INTERNATIONAL VENTILATOR USERS NETWORK

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VENTILATOR-ASSISTED LIVING



Noninvasive to Trach Ventilation ... and Back Again

Sven Andrén, Täby, Sweden (sven.andren@telia.com)

My son Jonathan, 23, who has SMA Type II, started Jonathan underwent a tracheotomy in 1996 because his breathing capacity had gradually diminished due to increasing scoliosis. In 1997 his spine was fused.

Unfortunately the trach tube caused him much pain because his trachea was a bit crooked and trach tubes are straight. Secretions were heavy. Innumerable experiments with all kinds of trach tubes were carried out but the problems persisted. His breathing capacity improved as a result of the spinal fusion, and he ceased to use the

ventilator during the night. Jonathan also became able to work at his computer during the day for three hours at a time without using the ventilator.

With the introduction of the CoughAssist[®] (J.H. Emerson Co., www. coughassist.com) in Sweden and with Jonathan under the encouraging supervision of a dedicated and skillful physiotherapist, Lena Sjöström, who specializes in breathing problems, we decided to proceed with decannulation. (After consultations with John Bach, MD, the possibility of decannulating Jonathan had been raised with our Swedish doctors, but it was ruled out as a possibility as long as the CoughAssist was unavailable in Sweden.)

In May 2003, seven years and two weeks after it was inserted, Dr. Gillis Andersson of Danderyds Hospital in Stockholm (his physician since 1990) removed the tracheostomy tube.

E.A. "Tony" Oppenheimer, MD, FCCP

(eaopp@ucla.edu), comments, "Airway secretions are a common problem for people with motor neuron diseases, such as SMA and ALS. This often occurs when the bulbar muscles of the pharynx become weak and are unable to coordinate their usual process of swallowing secretions to remove them from the back of the mouth and pharynx. A new tracheostomy also causes increased secretions around the area of the stoma (this may take six to 12 months to heal) due to irritation and/or infection at the stoma which may be associated with pus and pain. There may also be some irritation within the trachea adjacent to the trach tube." Jonathan claims, "I haven't felt this well since 1990." He uses the custom-made nasal mask – The Remmermasken® (Remmer Meditec, www. remmer.se) – and intermittent positive pressure ventila-



tion via a mouthpiece attached to his wheelchair with a PLV®-100 (Respironics, Inc., www.respironics.com) for about five hours per day. Socially, trying to carry on a conversation with a nasal mask is not ideal. The secretions have ceased to be a problem, provided that the CoughAssist is used regularly for about 10 minutes in the morning, at noon, and at bedtime.

SEDATION FOR SURGERY

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fter 45 post-polio years of avoiding surgery altogether, I have recently been forced into two significant surgical procedures. One was an emergency gallbladder operation (1999), performed laparoscopically under general anesthesia in a small community hospital. I was intubated, but was back using my BiPAP[®] S/T (www.respironics.com) three hours after the surgery. The other was a radio frequency (RF) cardiac ablation (May 2003) to correct a persistent arrhythmia called supraventricular tachycardia (SVT). This second procedure was performed under sedation (sometimes heavy), using my own BiPAP for mechanical ventilation, in a large, busy, regional medical center with teaching obligations.

Both surgeries went well, and, oddly enough, each lasted 2½ hours. The first was life-saving and not optional. The second got me off some drugs that had been compromising my energy and stamina for 10 years, making it hard to distinguish the side effects of the drug from the late effects of polio. The cardiac ablation also eliminated my increasingly frequent trips to the ER when the medications weren't sufficient.

The moral seems to be that recent advances in minimally invasive surgery provide new options. Cardiac ablation carries some risks, but so did the attempts to manage episodes of arrhythmia with drugs. Weighing the two sets of risks carefully, without prejudice, was essential. That was easier said than done because I've gone out of my way to avoid surgical options for many years, just on general principles. I'm now learning to be more reasonable about this.

