associated with general anesthesia and surgery. We have noted this to be true especially when such procedures are undertaken without the intimate participation of clinicians proficient in using noninva-

sive respiratory muscle aids. Lack of clinician familiarity with and confidence in using noninvasive techniques leads to patients remaining intubated for unnecessarily long postoperative periods.

... By avoiding tracheostomy with the use of noninvasive aids, natural airway secretion clearance mechanisms remained intact. This made airway secretion management a problem only during intercurrent RTIs or following intubation for surgery. Along with the use of mechanical exsufflation, the effective use of manually assisted coughing techniques can be important for avoiding pulmonary complications. For individuals with less than 1 L of vital capacity, the use of manually assisted coughing should be preceded by a glossopharyngeal breathing-assisted deep breath or an assisted deep insufflation with the use of a manual resuscitator, positive pressure blower (Zephyr, LIFECARE, Inc., Lafayette, Colo), portable ventilator, or intermittent positive pressure breathing machine, to maximize peak cough expiratory flows. Since manually assisted coughing techniques cannot be used efficiently during tracheostomy IPPV and are difficult to employ effectively even in the presence of a plugged tracheostomy tube, the techniques have been largely forgotten and widely underutilized. The minimum of 5 to 6 L/s of peak cough expiratory flow necessary for airway secretion clearance, however, can usually readily be provided for patients with neuromuscular ventilatory failure by using these techniques. In the presence of severe scoliosis or during severe RTIs, manually assisted coughing is often inadequate and mechanical exsufflation becomes vital.

The manufacture of mechanical exsufflators ceased in the early 1960s, and exsufflators have only recently become available (J.H. Emerson Co, Cambridge, Mass). Access to these devices has been restricted, therefore, to the relatively few individuals who have owned and maintained them over the years and to patient care networks in which the devices are shared and made available to patients in time of need. During use, the success of mechanical exsufflation can be observed objectively by the appearance of mucus in the patient's mouth or the excufflator mask, the increase in oxyhemoglobin saturation during and immediately following use by auscultation,

and the increase in pulmonary volumes observed with the clearance of mucous plugs. In addition, 6 to 11 L/s of peak expiratory flow can be conveniently and reliably generated during mechanical ex-sufflation. Clinical and physiological studies demonstrated the safety and efficacy of this technique in the 1950s, and we have come to rely on it to permit continuation on noninvasive ventilatory support during RTIs, for achieving earlier extubation of ventilator-assisted patients, and for preventing postoperative pulmonary complications particularly following abdominal surgery.

We are currently surveying the number of hospitalizations and serious pulmonary complications, including atelectasis and pneumonia, in 24-h noninvasive ventilatory support users, including some patients who use body ventilators as part of their daily regimen. Ninety-five such individuals for whom reliable data could be obtained reported 41 hospitalizations for pneumonia or atelectasis and 134 total pulmonary hospitalizations, mostly for management of intercurrent upper RTIs, in 1,376.8 patient years of 24-h use. This amounted to 0.43 percent serious pulmonary complications and 1.41 hospitalizations over 14.5 years of 24-h use of noninvasive ventilatory support. These figures, which thus far are significantly better than for patients using nocturnal ventilatory aid only, indicate that irrespective of the extent of ventilatory insufficiency, patients for whom alveolar ventilation is maintained within normal limits 24 h/d and who have access to effective noninvasive airway secretion clearance methods, have very low incidence of serious pulmonary complications. Since none of these patients received supplemental oxygen therapy, these results call into question the all-too-common practice of treating patients with chronic alveolar hypoventilation with oxygen therapy rather than ventilatory assistance.

In conclusion, the use of noninvasive IPPV techniques, and in particular mouth IPPV that can be effective and practical for both day-time and nocturnal ventilatory support, can indefinitely spare many individuals with ventilatory insufficiency from intubation or tracheostomy for ventilatory support. This can allow many to effectively use glossopharyngeal breathing for ventilator-free time, to provide perfect security in the event of sudden ventilator failure, and to give deep breaths for assisted coughing. Access to reliable and effective manually assisted coughing or mechanical exsufflation is also critical for the long-term success of an entirely noninvasive ventilatory support regimen.

I.V.U.N. Directory Update

Use this update as a companion to the Directory published in I.V.U.N. News, Fall, 1992, Vol. 6, No. 2. Corrections and changes are underlined.

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Portable Positive Pressure Ventilators: A History

by Jerry Daniel

Today's positive pressure ventilator, with its rugged portability, minimum size, and smooth 12V battery operation, is the end product of two entrepreneurial engineers working near Boulder, Colorado, in the late 1970s. Both Richard Apple and Tommy Thompson were designing and manufacturing volume ventilators based upon a small, general purpose motor used for car window mechanisms.

This highly efficient little motor is shaped like a flying saucer, but does not have coils of wire like traditional motors. The gearbox is built into the compact design. Apple chose a version with grease in the gearbox, while Thompson used an oil-filled gearbox.

