

IVUN News

From Trach to Iron Lung to Cuirass to Mask Ventilation

Bruni Bung

I contracted polio in 1958 at age 3. At the onset, I was completely paralyzed and used tracheostomy positive pressure ventilation for a few months. After a year and a half, I left the hospital and returned home to my family. I was able to walk again, move my arms and legs, and did not need any breathing aids. I lived a "normal" life and went to school until I was 12 years old.

Then I developed respiratory weakness and had to return to the hospital, where I used an iron lung. The first few months were terrible, being away from my family and friends. After a year in the hospital, I went to live at Pfennigparade (German for March of Dimes), a new rehabilitation center for polio survivors and others with disabilities that opened in 1969. In my unit there were 10 other ventilator users. It was a great time, experiencing and participating in a full life, having parties, attending concerts and plays, and traveling.

With my active lifestyle, I wanted to become more independent of the iron lung, and in 1970 I tried a cuirass. Because of my kyphoscoliosis, I had to have a customized chest shell. It worked well for the next 14 years. I finished school in 1974 and studied at university. I moved out of Pfennigparade in 1975 and went to live in an apartment shared by a friend who helped with attendant care. It was a great step toward independence. I found employment in a publishing house, and

obtained a driver's license and my own car.

My small lung capacity (550 ml) limited my ability to walk very far, and I used a wheelchair for longer distances. I stopped working in 1982 because I was too tired and had no energy. At the same time, I learned that some of my Pfennigparade friends were experiencing post-polio respiratory weakness – some even died. Adolf Ratzka told me about GINI's first post-polio conference in 1981, and I was



able to attend the second conference in 1983. It was a very enthusiastic meeting and I reported on it to other polio survivors and doctors in Germany.

Noninvasive positive pressure ventilation via mouthpieces and facial or nasal masks was the most important issue to me. Deciding to create my own mouthpiece, I found a dentist who constructed the face mask according to my wishes, paid for by my health care insurance. It was a new and wonderful experience to move freely

in bed at night, with a comfortable mask. My sleep improved as did my daytime condition. Since 1984, I have used this form of ventilation.

The first mask was made of dental acrylic, very light and well-tolerated by my skin. It consisted of two parts fused together: the dental piece and the mask, both molded from exact casts of face and teeth. (See *IVUN News*, July, 1987, for a fuller description of this mask.)

Since 1990, I have used a very small nasal mask, also made of dental acrylic by the same dentist. The mask covers only a part of the nose and is held in place by a dental piece which covers only the upper teeth. The mouth is completely free, and I am able to speak without limitation. After nine years, it is still working well.

I normally use a PLV-100 only at night, from 10 to 12 hours. In case of respiratory infections, I use the ventilator up to 24 hours. Once a year I go to the hospital for pulmonary function tests, blood gases, and overnight sleep evaluation. It is a hospital specializing in lung diseases with a unit for long-term home mechanical ventilation. Frau Dr. Karg is the unit's medical director and she is excellent. (I hate hospitals, but I am not afraid to go to this one.)

I have not regretted retiring from work because I have such an active social life with many friends. I also care for my aging parents. With the help of my assistants, I manage my life very well. I attended the Orlando meeting in March 1999 on noninvasive ventilation and showed my nasal mask at the mask-making workshop. ■

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Choosing a Generator

Richard Daggett

Being prepared for power outages caused by Y2K glitches or for earthquakes, tornadoes, hurricanes, ice storms, and other natural disasters is always smart, especially when you use a ventilator. Richard Daggett, ventilator user and president of the Polio Survivors Association in Downey, California, prepared these suggestions for selecting a generator for the July 1999 *Rancho Los Amigos Post-Polio Support Group Newsletter*. With his permission, his article is reprinted below.