There are still some special precautions ventilator users and perhaps polio survivors in general need to take when considering surgery. (See "Before Surgery," p. 8.) But in my recent experience, medical professionals are now ready to hear and to accommodate our insistence on noninvasive ventilation whenever appropriate. My physicians have also been willing to add (again on request) the extra layers of protection I might need during surgery and other procedures performed under sedation, such as endoscopic examinations or colonoscopy. My cardiac ablation surgery illustrates all those points.

RF cardiac ablation. Some arrhythmias are essentially wiring problems, due to alternative electrical pathways in the heart muscle. When these alternative pathways are activated, the heart may beat very rapidly but in a relatively controlled way (as in my case) or in a more disorganized and dangerous way. If the episodes are rare and brief, no treatment may be needed. Otherwise, various drug therapies are available to reduce their frequency. If the drugs fail or if, again in my case, high dosages of the most powerful available drugs cannot be tolerated, additional measures can be taken, but only in the ER. Most of these are temporary measures to convert the arrhythmia to a "normal sinus rhythm."

For SVT there is a surgical cure, known as radio frequency cardiac ablation. Catheters with small instruments are inserted into the right atrium of the

"There are still some special precautions ventilator users and perhaps polio survivors in general need to take when considering surgery".

(See "Before Surgery," p. 8.)

heart through one of the femoral veins and, if necessary, into the left atrium through a femoral artery. The electrical circuitry of the heart is then "mapped," and when the offending alternative pathways are found, they are ablated burned away. Most of the details are unimportant here. Suffice it to say that the procedure requires specially trained cardiologists and a fully equipped electrophysiology lab. It is performed under sedation and local anesthetic at the insertion site. People who can breathe in the normal way sleep through it supported only by nasal oxygen. The procedure normally lasts between two to three hours, but can take significantly longer in difficult cases. The success rate is 90% to 95%, and the rate of serious complications is under 3% nationally, though for some especially skillful cardiologists (mine included) the complication rate can be under 1%.

I slept throughout my 2½ hour procedure, using my own BiPAP with oxygen. The anesthesiologist timed things so that I was wide awake, able to breathe on my own for the trip back to my room, and to be watchful about the transfers, positioning, and subsequent (immediate!) return to using BiPAP.

The ablation went smoothly and was completely successful. Recovery time was trivial (I went back to my office on Friday after surgery on Wednesday), and there were no complications.

Lessons. Can this experience be generalized to other procedures? Yes. It generalizes to many diagnostic procedures that use sedation and to surgery performed with a combination of regional or local anesthetics plus sedation. I'm certainly not going to go looking for such opportunities, but I no longer regard them with as much apprehension.

One general caution. Sedation for these procedures is often handled by specially trained nurses. It took some persistence and flexibility on the part of my cardiologist to get what he wanted in the way of a consultation with an anesthesiologist - and that did not occur until half an hour before the procedure. An anesthesia consultation had been arranged when I had presurgical blood work and history taken the day before the ablation, but it did not happen. Nor did it happen early the next day, when I came back. These may have been entirely local problems, but the lesson to learn is persistence.

And humility. The anesthesiologist who was eventually assigned to my case was extraordinarily good - not only technically proficient but kind, attentive, and wise. The most important thing I learned was the necessity for him to be prepared to do more for me than my BiPAP could do, in the event that unexpected things happened. He described exactly how he would proceed short of full intubation. He had also read the records of my emergency gallbladder surgery and was prepared to replicate relevant parts of that if needed. All of this was quite reasonable. I had been so insistent on noninvasive techniques that I had not thought about



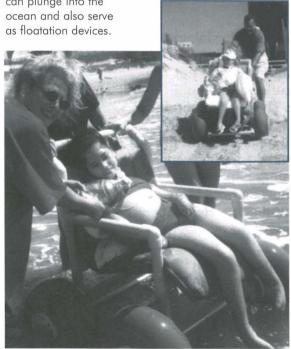
Larry Becker, a recently retired philosophy professor, had polio in 1952. He uses BiPAP®S/T with nasal pillows during sleep. Summer 2003 marked the second season of WAVE (Wonderful Adolescent Ventilator Excursion), a recreational program at the New Jersey shore for adolescents who require ventilator assistance or who have tracheostomies. Our experiences led to suggestions to encourage other technology-assisted children and teens to travel and experience new adventures.