The two engineers were able to build ventilators that were lighter and smaller than any of the positive pressure ventilators made up to that time. There was a profound need for a truly portable ventilator to mount on electric wheelchairs or to use for other mobility applications. Hospital ventilators were too large and cumbersome for home care needs.

Thompson had produced a series of ventilators, both negative and positive pressure, some large and some small. His Bantam for positive pressure use was housed in a small Samsonite overnight suitcase. The packaging was truly small and rugged, but battery operation was limited by its vacuum cleaner blower motor and unstable rate motor technology. His first negative pressure unit, the Maxivent, has the power and stable rate control to drive any of the negative pressure enclosures used today. Because of the motor power required, it operates only on AC and is tabletop size. The Maxivent is still marketed today, but by Puritan-Bennett.

With the new motor, Thompson turned his attention to piston-type volume ventilation and put this new design into the same Samsonite suitcase which had been so popular. Now he had a unit that was ruggedly portable, stable in rate,

and a miser in 12V battery operation.

Apple had worked for several home ventilator manufacturers in Colorado and felt he could produce a better positive pressure ventilator. In 1976 he went into his machine shop basement and designed his version of a truly compact and stable volume ventilator. He made several models and kept improving the design, finally coming up with his first production model, the Life Products No. 3 or LP3.

Apple made contact with Craig Hospital in Engelwood, Colorado, and received feedback from both patients and pulmonary medical professionals. He promoted the LP3 himself; product manufacturing was paid for by product sales — no venture capital. The first LP3s sold for \$2,300. But Apple was up against stiff competition because Thompson's suitcase ventilators were popular.

The LP3 used the minimum amount of aluminum for strength and light weight, and was similar to the Maxivent in performance and battery operation, but it had one feature that made it more user friendly. Apple designed a unique electromechanical system for changing the length of the piston stroke while the machine was operating, actuated by pressing on a toggle switch until the desired volume was seen on an indicator. The volume change on the Thompson units was done by holding down a spring tab while rotating a knob and had to be done with the machine off.

The competition between Thompson and Apple was going strong. There was a need to provide setup modes that were closer to the options on hospital units such as the MA-1. The LP3 and early Thompson units operated only in continuous cycle with a 1:1 inspiratory to expiratory ratio. Thompson and Apple found that they could offer mode setup options on their units with very few mechanical changes, using electronic control of motor speed and timed intermittent motor operation. This enabled setups of a short inspiratory time and longer expiratory time. Thompson's first suitcase unit to meet this requirement was the M25-B and Apple's LP3 was electronically enhanced to become the LP4. Some of these ventilators are still around today.

Jerry Daniel owns and uses two LP4s, and keeps one in the bedroom and one in the living room. He services the complete line of LP ventilators under the business name of VENTEK.

The early 1980s were a period of more advanced electronics in portable ventilators, with larger and more complex circuit boards. Thompson's Companion 2500 was the M25-B with more sophisticated electronics. He then came out with a completely new ventilator, the Companion 2800, with microprocessor control and the same motor, but with a tachometer. Apple used that motor in his LP5. The tachometer and microprocessor electronics gave split second rate and inspiratory time control. Apple then produced the LP6 with his own brushless motor design.

After this flurry of development, Tommy Thompson sold his company to Puritan-Bennett in Lenexa, Kansas, and Rich Apple sold his to Aequitron Medical in Minneapolis, Minnesota. Both engineers soon went into retirement in Boulder, Colorado.

LIFECARE's history is different. Jim Campbell, the founder of LIFECARE, is not an engineer, but a retired IBM business manager who formed his company in the late 1960s, purchasing a wide variety of negative and positive pressure ventilators from the National Foundation for Infantile Paralysis (later known as the March of Dimes). Campbell organized an excellent service operation, with district offices spread throughout the United States.

Many of the machines Campbell acquired from the National Foundation were large and heavy, and had poor or no battery operation. Parts became a problem. Campbell had to provide his large base of ventilator users with a state-of-the-art ventilator to compete with Thompson's and Apple's units. He entered into a legal agreement with Apple and Life Products for manufacturing rights to the LP3. He called his version the portable volume ventilator or PVV, and leased it to many positive pressure ventilator users. His engineers made only minor changes in design. Under the agreement with Life Products, he could only lease the ventilator.

In the early 1980s, Campbell had his engineers working on a portable ventilator to compete with the Companion 2800 and LP6. The PLV-100 came to market in 1984, and many of LIFECARE's PVV users were switched to the PLV-100 under lease or purchase. Campbell then went a step further by coming out with the first portable positive pressure ventilator, the PLV-102, to integrate oxygen into the positive pressure breath with proportional control and calibration of O₂.

Today, Aequitron Medical, Puritan-Bennett, and LIFECARE are companies of high integrity

that compete strongly in the limited portable ventilator market. All three companies have had problems with the Food and Drug Administration (FDA). While agreeing with the need to correct problems, the manufacturers often disagree with FDA's slow and bureaucratic methods. These manufacturers all listen to ventilator users and pulmonary health professionals to help them make a better product.