Generators produce AC voltage, the same type of voltage available in your home from your electric company. The amount of power that a generator can produce is rated in watts. The higher the wattage output, the more appliances and lights you can operate. The tag on the generator indicates the maximum number of watts the generator can provide and the rated watt output. A generator should never operate at maximum output for more than a few minutes. Rated output is a more reliable measure of a generator's capability and is the power produced for long periods. Typically, the rated power is 90% of the maximum power.

Load is the measurement of work the generator will have to perform. There are two types of load: resistive and reactive. In simple terms, a resistive load is a light bulb, a toaster, etc. A reactive load contains an electric motor, such as an air conditioner, refrigerator, ventilator, etc. Resistive loads are easy to measure. If you want to light four 100W light bulbs, you will need a generator that is rated at 400W. Reactive loads are more difficult, because these require varying degrees of

power. When they start, they may require up to three times more power, but when they are running (although doing no work), they require much less power.

You can purchase relatively inexpensive, recoil start generators rated as low as 400W – enough to provide light, but not much else. An 800W generator should be enough to operate most modern ventilators, and if you are looking for an emergency backup generator, this is probably the minimum size you should consider.

One major disadvantage to this size generator is that it is available only with a recoil starter. You must pull on a cord to start it, like a lawn mower, and this requires upper arm strength. Recoil starters are standard on less expensive generators, even if they have a higher-rated output. These smaller generators can be found at many home and garden supply centers for about \$500 to \$1,000. Common brands are Coleman and Generac.

Higher-rated and more expensive generators can be started with the push of a button. A good choice might be one of the units made by Onan or Honda. These are built better, run more quietly, and will last longer over time than an inexpensive unit.

With larger generators, you can choose gasoline or LPG (liquid petroleum gas) as the fuel to power them. Gasoline-fueled units are more common and have a larger choice of watt ratings. The main drawback to gasoline-fueled units is fuel storage. Gasoline is hazardous to store. It is also dirtier, and the smell can be invasive. LPG-fueled units are cleaner and safer, but their main drawback is the initial cost.

While electric generators are often advertised as “portable,” they are

not – unless they are very small units. Even small generators weigh quite a bit; they are not something you can throw in the trunk of your car.

Consider your generator to be a permanent fixture. It will be more convenient if the generator is wired to one or more electrical outlets in your home. A transfer switch must be used when connecting it to a building's electrical system. The transfer switch isolates selected circuits in the home from the utility power. It will add to the cost, but it is essential for safety. Connections for backup and stand-by power to a building's electrical system must be made by a qualified electrician and must comply with all applicable laws and building codes.

My advice is to buy the largest unit that is practicable and that you can afford. Remember this will probably be a lifetime investment. If you use any kind of powered life-support equipment, i.e., ventilator, bi-level pressure system, oxygen concentrator, etc., a reliable electrical source is not a luxury. It is a necessity for safety and peace of mind. I also suggest you purchase a unit made by a company with a good reputation and widely available service, such as Onan or Honda.

My generator is an Onan LPG-fueled unit with a rating of 2500W. It is hard-wired into three outlets in my home. I have two 7.5 gallon LPG tanks, with a fuel transfer switch that will automatically switch to the full tank when the other is emptied. I use a ventilator most of the time, and knowing that I have reliable standby electrical power provides a real sense of security. ■

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They Just Don't Get It

Ruth Celia Kahn

Neighbor: "How is Paul today?"

Me: "He's great, thank you."

Neighbor (shaking her head, sighing): "What can you do?"

Me: "You know, Paul and I have a very good life."

Neighbor: "He's so lucky to have you."

Me: "Well, I married a very wonderful man."

Neighbor: "Still, he's very lucky."

She didn't get it! Our neighbor and many of the other elders who live in this apartment building assume that my husband Paul and I lead a very difficult life — just because Paul uses a PLV-100 ventilator and an Everest & Jennings electric wheelchair. (Paul's disability is caused by centronuclear myopathy, a rare neuromuscular disease.) Our well-meaning neighbors do not understand that this wonderful technology does not merely enable Paul to exist; instead, it allows him the luxury to say, "I didn't get enough done today."