Traveling with Technology-Assisted Children

Tricia Cunningham, RRT, Voorhees Pediatric Facility, Voorhees, New Jersey (tcunningham@forkidcare.com)

When planning to travel with technology-assisted children, you must identify potential challenges – and medical and social barriers – and develop a plan to overcome each one. Thanks to the Americans with Disabilities Act (ADA), accessibility is federally mandated, but it has a broad range of interpretation. Although the ADA has reduced barriers to traveling, it is up to you to ensure that you and your child's needs will be met while traveling. Research and planning are key.

Many beaches have short wheelchairaccessible paths extending partly onto the beach. Some beaches provide all-terrain wheelchairs that enable people to move over the sand all the way to the ocean. These chairs can plunge into the ocean and also serve as floatation devices. **Medical issues.** Consideration of the climate and length of exposure is important for those with temperature instability. The length of an activity should be compatible to the degree of seating tolerance. Activities for those at risk for rapid or unexpected deterioration should be planned so that intervention is feasible.



Airway humidification must be maintained in children and teens with a tracheostomy. Heat moisture exchangers are suitable for short periods. but are ineffective for those relying on a speaking valve to communicate. The potential for airway drying and plugging should be

considered and may be addressed with normal saline given via nebulizer or lavage.

If traveling by ground, map the route and locate the hospitals along the way. Have a medical summary on hand, should it be needed at a local hospital or emergency room. The summary should include medical history, current medical problems, surgeries, allergies, medications, and common problems and their usual course of treatment.

Social factors. A basic human need, particularly for adolescents, is to fit in while traveling and discovering the world. The propensity to avoid toileting, meals, fluid intake, medications, and treatments must be addressed to avoid complications. Although care may be modified to accommodate an active schedule, a safe and effective balance is essential.

Transportation. When using public ground transportation, investigate the transport company. Ask about wheel-chair tie-down systems. Surprisingly, there are no specific regulations involving these systems, and belt attachments may vary. Question the preparation of the drivers. Have they received special training? Will it be a straight run to the destination site or will there be a transfer?

Buses built after 1990 must be accessible. Greyhound's website (www.greyhound.com) details their customer service for travelers with disabilities – in many cases they will provide an attendant with a free ticket.

SUPPLY LISTS

Make a detailed list of all equipment and supplies you need to bring. A list for medical supplies should be separate from traditional vacation needs. Items on the medical list should be checked and rechecked. Unlike a forgotten toothbrush, a simple trip to the store won't suffice if suction catheters run out. Review your care plan from sunrise to sunset, considering everything you will need for all ADLs, treatments, therapies, medications, and luxuries.

While a master list is needed for the entire vacation, a separate daily trip list should be used for each outing. A "go bag" should be easily accessible and contain all emergency equipment. Other essential, but non-emergency, equipment should be carried in a separate bag. For instance, a backup tracheostomy tube, a downsized trach tube for emergency insertion, trach ties, lubricant, and a syringe for cuff inflation should be kept close at hand.

a syringe for cuff inflation should be kept clear ing above the first floor. Inquire about swimming facilities, restaurants, and special seating for shows. Wheelchair seating is usually limited and it may be situated with individual travelers in mind. Traveling in groups may prove disappointing as seating for multiple

> **Power and backup.** Check the user manuals for the power requirements of all equipment including battery chargers, ventilators, monitors, and suction machines. Discuss your needs with the hotel's electrical specialist to ensure that the collective amperage will not overload the circuit dedicated to the room. Establish the availability of an emergency generator for use in the event of a power outage and make arrangements to gain access to it.

> chairs and caretakers may be scattered.

