

VENTILATOR-ASSISTED LIVING

SAINT LOUIS, MISSOURI

WWW.POST-POLIO.ORG/IVUN

Hypoventilation? Obstructive Sleep Apnea? Different Tests, Different Treatment

Judith R. Fischer, MSLS, Editor, Ventilator-Assisted Living (fischer.judith@sbcglobal.net)

People with neuromuscular disorders may be misdiagnosed and mistreated when they encounter breathing and sleep problems. Many general practitioners, and even some pulmonologists, neurologists and sleep physicians, may not fully understand respiratory insufficiency and physiology in this group.

Hypoventilation. Generally, in people with neuromuscular disorders who are having breathing problems, the main problem is hypoventilation (underventilation) – not breathing deeply and/or often enough. Muscle weakness, scoliosis and/or chest wall stiffness make it difficult or impossible to fully inflate the lungs.

Hypoventilation results in an imbalance in the carbon dioxide (CO₂) and oxygen (O₂) exchange in the blood – too much CO₂ is retained, too little O₂ is taken in. Because hypoventilation usually first occurs during sleep and because several of the signs and symptoms (see page 2) overlap, it can be misdiagnosed as obstructive sleep apnea (OSA).

Although any trained health care professional can perform simple pulmonary function tests (PFTs) of breathing ability during an office visit, the tests are most likely to be performed by a pulmonologist, neurologist, nurse or respiratory therapist. The challenge lies in understanding the results of these tests in the context of a person with neuromuscular disease.

Two important measurements of your ability to breathe deeply are the forced vital capacity (FVC) and maximum inspiratory pressure (MIP or PiMax). The SNIP (stiff nasal inspiratory pressure) test has been shown, in some studies, to be a more sensitive test of respiratory muscle weakness, but it is not widely used in the USA.

Forced vital capacity measures the volume of air you can breathe in and then blow out quickly and completely through a device called a spirometer. It should be measured in both the upright and supine (lying face-up) positions, because you can't breathe as efficiently lying down.

Another simple test that measures the strength with which you can breathe in is the MIP. A mouthpiece is attached to a negative pressure gauge via a narrow tube. With a noseclip pinching off the nostrils, you exhale and then suck on the mouthpiece as hard as possible; the gauge registers the pressure.

A result of <50% predicted FVC or a MIP <60 cm H₂O may signal that it's time to get some assistance with breathing.

However, the most important factor in diagnosing hypoventilation is an elevated level of CO₂ (above 45 mm Hg). This can be measured invasively with an arterial blood gas (ABG) analysis or noninvasively using exhaled end-tidal CO₂ monitoring or transcutaneous CO₂ monitoring.

continued, page 2

Thanks to Josh Benditt, MD, University of Washington, Seattle (benditt@u.washington.edu); Peter Gay, MD, Mayo Clinic; Diana Guth, RRT, Home Respiratory Care, Los Angeles (Diana@hrcsleep.com); E.A. Oppenheimer, MD, (retired) Los Angeles; and Jesper Qvist, MD, Respiratory Centre East, Copenhagen, Denmark (jq@dadlnet.dk), for their assistance.

Hypoventilation? Obstructive Sleep Apnea? Different Tests, Different Treatment

continued from page 1

The pattern seen on an overnight oximetry tracing may also be helpful for identifying early hypoventilation often seen first during the deepest rapid-eye movement (REM) sleep stage.

Signs and symptoms of nocturnal hypoventilation may include one or more of the following:

- ◆ fatigue or exhaustion after normal activity;
- ◆ excessive daytime sleepiness
- ◆ shortness of breath, breathlessness with minimal activity;
- ◆ claustrophobia or feeling that air in room is somehow bad;
- ◆ difficulty in speaking for more than a short time;
- ◆ quiet speech with fewer words per breath;
- ◆ inability to lie flat while awake due to shortness of breath;
- ◆ inability to lie flat during sleep/ need to sleep sitting up (orthopnea);
- ◆ trouble falling asleep and trouble staying asleep;
- ◆ anxiety about going to sleep.

Other signs and symptoms, which may also be seen in OSA, include:

- ◆ excessive daytime sleepiness and need to nap during the day;
- ◆ nightmares, night sweats, bedwetting, or need to urinate frequently;
- ◆ morning headaches;
- ◆ restless/fragmented sleep with frequent awakenings;
- ◆ shallow breathing or cessation of breathing for 10 seconds or more;
- ◆ awakening from sleep with choking sensation;
- ◆ worsening mental status, impaired memory, concentration, cognition.

Do not ignore these signs and symptoms hoping they will go away. They are serious. You may need evaluation and treatment immediately!

The treatment for hypoventilation is NOT oxygen but assisted ventilation, generally at night, with a bilevel ventilator. Bilevel units that offer the S/T mode (the unit operates in a spontaneous –S– mode, meaning the user can spontaneously initiate each ventilator breath, but switches to a timed –T– mode, referred to as the backup rate, when breaths are not initiated by the individual) are recommended for people with neuromuscular disorders.