Just like our neighbors' children, grandchildren, and great-grandchildren, we lead an extremely varied and busy life. Paul, now 53, is writing the latest draft of a play that will be produced in Boston next year, working on several other scripts simultaneously, writing an article for *New Mobility*, and editing two newsletters — *Access Expressed!*, published by VSA arts of Massachusetts, and *Rehab Update* for a research and training center at the New England Medical Center. (Paul does much of his writing using a Power Macintosh equipped with the PowerSecretary voice recognition system.) He also leads a support group for the Muscular Dystrophy Association of Massachusetts, helps to care for our four-year-old cat, Cairo, and manages his team of personal care attendants (PCAs). I am the president of Words &

Deeds, a consulting business dedicated to promoting the arts and social change.

Our neighbors do not understand that our marriage is a wonderful collaboration of love, shared interests and activities, responsibilities, and the joys and pain of personal growth. Paul and I met in the early 1980s, when I was a college student looking for an internship. Paul gave me my first writing job, editing a newsletter for a Boston-based information and referral agency. Paul and many other activists in the independent living movement taught me about the abilities of people with disabilities. Immediately, I could relate to the struggle we all share to be fully ourselves. It soon became apparent that Paul and I also shared a love of Renoir paintings, Gilbert & Sullivan operettas, Ruth Brown's rhythm & blues, Bertolt Brecht plays, and the poetry of Yeats and Ginsberg.

Our relationship deepened, but Paul's body was fading away. At that time, Paul was using a face mask and pressure-controlled ventilator. His energy level was extremely low and a greater portion of his day was spent sleeping with the face mask and ventilator. His carbon dioxide levels rose to dangerous levels when he did not use the ventilator. We realized that we were not going to have much of a future if Paul's health did not improve, and soon.

After making the rounds of doctors who only looked at Paul's disability, and not the complete person, Paul finally found a pulmonary physician, Barry Make, MD, who was not about to let Paul out of the hospital until a solution was found. Paul was fortunate to find partners in his health care who were willing to work with him to find the best solution.

The day after the tracheotomy in 1987, I went into Paul's room and met a complete stranger. There, sitting in Paul's wheelchair was a younger-looking man with a healthy glow. I almost said, "Excuse me, I must have the wrong room," until a second look revealed that this man was Paul.

Thus, Paul became an "astronaut on earth," as he termed it, tethered by tubing to the ventilator. Over the next six weeks, Paul mastered talking and eating, and learned all about the circuitry, supplies, and routines that would accompany him home. And, before I knew it, I was suctioning Paul's trach, doing "trach care,"

CONTINUED ON PAGE 4

International Ventilator Users Network (IVUN)

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and learning a new vocabulary which included such words as saline, drain sponges, water traps, low pressure alarms, and suction catheters. Finally, the hospital team realized that we knew practically as much as they did about how to care for Paul's new lifestyle. It was time to go home.

We were both scared as we left the hospital, armed with all the knowledge and supplies necessary to continue Paul's life. I respected Paul's anger and sense of loss, just as I enjoyed a thrilling sense of empowerment in learning how to "be" with Paul and his ventilators. Over the next year as we prepared for our wedding (on November 13, 1988 — a very lucky day for both of us), Paul trained his attendants in how to perform the new tasks associated with the ventilator and tracheostomy. Slowly, he began to trust in the reliability of the LP6 ventilator and began to use it with a sense of ease and gracefulness, learning to recognize all its noises. As for me, I have never slept better. The "whooshing" of the bedside ventilator reminds me of the sea, rocking me to sleep every night.