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CHAMP Camp,
1992



Camps for Ventilator-Assisted Children

April 17-23, 1993. Ventilator-Assisted Children's Center (VACC), Florida. Contact Cathy Klein, VACC, 3200 S.W. 60th Ct., Suite 203, Miami FL 33155-4076. 305/662-VACC.

June 6-11, 1993. Trail's Edge Camp, Michigan. Contact Mary Dekeon, RRT, C.S. Mott Children's Hospital, 200 E. Hospital Dr., F3064, Box 0208, Ann Arbor MI 48109. 313/936-7339.

June 28—July 3, 1993. CHAMP (Children Have A lot of Motivation & Potential) Camp, Recreation Unlimited near Columbus, Ohio. Cost per week is \$150 (scholarships available). Contact David Carter, RRT, CHAMP Camp, P.O. Box 40407, Indianapolis IN 46240. 317/875-9496 or 800/96-HAPPY.

August 15-20, 1993. SKIP Camp, Camp Courage, Minnesota. Contact SKIP Camp, 11208 Minnetonka Mills Rd., Minnetonka MN 55343. 612/620-6027.

September 2-5, 1993. SKIP of Louisiana. United Seashore Methodist Assembly, Biloxi, Mississippi. Alternate date: September 9-12, 1993. Contact Judy Abney, SKIP of Louisiana, 118 Ned Ave., Slidell LA 70460. 504/649-0882.



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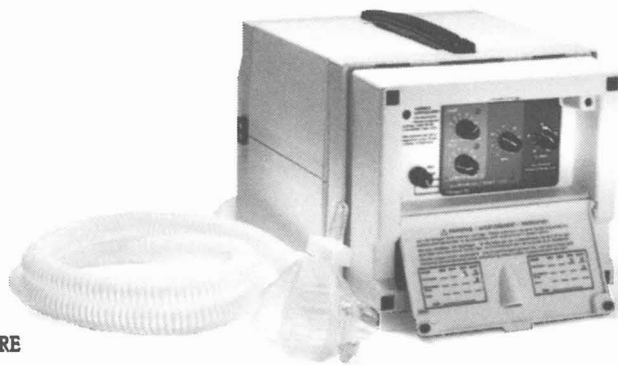


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Profile: Bill Kibbie

by Betty Scharf, RN

"If you are distressed by anything external, the pain is not due to the thing itself, but to your own estimate of it. This you have the power to revise at any moment."

— MARCUS AURELIUS

Do you think ALS is terminal?" Bill Kibbie asked. "What's terminal about it?" Since Bill has lived for 20 years with ALS, I had to stammer, "Bill, you are probably going to die of old age."

Now 61 years old, Bill has used a ventilator for the last 15 years. He is a living testament to the philosophy that life is precious and that one can enjoy purposeful days and accomplish a great deal despite being a complete quadriplegic. Bill says, "After I went on the ventilator, I've been very busy. I've bought two homes, and received patents for my inventions. So, it isn't the end of life."

Bill is aware that life with a ventilator is not for everyone and he thoughtfully states, "Some people do not want to live like this, but for those who do want to live, it is not bad." Bill concurs that part of his optimism is due to the unique fact that he can still speak — an ability due partly to the way his trach is used and partly to the fact that his tongue, lips, vocal cords, and palate are relatively unimpaired.

Bill has no family, and has had to take the responsibility for arranging his home environment, hiring his caregivers, and planning his care down to the last detail. Bill is aided in his extraordinary accomplishments by his extraordinary nurse and friend of 15 years, Mary Barrett, RN. Mary not only oversees Bill's care under his direction, but helps him hire and train round-the-clock nursing personnel.

Bill observes that he would be reluctant to ask a wife or family member to live with the care and expense of ALS. He has had the energy to patent his inventions, see friends, and even celebrate New Year's Eve with champagne, albeit down his feeding tube.

Diagnosed at age 41, Bill was an insurance specialist with State Farm Insurance. As I looked around at his equipment and nurses, I joked, "You were obviously well covered with insurance." His eyes sparked and with a wide smile he said, "You bet." He said his company has been very good to him.

Bill is sensitive to the fact that not all PALS (Persons with ALS) have the good fortune to have the kind of insurance that has provided him the opportunity to lead the kind of life he enjoys. He has high hopes for health care reform that will make ventilator use available for all PALS who choose that path. Bill knows there are enormous savings that can be made in home care. And he does it with everything from bra hooks to baby bottle nipples! Here's how.

NUTRITION AND FEEDING. Bill has a feeding tube that is inexpensive and easy to change. He uses a simple urinary soft rubber catheter tube. He does not use the balloon to keep the tube inside the stomach. He believes balloons or other devices lead to corrosion inside the stomach wall after longterm use.

Tubes require some kind of stability so they do not come out or even sink in. Bill and Mary have devised their own system. A Stomahesive covering of the kind for ostomy appliances is carefully positioned over the gastrostomy. Next the tube is threaded through a baby bottle nipple that is taped onto the flange. The nipple tip is cut to securely hold the feeding tube catheter in place. It is easily changed every few months.

Bill only takes normal food that is blenderized and fed with a syringe into the feeding tube:

Breakfast: Protein: yogurt. Several kinds of soft fruits, oat bran.