Bilevel ventilators provide pressure support ventilation which is achieved by the difference in two set pressures: IPAP (inspiratory positive airway pressure) and EPAP (expiratory positive airway pressure). The IPAP and EPAP pressure settings can be adjusted separately.

People with neuromuscular disorders have more trouble breathing in. They generally need IPAP that is set at least 5-10 cm H₂O higher than EPAP and EPAP that is set at the minimum level. Higher EPAP makes it too difficult for them to exhale. "In my home care company, we start out people new to bilevel with 'training wheels' – a minimum span of 5 cm H₂O. After they become acclimated to the treatment, we increase the span if the individual is more comfortable and/or needs more volume," says Diana Guth, RRT.

For reimbursement of a bilevel unit in the USA by Medicare, the requirements are a diagnosis of a progressive

continued, page 10

Swedish Respiratory Unit for Ventilator-Assisted Children

Alette Bagge, RN, LIVA, Astrid Lindgren Children's Hospital, Stockholm, Sweden (allette.bagge@karolinska.se)

The improved care of newborn children has resulted in an increase in the number of technology-dependent children who are cared for in hospital. Since 1990, the Department of Pediatric Intensive Care at Astrid Lindgren Children's Hospital in Stockholm has cared for ventilator-assisted children in a separate long-term intensive care unit (LIVA).

The LIVA unit offers a more home-like and stimulating environment that has a favourable effect on the children's psychomotor development. Eventually the children are discharged to home or other accommodations.

Three of the four beds are occupied by hospitalized children, and the fourth bed is used for short-term care of children who had previously been on the unit or whose parents need respite.

The home-like atmosphere of the unit has rooms for different activities: bedrooms, playrooms and dining room.

The children leave their bedrooms during the day. Pre-school and school activities take place outside the hospital. Other activities such as walking in the surrounding areas, visits to the Skansen Zoo and Park, and visits to the cinema and theatre are encouraged. The need for ventilatory support should not be an obstacle.

Currently, 47 technology-dependent children are being cared for at home. 85 children have been discharged, and 23 children have been decannulated. Eighteen children have died. Duration of tracheostomy ranges from 2 months to 14 years. Length of stay ranges from one day to seven years. Fifty of the

admitted children were less than one year of age.

Diagnoses include neuromuscular disorders, CCHS, upper airway disorders, lower airway and pulmonary disorders, craniofacial malformations, and cerebral palsy. The majority of the children (38) use tracheostomy ventilation. Ventilators are the Eole 3 XLS (Saime S.A., www.saime.fr) and BiPAP® Syncrony and Harmony® (Respironics, Inc., www.respironics.com).

Our large multidisciplinary team consists of an anesthesiologist, pediatrician, social worker, nurses, physiotherapist, dietitian, ENT specialist, dentist, surgeon, speech, play and occupational therapists, department of technical equipment, and administrative staff.

The respiratory dispensary at Danderyd's Hospital produces custom-made tracheal cannulae.

Optimal care is guaranteed by our knowledgeable, responsible staff. Constant training and education in the care of technology-dependent children requiring long-term care occurs on our unit, led by the clinical nurse specialist. This training is also aimed at parents, personal assistants, home care providers and other staff at the local authorities who are responsible for the care of these children. Prior to discharge, contact with the relevant local authorities is intensified. ●



Bea and her twin sister. Bea was in a car accident and had a neck injury. She lives at home now with her family, two dogs and attendants.

Masks, Part II: Noninvasive Interfaces

*Diana Guth, RRT, Owner, Home Respiratory Care, Los Angeles, California (Diana@hrcsleep.com)

Just what is an interface?

It's a term that is often interchangeable with "masks," but an interface is what enables the delivery of air to a person by connecting to one end of the tubing that is connected at the other end to a ventilator or CPAP unit. Invasively, it's a tracheostomy or endotracheal tube. Noninvasively, it's a range of masks and other appliances that are discussed in the following text.

My "**TOP PICKS**" are strictly subjective. They are based on more than 20 years of experience in home respiratory care. For a complete listing of noninvasive interfaces, check IVUN's *Resource Directory for Ventilator-Assisted Living* (www.post-polio.org/ivun/d-ve.html).

Nostril-type interfaces. Often known as nasal pillows or cushions, these interfaces fit into the nostrils. They are held in place with straps, rigid headpieces or dental retainers, and are available in a wide range of sizes. Some are easy to put on and take off, some provide a clear line of vision allowing the user to wear glasses, and some are more comfortable due to a lack of straps on the side of the face.

Nostril-type interfaces can cause the nostrils to widen, which may be cosmetically undesirable. This style is best suited to nose breathers or nose breathers/mouth leakers if used with a chinstrap; those with prominent nose bridges; individuals who require lower pressures, unless a heated humidifier is used; individuals who are claustrophobic; and those who have limited use of their hands.