We have continued to adapt. About a year after the tracheotomy and several infections from the standard Shiley tube, Paul started using a customized Shiley tube that was longer and sat in a more comfortable place in the trachea. During the first two years with the trach, Paul could only talk during the inspiratory phase of the ventilator. Now, in the daytime there is no exhalation valve on the ventilator circuitry, and at night he uses a Passy-Muir valve. Both set-ups enable him to have fluent and continuous speech.

Last year, when Paul was informed that the LP6 ventilator was no longer being manufactured and maintained, he switched to

the PLV-100 which he likes better because it is quieter. His general health is excellent, and his powerful immune system seems to keep him from getting most of the viruses and other illnesses carried by me, his attendants, and our friends. His PCAs, funded by Medicaid, are vital to Paul's independence. I assist with Paul's care as needed, but we both feel more autonomous with Paul having his own attendants.

These last 11 years have been the richest, most action-packed years of our lives. Our marriage is built on a solid foundation of reliable technology, mutual support, and

lots of love. Together, we have watched each other grow personally and professionally. Together, we celebrate our lives with cherished friends. And together, we have survived threatened state and federal cutbacks in services for people with disabilities, a reorganization in the way PCAs are paid, and the attitudes of our neighbors who do not understand the power of wheelchairs and ventilators to transform and sustain a life. ■

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Bi-level Positive Pressure Ventilation: New HCFA Policy

Effective October 1, 1999, the Health Care Financing Administration (HCFA), which administers Medicare and reimburses for durable medical equipment through Durable Medical Equipment Regional Carriers (DMERC), is instituting new codes and coverage and payment rules for bi-level positive pressure ventilation used for nocturnal hypoventilation in people with neuromuscular disease, COPD, and central or obstructive sleep apnea.

At press time, HCFA had not reached a decision about the appropriate durable medical equipment (DME) payment category for "respiratory assist devices (RADs)" with bi-level pressure capability with a backup rate feature. Temporarily, these units with backup rates are in the frequently and substantially serviced DME reimbursement category. Bi-level pressure support units without a backup rate feature have been placed in the capped rental DME reimbursement category.

Ventilator users who use volume ventilators or negative pressure most of the time are NOT affected by this policy. Ventilator users who are already using bi-level devices nocturnally are NOT affected; they are grandfathered in, but their supplier must obtain a signed and dated statement from the treating physician declaring that the patient continues to compliantly use the device at least 4 hours per 24 hour period and is benefiting from its use, and a Medicare beneficiary statement completed by the patient. However, those people who will need to use nocturnal ventilation in the future may find it harder to get these units approved because of stricter medical criteria.

The American College of Chest Physicians and the American Association for Respiratory Care are pressing HCFA to accept the Consensus Conference Report published in the August 1999 issue of *Chest*, "Clinical Indica-

CONTINUED ON BACK COVER

Managing with Advanced Muscular Dystrophy

Tom Schock

I am 44 years old, and for the past 11 years, I have been using tracheostomy positive pressure ventilation with an LP6 Plus, due to respiratory muscle weakness caused by Duchenne muscular dystrophy. When I was 27, I went into respiratory failure and started using an Emerson iron lung. At first I used the lung for nine hours per night, but breathed independently during the day.

By the time I was 33, I was spending 14 hours per day in the iron lung and elected to have a tracheotomy. I reasoned that I would be able to be up and about more during the day and evening if I used a ventilator mounted on my electric wheelchair. With a trach, I would still be able to breathe if food or pills got stuck in my throat (I have a hard time coughing due to diaphragmatic muscle weakness.) I also thought it would be easier to be lifted in and out of a regular bed than an iron lung. I decided against a breathing mask because I did not want to exacerbate my skin problems; I also did not like the way it looked on me.

After the tracheotomy, I lost the ability to breathe for myself, due, I think, to the fact that I was unable to exercise my breathing muscles for several days because the medical personnel started me on trach positive pressure ventilation while the incision healed. Ever since, I have required the ventilator 24 hours per day, and I have only 1.5 minutes of free time.