Lunch & Dinner: Protein: fish, chicken = 20% of calories; carbohydrates: rice = 20% of calories; and vegetables = 60% of calories.

Foods not recommended by Bill are pasta, potatoes, bread, apples, bananas — foods that he believes bind. Bill takes multivitamins and minerals along with a daily stool softener. He has maintained good health, color, and weight with the above eating plan. His diet only varies on New Year's Eve!

Continued on page 10

Profile: Bill Kibbie

Continued from page 9

KIBBIE BED. Bill has a patent on the unique wooden outer cradle for his vibrating bed. Bill uses the vibration daily during his respiratory care. The cradle turns side to side for this treatment. The bed also positions Bill into a standing position. For standing, he is carefully strapped onto his mattress — even his head is held in place by a strap around his forehead. The bed is then put in a standing position. Bill “stands” for one hour daily. This exercise has many positive benefits for any person who is bedridden. The “stand” puts pressure on the feet to prevent foot drop and pressure on the skeletal system to help prevent calcium loss, and relieves pressure on his back. It also gives him a psychological lift to be in a standing position.

FLEXIBILITY. Bill receives range of motion exercises three times daily. He uses a large padded footboard and wears foot splints. His hands rest on slightly elevated hand/arm supports.

TRANSPORTATION. Bill uses a van for doctor visits and getting around. He finds traveling in an electric wheelchair uncomfortable, so he uses a regular hospital gurney for traveling. He has added shelves for his ventilator and for extra space and support for his arms.

RESPIRATORY CARE. Bill chose to have a tracheostomy 15 years ago when his secretions were putting him at high risk for pneumonia, etc. Bill put his inventive mind to work again. He uses a stainless steel trach that doesn't wear out and therefore does not need expensive periodic replacement. He has fastened the inner cannula with a bra hook and a round metal disk to keep it in place. He does *not* use a cuff. (A cuffed trach is a balloon-like device that can be inflated inside the trachea to hold the trach cannula in place. An inflated cuff prevents air from moving through the vocal cords for speech.)

Bill feels that with the proper ventilator settings all PALS who have a trach need not use a cuff and *may* be able to speak (if their vocal muscles are not impaired). Cuffs can cause ulceration and infections that may result from the cuff's pressure on the inside of the trachea. Dr. Earl Kiernan, Bill's pulmonary physician, has become his friend and supporter.

Bill has his friends sew baby diapers into 3 X 4 inch squares. He uses these by folding one and holding the long edge in his teeth to act as

a wick for his excessive secretions. For reuse, these “Kibbie mouth sponges” are soaked in bleach and then in baking soda water to remove any taste of bleach.

Bill's mouth is suctioned with a tonsil tip (Yanquer) hard plastic catheter. The tip is kept soaking in a quart-size plastic bottle filled with vinegar/water solution — 1 part vinegar to 5 parts water. For suctioning his mouth, Bill has connected his tubing, through a small hole in the wall behind his bed to a garage vacuum cleaner (the kind that collects water) that sits outside his house (only in California!). When the vacuum cleaner is full, the secretions are carried to the toilet and flushed away.

For suctioning his trach, Bill uses a regular portable suction machine. Bill has devised a clever way to suction his trach without removing the ventilator tubing by attaching a Portex device to the end of the trach. It has a small lid that can be opened to put the suction tube through. While Bill is being suctioned, his ventilator continues to give him air.

Over the years, Bill has increased the amount of normal saline he uses to thin secretions. He is able to tolerate 10 ccs of normal saline for as long as an hour. He then is suctioned for the final cleaning. (Most PALS *cannot* tolerate this amount of normal saline for that long at the beginning.) Bill also uses soft rubber suctioning tubes which are not as painful as the firmer plastic ones.

Bill believes that his relative freedom from pneumonia is due to the 10 ccs of normal saline wash and soak, vibrating his bed for 20 minutes while lying on each side, the use of the rubber suction tubes, and good nutrition.

URINARY CATHETER. Due to prostate problems, Bill decided to live with a urinary catheter. He has been relatively free of the infections that are common with longterm catheters. His catheter is replaced twice a week. Daily hygiene includes an antibiotic ointment (gentamicin) around the urinary entrance and a paper towel wrapped around the first foot of catheter tubing. This wrapping discourages bacterial contamination.

STERILIZATION. Bill has devised a number of ways to semi-sterilize syringes, tubings, and respiratory care items. A bookcase-like piece of furniture next to his bed has ultraviolet lighting placed inside each shelf to kill much of the usual bacterial growth. Suction catheters are placed there. Curtains cover the front of the bookcase. Cold sterilizing fluids, ultraviolet light, vinegar

water, and bleach are all used in various ways to cleanse his equipment.

ENVIRONMENT. Bill has a very large room from which he "directs." He is the only PALS I know with his FAX machine close by. Several cameras are transmitting from around his house — you can't drive into Bill Kibbie's driveway without him seeing you coming.