All durable medical equipment should be backed up, even seating, to avoid becoming stranded during vacation. Power strips will most definitely be needed, but extension cords may not be permitted. Long-lasting rechargeable batteries are essential to facilitate outings and in the event of an unplanned power failure. Newer and smaller external battery packs lasting about three hours or more are available. Using an auto adapter power cord can save valuable battery power while driving to your destination. When planning your trip ... be prepared, be creative, and be ready to improvise!

Trains (www.Amtrak.com) now offer accessible seating, including a transfer seat and wheelchair storage. When traveling by ship, motion sickness medication and reliable wheelchair brakes are a must. A review of the tide charts enables easier boarding and disembarking. For travel by air, advance planning is vital (see "Air Travel and Ventilator Users" on p. 6).

Hotel. When choosing a hotel, ask to speak with an on-site manager rather than a customer service representative. Bring a tape measure, ask a lot of questions, get answers, and make frequent references to the ADA. You'll find that this will be a learning experience for both you and hotel personnel.

Ask about the accessibility of parking and loading areas. Where will you be entering and exiting in relation to your accommodations? Are there ramps on every floor? Where are the locations of wheelchair-accessible elevators? Knowing this in advance, and mapping your route upon arrival will facilitate quick and easy transit to and from daily activities.

Newer hotels offer large, roll-in showers with detachable hand-held showerheads to make bathing safe and easy. Only a few of these rooms may be available and reservation clerks may not be aware of them. Shower chairs and stretchers are ideal, but they are also costly, so consider using a less expensive beach or plastic lounge chair. Arrange to have a room with a small refrigerator for storing medication or special foods. Contact the plant operations supervisor of the hotel to arrange for a stairway fire exit chair when stay-

AIR TRAVEL AND VENTILATOR USERS

Judith R. Fischer, MSLS, Cypress, California (jfisc48232@aol.com)

More and more ventilator users are taking advantage of improved ventilator technology and portability to travel by air, both professionally and personally. Advance planning and attention to detail involves obtaining reliable and accurate travel information. Working together with one's physician, home health agency, respiratory therapist, and the airline is critical for successful travel.

Flying's most serious medical concern for ventilator users is the quality (low cabin humidity and temperature) and pressure of the cabin air. Airplanes generally cruise above 30,000 feet, with the cabin or barometric pressure adjusted to between 5,000 to 8,000 feet, which is equivalent to standing on a mountain.

Because the plane's barometric pressure is lower than at sea level, a person's arterial oxygen can drop from 5 percent to 20 percent, decreasing oxygen availability throughout the body. With less oxygen in the bloodstream, vital organs can be deprived, and hypoxia can develop.¹ Ventilator users who have access to a finger pulse oximeter may want to take it along to monitor drops in oxygen saturation in-flight.

Ventilator users who need to use their ventilators in-flight must prepare for air travel well in advance. First, they should contact the reservation agent and explain their needs so that the use of the ventilator in-flight becomes part of their passenger record. Then, to ensure that the arrangements are correct, they should contact a customer service representative and explain about the ventilator again, emphasizing that it is different from using oxygen in-flight.

The airline's medical and engineering departments may need to approve ventilator use in-flight. The ventilator user should prepare a list including the ventilator's name and model number, complete specifications, and the manufacturer's name, address, phone, and website. The ventilator user also needs to determine if the ventilator will fit under the seat (unless the individual is willing to pay for an extra seat) or if he or she can hold the ventilator.²

The airline's medical department often requires a ventilator user to obtain a letter from his or her pulmonologist stating the individual's medical diagnosis and ability or fitness to travel. This letter should be ready to present at departure, along with the ventilator specifications and any documentation received from the engineering department, if requested by the ticket and gate agents. With strict new security regulations and screening, these documents can help to expedite passage through security checkpoints. Travelers should bring multiples copies of important papers.

If the ventilator user plans to plug the ventilator into the aircraft's electrical system, he or she must obtain permission to do so. The Federal Aviation Administration (FAA) does not require airlines to provide this service, and it is not a universal practice. Individuals report that United and Northwest are the most flexible in allowing use of their electrical outlets.