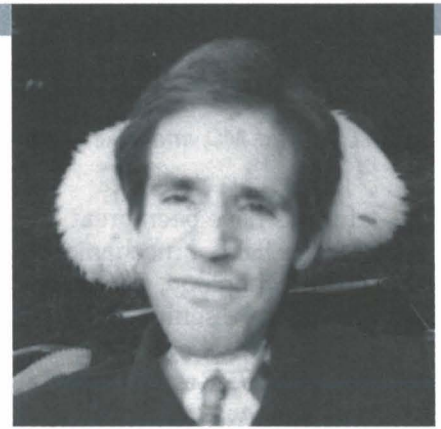
My respiration via tracheostomy positive pressure ventilation has gone relatively smoothly. I have not had any serious respiratory infections, except for effusion or "fluid on the lungs." I have been able to use the same type and

size of trach tube, Shiley 4, for many years without complications. However, for the last two years I have had a chronic throat infection. When the infection flares up, bits of hardened mucus or phlegm collect in the inner cannula of my trach tube causing an obstruction in my airway. Luckily, I have not had many serious emergencies. Three years ago, I started using a Passy-Muir valve which allows me to speak almost continuously. Before the Passy-Muir, I used a cuffed trach tube which made it possible for me to speak intermittently.

I have possibly the best living situation imaginable for someone with my condition. I live in a pleasant suburb of Boston in an apartment in my parents' house which has a large yard. In the spring and summer, I am able to sit out in the yard if I do not feel up to going out in my van. I can also go for walks on a bike path nearby.

I have Personal Care Attendants (PCAs) who stay with me around the clock to help with my personal care, domestic chores, and assist me with almost everything I am unable to do by myself. Massachusetts Medicaid pays for my attendant care, but I hire, train, manage, and fire (if necessary) my own PCAs. My parents provide some additional assistance. This works well because I am unable to do very much with my body except for thinking and talking.

With the help of my father and some of my attendants, I have managed to set up my apartment so I can control various electronic devices with switches and microphones. I have an environmental control for the TV and stereo that can also be used for a fan or an



electric blanket. I make phone calls with a chin switch and a microphone which are connected to my phone.

I control my computer with a voice recognition program called Dragon Dictate. I write an occasional article for *Disability Issues*, the newsletter of the Information Center for Individuals with Disabilities in Boston. I especially like listening to rock 'n' roll and blues music, and watching pro basketball, movies, and educational shows on TV. I am glad there are several things I can do by myself which are very enjoyable.

I try to live as full a life as possible, given the difficulties and limitations which my disability presents. I have a caring, helpful family, and a few good friends. The presence of these people and their support helps me to deal with the large impact muscular dystrophy has had on my life.

I think I have adapted to my situation well, but it does get very challenging sometimes. A major difficulty is being at peace with my fear of having my airway blocked and not being able to breathe. I also have difficulty coming to terms with the fact that I am unable to do many things I would very much like to do. I try to focus on what I can do, not what I cannot do. ■

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A New Era for Home Ventilation Technology

Susan L. Millard, MD, and Mike Kazmierski, RRT

The late '90s have been great years for the field of mechanical ventilation technology, especially for the homecare setting. In 1998, the TBird® Legacy ventilator from Thermo Respiratory Alternate Care was approved by the FDA for pediatric and adult patients, as well as Impact Instrumentation's Uni-Vent™ Eagle™. Pulmonetic Systems' LTV1000™ ventilator presents an even more exciting advance in ventilator technology approved for homecare use this year by the FDA, because it is compressorless.

We have used the LTV1000™ successfully on two of our pediatric patients here at DeVos Children's Hospital. One patient was recently discharged home. He is a toddler with bronchopulmonary dysplasia, a disease resulting from prematurity and lack of sufficient surfactant to coat the lung sacs (alveoli) and allow proper gas exchange. He had previously been sent home with an LP10 ventilator and required continuous flow to be adequately ventilated at home.