Bill has many visitors because people like to visit with Bill. Mary says they regularly come to "roast" Bill. One gets the idea of an executive board room with Bill as the CEO with a great sense of humor.

Bill wants to share what he has learned during the past 15 years. He wants to see our government reform health care so that it includes home care for ventilator users. He wants that care to reflect ways that can be reasonable and economical. Bill has become an activist, so you'll be hearing more from Bill Kibbie.

ADDRESS: Bill Kibbie, 13942 Deodar St., Santa Ana CA 92701, 714/541-6062.

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*Additions of recent articles to the bibliography published in the Fall 1992 issue of *I.V.U.N. News*, arranged in order of most current publication date.

Internet PALS Sought

Bob Broedel has offered to create a directory of contact people, computerized bulletin board systems, BITNET/Internet discussion groups, etc. Anyone interested in ALS with e-mail capability can call Broedel, 904/644-6840 or write Bob Broedel, Engineer, Meteorology Dept., Love Bldg., Room 404, B-161, Florida State University, Tallahassee, FL 32306-3034.

Lyon Meeting Information Available

Over 1,400 health professionals and ventilator users attended the Fourth International Conference on Home Mechanical Ventilation in Lyon, France, in early March.

Conference organizers, Dr. Dominique Robert and Dr. Patrick Leger, report that proceedings of the scientific sessions will be available in both English and French by the end of 1993.

Abstracts from the practical education sessions and poster sessions were distributed at the conference and are available. For more information contact: J.I.V.D., Hôpital de la Croix-Rousse, Service de Réanimation et Assistance Respiratoire, 93, Grande rue de la Croix-Rousse, 69317 Lyon, Cedex 4, France. Telephone (33) 78 39 08 43; FAX (33) 78 39 58 63.

New SSI Rule May Benefit Children

Children with disabilities may receive higher SSI benefits as a result of a new method used by Social Security to compute the effect of their parents' income on their monthly payment. The new rule, effective November 1, 1992, eliminates two of the three formulas previously used to determine how that income will affect a child's eligibility for SSI and the amount of the monthly benefit payment.

Two groups of children are encouraged to contact Social Security to determine if the new rule affects their eligibility: 1) children whose applications for SSI benefits were filed before November 1992 and who were denied benefits based on their parents' income; and 2) children for whom no application was filed because it was believed their parents' income would make them ineligible.

For more information about the new SSI rule for children, call 800/772-1213, weekdays between 7 a.m.—7 p.m. or contact the local Social Security office.

Sailing with a Ventilator

by Audrey King

The travel bug bit me again! I succumbed to temptation and sailed Holland on a century-old two-masted clipper in September 1992. After all, my reputation for challenging the improbable simply had to be maintained!

We were a group of 20 (about eight wheelchair users and me as the only ventilator user) with a wide range of interests, abilities, and energy. My first glimpse of us all at the airport gave me instant respect for Cathy, our visionary tour organizer at the Ontario March of Dimes. We got off to a roaring start, delaying the plane, of course. The KLM crew were fabulous. They patiently assisted, moving us all to business class where the seats were roomy and the food served on tablecloths with real china.

The overnight flight was uneventful. I kept my ventilator stowed nearby just in case I wanted to snooze, but sleep was an impossibility for anyone. Time went fast and before we knew it we were descending through the gorgeous red-tinted clouds of a Dutch dawn to Schipol International Airport. Disembarkation went without a hitch. Luggage was collected and an accessible Jonk Tours motorcoach awaited to take us to Amsterdam.

I was impressed with the motorcoach and regretful that such a service does not exist in Canada. The lift at the rear side of the vehicle was fast, and the tie-downs for up to eight wheelchairs ingenious, safe, and quickly affixed by the driver. The ride was comfortable and the morning glimpse of rural Holland misty and tranquil.

As we approached the city, the charm and character of Dutch homes became more evident; little, tidy, and quaint with dainty lace curtains and small doorways. The bricked streets of Amsterdam seemed frighteningly narrow. Obviously the town was built hundreds of years before wheelchairs or highway coaches were even conceived of. Accessibility could be a problem.

We found the *Lutgerdina*, our floating home for the next eight days, docked and waiting by

Audrey King, respiratory polio survivor since age 9, frogbreathes during the day, and at night uses a Healthdyne face mask with a PLV-100 ventilator.

the Central Station. Many of our group later confessed that their first sight of this 110-foot clipper, built in 1897 to transport coal and sand on the Rhine, was a shock. She was not large. She was not new. Her paint was peeling and she did look a little tired and worn. Inspection below deck revealed we would be sleeping four or six to a cabin with a sink squeezed between double bunks and barely enough room for even one wheelchair. It would indeed be a challenge to get a suitcase open, let alone find a place to stow it.

The *Lutgerdina* had been ingeniously refitted with accessibility in mind. A ramped gangway from the main deck brought one to a closet lift besides the stairs which enabled access below deck. Here a large common area featured a basic kitchen and two large tables with benches built along two sides. This openness encouraged sociability and enticed us to congregate and participate in every activity, including meal preparation.