Most airlines will allow dry or gel-cell batteries onboard if they fit under the seat. The HT50® ventilator (www.newportnmi.com) is popular with travelers because of its 10-hour internal battery. However, even when a battery is advertised to provide power for a certain length of time, the battery should be tested far in advance to ensure its performance.

Many airline personnel aren't aware of the FAA regulations relating to technical specifications of modern portable ventilators, and some require the ventilator to be turned off during takeoffs and landings. The FAA has approved some ventilators for flight such as the LTV[™] series (www.pulmonetic.com) and certified that they do not interfere with radio and other transmissions.

Individuals who do not need to use their ventilators during the flight have the options of renting a ventilator from a home health care dealer at their destination, carrying the ventilator onboard (if it meets the storage specifications), or carefully packing it for shipment as checked baggage. Each has advantages and risks.

Laura Hershey, a writer, consultant, and disability rights activist who travels frequently, always brings her bilevel positive airway pressure device with her when flying. "The only time I tried to rent one at my destination, I ended up with a different type of machine that was very uncomfortable for me to use," Hershey said. "Also, I don't want to mess with settings upon arriving in a hotel room late at night. So I pack my (equipment) carefully with lots of padding to protect it, and I have never had it damaged." She recommends bringing extra tubing, filters, connectors, and masks.

Ventilators and other medical equipment and supplies do not count toward the limit on carry-on items. Ventilator user Alan Fiala relates, "I told the flight attendant that my ventilator in the carry-on bag was an assistive device for a disabled person and it was to go in a closet. This worked, except on Southwest's planes which have no closets."

Using Oxygen In-flight

Even individuals who use mechanical ventilation only at night may need supplemental oxygen in-flight. Linda Bieniek relates, "In the past, I developed respiratory infections each time I flew. But since I started using oxygen in-flight, I have not had this problem. I highly encourage people who only use a ventilator at night and even those who have neuromuscular conditions without breathing problems to explore the value of this option."

A physician must determine and write the order for the oxygen flow, usually available in either 2 Lpm or 4 Lpm.¹ The order must be presented to the airlines two to seven days in advance so that they can secure and obtain the oxygen. Although most major airlines are certified by the Federal Aviation dministration and equipped to supply oxygen for an entire flight, most economy airlines carry oxygen only for a medical emergency.

Fees for oxygen vary from airline to airline, nationally and internationally, but average about \$75 for each leg of the itinerary. The cost of a roundtrip ticket with several connections can become expensive and prohibitive.² The websites of each individual airline offer related information about oxygen in-flight; Continental's site is the most comprehensive.

It is advisable to confirm the oxygen request with the ticketing agent at check-in so he or she can phone ahead to the gate agent to verify that the oxygen request has been filled and is on the plane.

References

Oppenheimer, E.A. (2001). More on oxygen use. *IVUN News*. 15(4), 4.
 Wolfe, J.A. (2002). Managed care guidelines for home oxygen. *RT*. 15(5), 42-44.

Some ventilator users who are ambulatory may not have enough arm strength to pull carry-on items containing ventilator equipment and supplies onboard or lift them into the overhead compartment. Fellow passengers may be willing to help. Flight attendants and airline staff may or may not provide assistance, citing liability concerns or airline rules. Some airlines require a traveler with a more severe disability to have a traveling companion to help in case of emergency evacuation. (Aviation Consumer Protection Division, Department of Transportation, http://airconsumer.ost.dot.gov)

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Sedation for Surgery

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backup procedures – even though I knew very well that one of the rare complications of cardiac ablations yields a pretty colorful emergency.

I'm very glad I chose to have the ablation. The best thing, of course, is being free of the episodes of arrhythmia and the trips to the ER. The next best thing is being free of the side effects of the calcium channel blocker (Cardizem) I had been taking. I had not fully realized, until I came off of the medication, how much it was compromising my limited reserves. I feel 10 years younger, breathing is easier, my balance is somewhat better, and I have more energy. ●

Before Surgery ...