The LTV1000™ ventilator is unique because of its small dimensions and diversified applications. It weighs only 12.6 pounds and looks like a thin laptop computer with dimensions of 3"x10"x12." This is a welcome new size because in the past pediatric intensivists and pulmonologists often sent home infants who were smaller than their ventilators.

The LTV1000™ is much more convenient when considering mobility. Formerly, occupational therapists required specific load-bearing modifications for baby buggies or strollers in order to discharge infants and toddlers from the hospital to home with their ventilators.

Another important innovation of the LTV1000™ is that it allows multiple ventilator settings such as SIMV, assist-control, CPAP, as well as a pressure support feature which used to be available only on hospital ventilators. This versatility will allow many children to go home from the hospital earlier than in the past. PEEP is provided by an exhalation valve; a flow resistor type of external PEEP valve is not required.

Another extremely important feature is the tidal volumes range from 50 ml to 2000 ml. Earlier ventilators such as the LP10 could not be easily used for small infants because the lowest tidal volume available was 100 ml. Physicians would often have to use hospital ventilators and wait for the infants to "grow into" a home ventilator prior to even considering a discharge from the hospital. There is also a nipple adapter for oxygen enabling a home oxygen concentrator to be used if necessary. A pressure support mode of ventilation is available only for the hospital model. (The LTV900™ is the home use model; it does not have a pressure support mode or internal oxygen blender.)

Adult ventilator users will also appreciate the small size and weight, as well as the machine's quiet operation. People with obstructive sleep apnea may use the non-invasive positive pressure mode

Mike Kazmierski, RRT is the chief pediatric respiratory therapist in the Pediatric Intensive Care Unit at DeVos Children's Hospital. He has been responsible for organizing discharges of numerous and complex ventilator patients.

Susan L. Millard, MD, is an Associate Clinical Professor in the Department of Pediatrics and Human Development at Michigan State University. She is the co-director of the Cystic Fibrosis Care Center at DeVos Children's Hospital and follows many infants and children requiring home ventilation.

(with a reduced alarm package) for nasal night-time ventilation and relief of upper airway obstruction.

The internal battery runs for about one hour, and two external batteries are offered – a smaller one runs for three hours and a larger battery runs for nine hours – but any gel cell battery can be used. A cigarette-lighter adapter is used for power during transport in automobiles. Alarms are a vital safety issue for home ventilators and this unit has variable alarms for apnea (10-60 seconds), high pressure, low peak pressure, and low minute volume. There are also fixed alarms such as low/empty battery, low/lost external power, and setting defaults. Extended features include the ability to display various languages such as French, German, Spanish, and Italian. ■

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Ed. Note: Currently, there are about 400 of these new ventilators in use. The LTV1000™ costs the dealer \$11,900; the LTV900™ \$8,500. There is a one-year warranty. If service is required after that, the technical support staff will try to repair it by phone but if that is not sufficient, the machine can be mailed back. The LTV1000™ should be reimbursable by Medicare and Medicaid, as well as private insurance companies. The units have a CE mark for European sales. Direct inquiries to Pulmonetic Systems, Inc., 930 South Mt. Vernon Avenue, Suite 100, Colton, CA (California) 92324 (800-754-1914; 909-783-2280; www.pulmonetic.com).

Several ventilator users have switched to the LTV1000™ and have commented about it through Jim Lubin's Vent Users Support Page (www.eskimo.com/~jlubin/disabled/vent).

IVUN News would be interested to hear from readers who have tried Impact Instrumentation's Uni-Vent™ Eagle™. Please contact *IVUN*, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915 USA; gini_intl@msn.com.