A thick, supposedly soundproof, sliding door separated the adjacent sleeping cabins for the convenience of those who wished to retire at a reasonable hour. It didn't work, and a market in earplugs was soon established. I simply burrowed under my thick duvet (sleeping with a mask and airhose guarantees a ready supply of air without fear of suffocation).

The two accessible washrooms with corner showers and wall heaters were roomy and convenient. In the tiny cabins, upper bunks could be fastened against the wall for ease of transfers. This design worked well, depending on the number of suitcases temporarily stowed up there or the presence of a still sleeping body. In the morning it was not uncommon for me to dress, wash, and clean my teeth "horizontally" in the darkness of my lower bunk while waiting for a "horizontal" transfer.

I experienced no difficulties traveling with my ventilator, but it did take a night or two to establish the most reliable source of power. Prior to the trip, I had, as usual, researched the nearest resources and carried letters to allay potential airport security fears as well as ease permission, if necessary, to carry my equipment on board. Although I had also obtained advance information about the boat's electricity and carried a 110-220V transformer, it was not possible to run the ship's generator at night.



Audrey on the floor of the Waddenzee

The skipper diverted the required 12 volts from the ship's 24V battery for night-time ventilator use. The ventilator functioned normally but voltage fluctuations kept triggering the ventilator alarms. (This does not increase popularity with bunkmates!) The skipper solved the problem by running a cable from the ship's emergency 12V battery at the front of the boat down through my overhead porthole. I could also have used the 12V battery of my wheelchair, but it too could only be charged when the generator was running during the day. (On future trips I plan to carry an extra 12V battery.)

We spent two days immersing ourselves in the sights and culture of Amsterdam. We pulled anchor and sailed through the locks to Muiden; the next day to Markken, then Hoom, famous for the Dutch East India Company. Everywhere there were canals and old brick streets to negotiate, plus lots of little shops along narrow alleyways and a danger of easily getting lost.

Both disabled and nondisabled alike were expected to hoist the mainsail, haul in the yard arm and change tack. Everyone was needed and it wasn't long before even the most timid took a turn at the wheel or a rope. The crew were wonderful. Young, energetic, entertaining, encouraging, hospitable, and mischievous to boot. We were the first international group for them and they seemed fascinated by Canadians.

We sailed through the locks and barrier dams of the IJsselmeer, the wind in the huge brown sails carrying us swiftly and silently towards the North Sea. We anchored in a shallow part of the Waddenzee and waited for the tide to rest our

flat-bottomed boat on a sand bar. Once grounded, the crew hastily assembled a steep makeshift chute, and, one by one, we went over the side, each of us cradled trustingly against the crew member slowly easing us down. Being on the floor of the sea with the crabs and the wind in the middle of nowhere was truly an amazement.

It was sad to leave the *Lutgerdina* and her crew. With mixed emotions we boarded the motorcoach and headed sought to Loosdrecht. From the dock of the Baron Loosdrecht Hotel we loaded our tired bodies and gear onto the little ferry from Robinson Crusoe Island. Although the island, situated on a shallow peat lake, was surprisingly tiny, the cabins it featured were large. It was a relief for many to have roomy bedrooms and to finally be able to easily access their luggage.

The island featured "accessible" water sports. After a good night's sleep, with energies renewed, watersport activities captured everyone's interest. The kayaks, canoes, and catamaran were in constant use during the next few days. The prize winning Rollerboat, a sailboat one can access in a wheelchair, provided particular excitement on a windy day. Thank goodness I came equipped with an extra seat belt.

Two weeks so packed with challenge and adventure passed very quickly. Before we knew it our motley group was gathered once again at the airport, delaying the plane again, of course, as we boarded, tired but happy and full of tales to tell.

ADDRESS: Audrey King, MA, Coordinator, Family & Community Liaison, The Hugh MacMillan Rehabilitation Centre, 350 Rumsey Rd., Toronto, Ontario M4G 1R8 Canada.

Editor's Note: Audrey's tour was organized by Catherine Smart, Coordinator of Camping and Recreation, the Ontario March of Dimes, 416/425-0501. Another Dutch boating experience is planned for June 1993.

Deadline ...

for submission of articles, stories, information, etc. for the Fall 1993 issue of *I.V.U.N. News* is August 15, 1993.

Please send to:

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Mobility and ALS

by Marcy Ballard

On May 27, 1992, my husband Jim's physician finally diagnosed ALS as the condition responsible for his severely weakened body. On June 10, Jim was emergency hospitalized due to respiratory distress, and he soon had a tracheostomy and a ventilator. The pulmonary specialist assured Jim that he could be "on" the ventilator at night, "off" in the daytime, and have a normal life with some good quality time. After 12 weeks in the ICU, heroic attempts on Jim's part to be weaned from the ventilator came to a halt. Family members dubious of the successful weaning of a 68-year-old man who had respiratory failure within a week of his diagnosis suspected that he was most likely experiencing increasing respiratory difficulties due to the progression of ALS. Jim was then moved to a private room and our family was trained in dealing with the ventilator, suctioning, and other aspects of home care.