- Be certain your ventilator or one you are willing to use is a standard model, already familiar to the hospital staff. The more unusual your ventilator, the more resistance you will face in the decision to use it during surgery.
- Use an interface if it covers your nose with an oxygen port. The anesthesiologist will want to have one, whether it is used or not.
- Insist that the sedation or anesthesia be supervised by an anesthesiologist and that you have a chance for a meaningful consultation with him or her prior to the surgery. Discuss backup procedures should your ventilator be insufficient.
- Weigh the risk-benefit ratio so it genuinely favors the surgery, but do not discount the genuine risks of non-surgical treatment.
- Bring to the hospital a copy of the records of any previous surgery, along with an updated advance medical directive, living will, durable power of attorney for health care, etc. Make sure all of this not only gets into the chart, but is also read by all of your physicians.
- List all the things you don't want to happen with transfers and positioning on the operating table, and stay alert enough during the preliminaries to advise the nurses and physicians.
- Plan with the team to get yourself quickly and fully awake after surgery. Then be watchful until things seem to be settled.
- Stay calm. That reassures the medical people, which in turn benefits you.

FluMist Caution

In June 2003, the FDA approved FluMist, a new way to give the flu vaccine to people ages 5-49. It is inhaled rather than injected. However, FluMist is NOT advised for people with chronic diseases and asthma, and it is almost three times as expensive as the injectable vaccine. FluMist is expected to be available for the 2003-2004 flu season. People with neuromuscular diseases and conditions should check with their physicians about the advisability of using FluMist.

Journal Articles

Recent medical journal articles on aspects of mechanical ventilation. If you are not a member of the professional organization that publishes the journals, you can usually obtain abstracts of the articles free online; the article itself can be purchased separately.

Bach, J.R. (2003). Successful pregnancies for ventilator users. *Am J Phys Med Rehabil*, 82, 226-229. (www.physiatry.org/publications)

Bourke, S.C., Bullock, R.E., Williams, T.L., Shaw, P.J., & Gibson, G.J. (2003). Noninvasive ventilation in ALS: Indications and effect on quality of life. *Neurol*, 61, 171-177. (www.aan.com)

Buyse, B., Meersseman, W., & Demedts, M. (2003). Treatment of chronic respiratory failure in kyphoscoliosis: Oxygen or ventilation? *European Respiratory Journal*, 22(3), 525-528. (www.ersnet.org)

Gabrielli, A., Caruso, L.J., & Layon, A.J. (2003). Yet another look at noninvasive positivepressure ventilation. *Chest*, 124, 428-431. (www.chestjournal.org)

Hayashi, H., & Oppenheimer, E.A. (2003). ALS patients on TPPV: Totally locked-in state, neurologic findings and ethical implications. *Neurol*, 61, 135-137.

Hill, N.S. (2003). Practice guidelines for noninvasive positive-pressure ventilation: Help or hindrance? *Chest*, 123, 1784-1786.

Laghi, F., & Tobin, M.J. (2003). Disorders of the respiratory muscles. *Am J Resp Crit Care Med*, 168, 10-48. (www.thoracic.org)

Liesching, T., Kwok, H., & Hill, N.S. (2003). Acute applications of noninvasive positive pressure ventilation. *Chest*, 124, 699-713.

Sinuff, T., Cook, D.J., Randall, J., & Allen, C.J. (2003). Evaluation of a practice guideline for noninvasive positive-pressure ventilation for acute respiratory failure. *Chest*, 123, 2062-2073. Air Travel and Ventilator Users continued from page 7

Linda Bieniek, another frequent traveler who has used nocturnal ventilation for the past 15 years, states, "When I ask for assistance, I am very specific and explain that I have weak muscles from polio. Although I can walk onto the plane and may look fine, I need assistance with my carryon bag containing breathing equipment that I use at night and don't want to chance checking through baggage. Although I dislike having to ask, I have learned that when I struggle, I pay a high price in terms of pain, fatigue, and possible injury."