“From the ICU to Home Care: A Patient’s Perspective” is a 40-minute video featuring ventilator user Audrey King (presented at the Orlando noninvasive ventilation conference in March 1999). Produced by The CHEST Foundation, the video includes an interview with King and Allen Goldberg, MD, president of the American College of Chest Physicians (ACCP). Proceeds from the video sales will fund the Margaret Pfrommer Memorial Lecture on Mechanical Ventilation during ACCP’s annual meetings. Order for \$25 postpaid from The CHEST Foundation, P.O. Box 93794, Chicago, IL (Illinois) 60673-3794 (800-343-2227; 847-498-5460 fax; www.chestnet.org).

American Association of Spinal Cord Injury Nurses (AASCIN) announces the availability of research grants (\$2,000-\$20,000) for the year 2000. Deadline for submission for the one-year grant is December 1, 1999. Contact the AASCIN, 75-20 Astoria Boulevard, Jackson Heights, NY (New York) 11370 (718-803-3782, ext 324; 718-803-0414 fax).

Trach Inventions/ Adaptations

Erika Elliott designed the **Trach Pouch** to prevent her child Bailey from throwing off the T-vent. “We had tried using bibs or bandanas to cover the T-vent, but they restricted the airflow.” The Trach Pouch is available in boy, girl, or neutral colors. Send your child’s neck measurement. Cost is \$5.00 each plus \$1 s&h in the USA. Please send check or money order to: Trach Pouch, c/o Erika Elliott, P.O. Box 1282, Bothell, WA (Washington) 98041 (erika@seanet.com).

The Wenmar Bridle™, designed by two health professionals, helps secure ventilator tubing to the tracheostomy tube by means of high quality velcro to prevent disconnects. Easily adjustable fit. Available for \$5.95 each (case of 25 for \$3.95 each) from Wenmar Designs, Inc., 820 Beryl Street., San Diego, CA (California) 92109 (800-847-4612; brosbrook@aol.com).

Trach button solution offered by Lori Generes (those2@ix.netcom.com) of Houston, Texas: “My husband Paul and I scoured our local hardware store looking for just the right thing that would keep the stoma open but would allow me to get rid of the cumbersome Jackson trach that I had for so many years.

Of course, I had checked with my physician before venturing out to Home Depot, but she said that there were no alternatives and tried to help me feel “comfortable” with my trach.

We found something called a connecting screw (Connecting Screws Handi-Pack, Part #11/8 MIN 17/16 Max, Midwest Fastener Corporation).

It consists of two pieces, and I use the durable plastic part without the screw. Paul trimmed the end about 1/8 of an inch so it did not scrape the back of my trachea. It fits my size 4 trach perfectly. It has a lip around it which prevents it from going into the trach opening, and I fasten it with a clear bandage.

I clean it with peroxide and water just as I did with my Jackson trach and use a new one about every 6 months (at 65 cents each, it is quite affordable).

It is so much more comfortable, and I have found that I do not get as many respiratory infections.

I still have the opening if needed for suctioning but not the whole tracheostomy tube. If I do need to suction, I simply remove the button, suction, and put the button back on after suctioning.”

Reports and Guidelines

CLINICAL INDICATIONS FOR NON-INVASIVE POSITIVE PRESSURE VENTILATION IN CHRONIC RESPIRATORY FAILURE DUE TO RESTRICTIVE LUNG DISEASE, COPD, AND NOCTURNAL HYPOVENTILATION – A Consensus Conference Report. *Chest*, 116:2: 521-534. (www.chestnet.org).

IDIOPATHIC CONGENITAL CENTRAL HYPOVENTILATION SYNDROME: DIAGNOSIS AND MANAGEMENT. *American Journal of Respiratory and Critical Care Medicine*, 160: 368-373. (www.atsjournals.org).

PRACTICE PARAMETER: THE CARE OF THE PATIENT WITH AMYOTROPHIC LATERAL SCLEROSIS (an evidence-based review), *Neurology* 1999; 52: 1311. The Quality Standards Subcommittee of the American Academy of Neurology is charged with developing practice parameters for physicians. This evidence-based review addresses some of the major management issues, including respiratory, in patients with ALS, and highlights the many areas in which more research is needed.