Unfortunately, our HMO, which would provide the home nursing care, required Jim to be in their ICU for three weeks before his final discharge home. During this time, he suffered from ICU psychosis and called the particular hospital, unlike his previous hospital experience, a labor camp. He finally came home in late August.

The challenge once Jim was home was to become mobile. Jim wanted more than anything to go to his favorite spot in the Sierras. But coming home with a huge 120V battery difficult to lift and a wheelchair with permanent ventilator and battery trays underneath made any trips impossible without a van — the wheelchair was designed for someone nonambulatory who traveled in a van. Jim was (and is) ambulatory; he walks up and down stairs to and from the car while being given puffs of air from an ambu bag. He sits in the passenger seat in the car, hooked up to the ventilator placed on the seat behind him. Jim uses a wheelchair outside, but is mainly ambulatory inside our home.

Our discovery of John Cains, a design genius at Grandmar Enterprises (510/428-0441) in Emeryville, California, enabled us to become mobile. Screws and bolts (18!) had had to be removed from the wheelchair tray, then put back again when we went out, so John designed two wheelchair trays: one for two 12-volt batteries and one for the PLV-102 ventilator, both of which can be easily hooked and unhooked. He also designed simple red and black plastic connectors to hook the external batteries up to the ventilator. John gave us the knowledge and confidence to help Jim do many of his previous activities. Jim went to the movies recently and even ate nachos!

ADDRESS: Marcy and Jim Ballard, 2 Arbor St., San Francisco CA 94131.

Nasal Mask Adjustments

Many respiratory polio survivors are exchanging their old ventilatory aids, such as a chest shell or body ventilator or rocking bed, for the new and more efficient nasal or oral/nasal mask. Adjusting to the new technology is not easy, with numerous complaints about claustrophobia, problems with leaks, facial sores, and nasal congestion.

Polio survivors, being the inventive lot that they are, have come up with solutions. Most put some kind of ointment (Destin, for example) on the facial sores then covered by a telfa pad or micropore tape, and several put a piece of cloth between the skin and the mask. One individual even used three chewed sticks of bubble gum (sugarless, of course) to seal a leak.

Many find adjusting to Bi-PAP to be easier. Dr. Peg Nosek writes, "If you have recently developed nocturnal hypoxia, the Bi-PAP is far preferable to volume ventilators ... It is a minimal intervention, cheaper, and easily portable ... Even more important than the machine is use of nasal or oral/nasal masks (custom-made). Using this machine and a nasal mask has made a dramatic difference in my stamina, productivity, and longevity. My only problems have been with nasal, sinus, and throat dryness. I understand that Respironics now has a humidifier as an accessory."

LIFECARE is offering an instruction manual, *Custom Nasal Mask*, showing how to create a custom-fitted silicone mask step-by-step. Call 800/669-9234 for information on receiving a copy of this manual and/or for information on ordering LIFECARE's nasal mask kit.

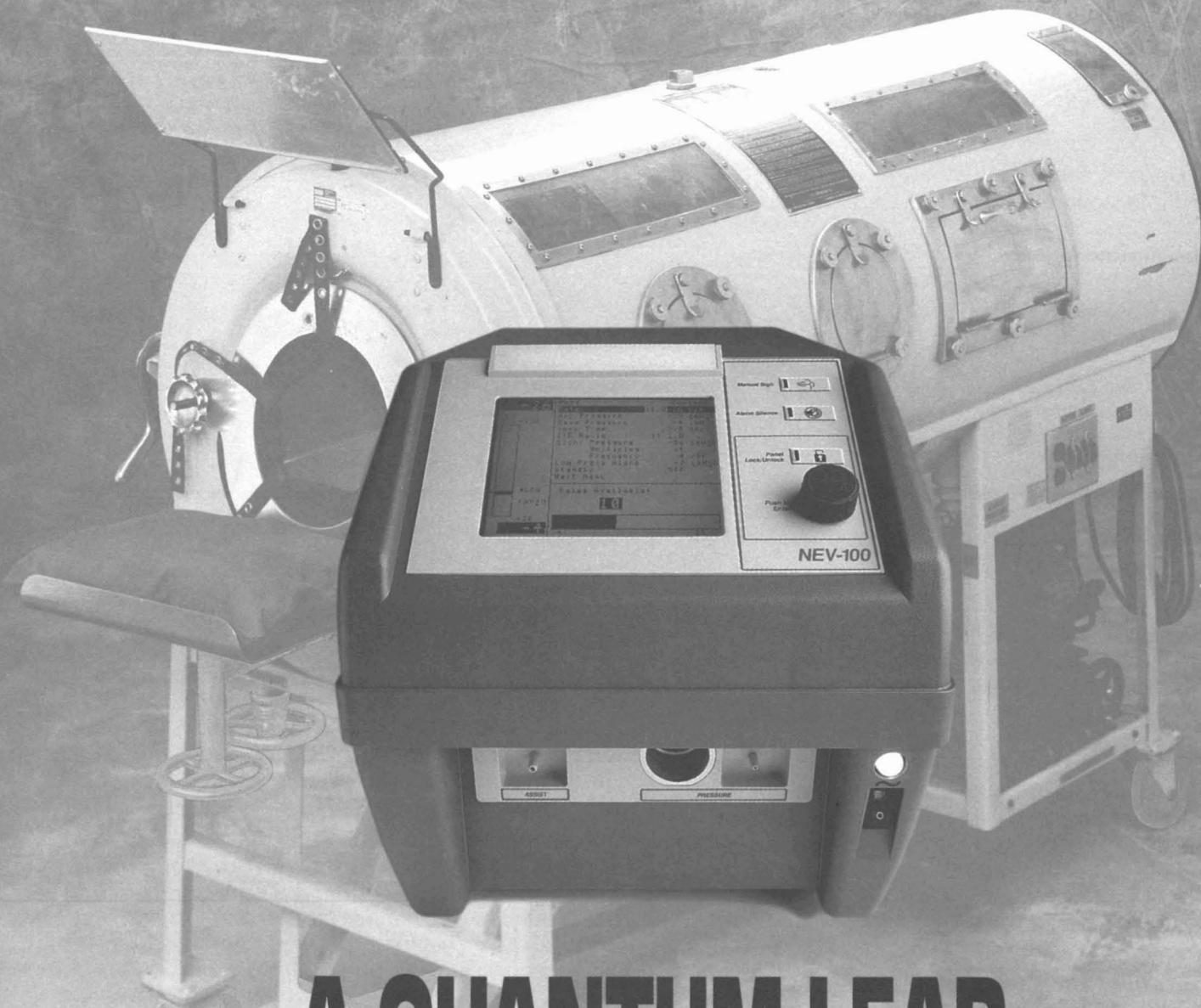
Other *I.V.U.N. News* readers with tricks and techniques for adjusting to oral and nasal masks are encouraged to share their ideas by sending them to the I.V.U.N. office.