All airlines are required to have a Complaints Resolution Officer (CRO) immediately available – even if only by phone – to resolve disagreements that may arise between the carrier and passengers. The Federal Aviation Administration website (www1.faa.gov/acr/dat.htm) provides the complete rules and regulations of the Air Carriers Access Act for people with disabilities.

Arrangements for arrival at the destination also require advance planning. Ventilator users should contact a home health agency there to discuss their equipment to ensure that the RTs on staff are familiar with it and can provide support in case of equipment failure or other emergency. Ventilator users also should have the names and contact information for respiratory health professionals in the area knowledgeable about neuromuscular conditions and home ventilation. These professionals can be located using the International Ventilator Users Network's *Resource Directory for Ventilator-Assisted Living* (www.post-polio.org/ivun/d.html).

References

 Davis, R. (2001). Do passengers get enough oxygen? USA Today. March 6, 1-2.

2. Hinderer, L. (1998). Airline travel with ventilators. *IVUN News*. 12(1), 4,8.

Adapted with permission from an article that appeared originally in ADVANCE for Managers of Respiratory Care, April 2003. Thanks to E.A. Oppenheimer, MD; Bruce Krieger, MD; and Joe Lewarski, RRT, for their review of this article. **Action Alert!** Medicare reimbursement for bilevel ventilators with backup rates, e.g. BiPAP® S/T, VPAP® II ST-A, may be changed from the "frequent and substantial servicing" category to the "capped rental" category. If the change is approved, rental payments, which include service and followup from a respiratory therapist through a durable medical equipment (DME) dealer, would be capped after 15 months. This could be potentially harmful to ventilator users with more complex medical conditions who need regular in-home monitoring. Public comments are being solicited until October 21, 2003. Your help is needed in writing a letter about the effects of the proposed change in reimbursement status. For complete background on this complicated and important issue, click on www.post-polio.org/ivun.

New Equipment & Interfaces

Nippy 3 is the latest model in the Nippy series of pressure-controlled ventilators from B & D Electromedical in Britain (www.bdemed.fsnet.co.uk). Modes are CPAP, pressure control, pressure support, and intermittent positive pressure ventilation. Very lightweight – 3.5 kg or just under 8 lbs. with pressure range up to 30 cm H₂O. Nippy 3 received the CE mark for European sales, but it is not available in the US.

ComfortFull[™] Full Face Mask is the newest mask in the Comfort Series[™] from Respironics[™] (www.respironics. com), designed for people who cannot tolerate nasal masks due to mouth breath-



ing. Features include a soft, dual-flap cushion, quick- release swivel, and adjustable forehead arm for optimal seal and stability – without overtightening the headgear. Quick Clips[™] and ball-and-socket headgear clips increase night-time mobility. Available in three sizes.

New Masks from Hans Rudolph, Inc. (www.rudolphkc.com)

V.I.P. 7500 Series Oro-Nasal Vmask[™]. Features include anatomically contoured soft silicone rubber face mask which fits under the chin; straight or elbow swivel ports; safety quick-release or standard headgear; and locking-type clips to eliminate nuisance slipping. Available in five sizes with ribbed support in the face seal for leak-free ventilation.

ALIZES™ nasal CPAP/bilevel mask,

has an adjustable nose strap that allows fitting and forming to any size or shape of nose. The Comfort Seal[™] foam accessory provides a comfortable and leakfree seal. The mask is dishwasher-safe. ●





Trach Necklaces and Scarves

Maxine Hope, a speech and language therapist, creates unique necklaces and scarves from "hairy" synthetic yarn. One of her customers (with bilateral vocal cord paralysis) bought them to cover her tracheostomy. The necklaces, on silver or gold wire, are \$23 including shipping; the scarves are \$65 including shipping. Any color combination.

Contact Maxine Hope, P. O. Box 418, Clinton, NY 13323 (Maxwell428@aol.com).

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HOW TO CONTACT US ...

INTERNATIONAL VENTILATOR USERS NETWORK

POST-POLIO HEALTH

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