The committee includes R.G. Miller, MD; J.A. Rosenberg, MD; D.F. Gelinas, MD; H. Mitsumoto, MD; D. Newman, MD; R. Sufit, MD; G.D. Borasio, MD; W.G. Bradley, DM, FRCP; M.B. Bromberg, MD, PhD; B.R. Brooks, MD; E.J. Kasarskis, MD, PhD; T.L. Munsat, MD; and E.A. Oppenheimer, MD. ■

SUPPORTED BY



The Revised Edition of the **Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors** is now available. The 120-page book in dictionary format contains 90 entries, a compilation of the research and experience of more than 40 experts. Cost (postpaid) is \$18.50 USA; \$19.50 Canada, Mexico, and overseas surface.

(US funds only)

Inside this issue ...	
Choosing a Generator	2
Managing with Advanced Muscular Dystrophy	5
New Ventilator Technology ..	6

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Calendar

1999

October 9-13. European Respiratory Society (ERS) Annual Meeting, Madrid, Spain. Contact ERS, 1 Boulevard de Grancy, CH-1006 Lausanne, Switzerland (www.ersnet.org).

November 1-14. American Academy of Physical Medicine and Rehabilitation (AAPM&R) 61st Annual Assembly and Technical Exhibition in conjunction with 13th World Congress of the International Federation of Physical Medicine and Rehabilitation. Hilton Washington & Towers, Washington DC. Contact: AAPM&R, 1 IBM Plaza, Suite 2500, Chicago IL (Illinois) 60611-3604 (312-464-9700; info@aapmr.org, www.aapmr.org).

December 10-11. Rehabilitation Approaches for Tracheostomized and Ventilator-Dependent Population. Bay Front Medical Center, Saint Petersburg, Florida. Offered by Mary Mason, MS, CCC-SLP. Contact Professional Marketing Seminars, 800-223-5766 (www.speechpaths.com).

December 13-16. American Association for Respiratory Care (AARC). Annual Meeting. Las Vegas, Nevada. Contact: AARC, 11030 Ables Lane, Dallas, TX 75229-4593 (972-243-2272; 972-484-2720 fax; www.aarc.org).

2000

June 8-10. Eighth International Post-Polio & Independent Living Conference. Saint Louis Marriott Pavilion Downtown, Saint Louis. Contact GINI, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915 (314-534-0475; 314-534-5070 fax; gini_intl@msn.com; www.post-polio.org).

2001

March. Eighth International Conference on Home Mechanical Ventilation, Lyon, France. Journées Internationales de Ventilation à Domicile (JIVD), Hôpital de la Croix Rousse, Service de Réanimation Médicale et d'Assistance Respiratoire, 93, Grande Rue de la Croix Rousse, F-69317 Lyon Cedex 04, France (+33 4 78 39 08 43; +33 4 78 39 58 63 fax; 100732.3540@compuserve.com). ■

tions for Noninvasive Positive Pressure Ventilation in Chronic Respiratory Failure Due to Restrictive Lung Disease, COPD, and Nocturnal Hypoventilation – A Consensus Conference Report.” (Chest, 116: 2: 521-534.) ■

To read the full RADS policy in the DMERC Supplier Manual, Chapter IX, page IX-145 through IX-154, go to: www.cignamedicare.com/publications.htm – under “Durable Medical Equipment” scroll down and click on “DMERC Regional Medical Review Policies,” then scroll down again until you come to “Respiratory Assist Devices” and click. For the RADS policy update, dated August 3, 1999, go to: www.adminastar.com/anthem/affiliates/adminastar/about/news/index.html.

For the latest developments, contact IVUN, 4207 Lindell Boulevard, #110, Saint Louis MO (Missouri) 63108-2915 (314-534-5070 fax; www.post-polio.org/ivun.html).