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Potpourri

BOOKS, MANUALS, ETC.

Ventilators: Alternatives for Long-Term and Home Use: A manual for people who are considering the long-term use of a ventilator at home by E. A. Oppenheimer, MD, and Adrienne Baldwin-Myers, RN, MSN. An excellent resource with discussion of all the forms of negative and positive pressure mechanical ventilation, with illustrations, specifications — everything anyone could ever want to know about ventilators. Order for \$15 postpaid from E.A. Oppenheimer, MD, Pulmonary Medicine, Southern California Permanente Group, 4950 Sunset Blvd., Los Angeles CA 90027-5822. 213/667-6796.

Phantom of the Night: Overcome sleep apnea syndrome and snoring. Win your hidden struggle to breathe, sleep, and live by T. Scott Johnson, MD, and Jerry Halberstadt, New Technology Publishing, Inc., ©1992, 184 pages. Available for \$24 postpaid (5% sales tax to MA residents) from New Technology Publishing, Inc., P.O. Box 9183, 955 Massachusetts Ave., Cambridge MA 02139. 617/661-3851.

Living with a Ventilator by Thomas Klaus, MD, and Dan Dubowski, RRT, Bantam paperback ©1993 (just published), \$5.95. Dr. Klaus is Medical Director of Lake Erie Rehabilitation Center in Erie, Pennsylvania, where Dubowski is a respiratory therapist and President of the National Association of Ventilator-Dependent Individuals (NAVDI).

Longterm, Home-based Care: A Report prepared by Richard Daggett and the Polio Survivors Association (PSA), Downey CA. This excellent and well-documented report promotes home-based longterm care as an integral part of health care reform. Supplies are limited. A summary of the report appears in PSA's newsletter. For a copy, write to: PSA, 12720 La Reina Ave., Downey CA 90242, 310/862-4508.

VIDEOS

"Caring for the Caregiver," explores ways caregivers can take better care of themselves, reduce stress, make life easier and more enjoyable, and find help when it is needed. Produced, directed, and edited by Ismail Tsieprati, a filmmaker who has ALS, and his wife and primary caregiver, Cheryl. Cost of the video is available to *I.V.U.N.News* readers for a special price of \$14.95 postpaid. Send check or money order to Valona Productions, 14621 Titus St., Suite 108, Van Nuys CA 91402. 818/785-9982.

"Preparing the Patient and Family for Ventilator Care at Home: A Team Approach," is a 17-minute video made by Fairview General Hospital. Available for a one-week rental \$65 (postpaid) or for sale \$300 (postpaid) from Fairview Audio Visuals, 17909 Groveland Ave., Cleveland OH 44111, 216/476-7054.

Calendar

Pediatric Ventilator Users Network Meeting, May 28-June 1, during the Canadian Society of Respiratory Therapists, 28th Annual Educational Forum, Executive House, Victoria, British Columbia. For exact date and time, contact Jan Nelson, Aquitron Medical, 800/497-4979, ext. 256.

European Respiratory Society (ERS) Annual Congress, September 25-29, 1993, Florence, Italy. Contact ERS, 66 Boulevard Saint-Michel, F-75006 Paris, France, or the American Thoracic Society, 1740 Broadway, New York NY 10019-4374.

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