*Disclosure: Author participates occasionally in focus groups and beta-testing for ResMed Corp.

TOP PICKS: Mirage® Swift™ (ResMed Corp.) and Breeze SleepGear™ with Nasal Pillows Assembly (Puritan Bennett).

Nasal masks. These interfaces fit around the nose and are held in place with straps or rigid headpieces. The largest selection of interfaces is in this category. In addition to the usual range of sizes, nasal masks are also available in shallow and narrow depending on the model. Some nasal masks have adjustable forehead mechanisms for proper fitting.

Most nasal masks have double cushions – air is trapped between the two cushions to seal the mask without putting undue pressure on the bridge of the nose. The inner cushion is more rigid, made of silicone, rubber or gel. The outer cushion is thin and contoured to the inner cushion. Some cushions are removable for cleaning and mask size interchange.

Nasal masks are best suited to nose breathers or nose breathers/mouth leakers if used with a chinstrap.

TOP PICKS: Ultra Mirage™ and Activa™ (ResMed Corp.), ComfortGel™ and ComfortLite™ (Respironics, Inc.), FlexiFit™ 407 (Fisher & Paykel Healthcare Inc.) and Breeze SleepGear™ with DreamSeal® (Puritan Bennett).

Full face masks. These fit around both the nose and mouth. Some fit from the nose bridge to under the lower lip. Others fit from the nose bridge to below the chin. The Total™ Face Mask (Respironics, Inc.) fits over the entire face. Face masks look cumbersome, but they are quite comfort-

"When choosing an interface, go to a home health care company that employs experienced respiratory therapists and offers a variety of interfaces to try. You want a comfortable, well-fitting, easy-to-use interface that provides effective assisted ventilation. Remember to lie down to test the interface in the body position in which you sleep!"

able. In my experience, individuals prefer the face mask to a nasal interface with chinstrap or oral interface.

Full face masks all have fail-safe valves that allow the user to breathe room air if there is a power failure. They are all held in place with straps of varied elasticity or have headgear that can quickly disengage if the mask needs to be suddenly removed and the individual has adequate hand and arm dexterity.

Face masks are best suited to nose breathers or nose breathers/mouth leakers; people who are unable to keep the mouth closed; and people who are uncomfortable with the nasal interface/chin strap combination.

TOP PICKS: Ultra Mirage® Full Face (ResMed Corp.), FlexiFit™ 431 (Fisher & Paykel Healthcare Inc.) and ComfortFull™ (Respironics, Inc.).

Oral interfaces. Usually referred to as mouthpieces, these come with and without outer mouthseals. Some mouth breathers can use this interface.

Two models with mouthseals are the Oracle™ 452 (Fisher & Paykel Healthcare Inc.) and the Bennett Seal Mouthpiece Assembly (Puritan Bennett). The Oracle fits into the mouth with a flange that fits in front of the teeth: an outer seal covers the mouth. The Bennett is a standard mouthpiece with an outer seal. Both are secured with a single strap over or under the ears, although the Oracle's strap is optional.

Mouthpieces without an outer seal are generally used for mouth intermittent positive pressure ventilation (MIPPV),

also known as "sip and puff." Some individuals with neuromuscular disorders use MIPPV with volume-cycled ventilators during the daytime with small angled mouthpieces or straw-type mouthpieces. (Some individuals have even learned to sleep with these.) The mouthpiece can be mounted close to their head so that they can take a breath and speak after each breath. Individuals with use of their hands can hold the mouthpiece to take a breath when they need one.

Custom masks. With the increased use of CPAP units to treat obstructive sleep apnea and bilevel ventilators to treat hypoventilation in people with neuromuscular diseases, the commercial mask market has exploded and broadened the range of available masks so that well-fitting masks are easier to find. Some ventilator users have had their dentist configure an appliance that fits in the mouth and extends upward over the nose. Custom masks are available in the USA and Europe – go to www.post-polio.org/ivun/d-ve.html.

Pediatric masks. Commercial masks for children, particularly infants, are limited. In the USA, respiratory health professionals adapt adult commercial masks. Soft Series™ (Respironics, Inc.) masks in pediatric and small sizes frequently fit. Adult nasal masks used as full face masks, such as the ComfortGel™ (Respironics, Inc.) have also been successful. In Europe, some hospital pediatric departments make custom masks for their patients.

continued, page 9

His Choice: My Life

Deshae E. Lott, Bossier City, Louisiana (deshaelott@hotmail.com, www.deshae.net)

Granted, no single response to life with a ventilator can be universal. However, I'm glad I didn't see "Million Dollar Baby" before I required mechanical ventilation. It would have been anything but inspiring. In fact, I'm glad that my specialists' reading of pulmonary function tests, sleep studies and blood work made them believe my respiratory failure, if it were to come, would be many years down the road.

As much as we want our physicians to acknowledge our concerns, pinpoint their source and alleviate our distressing physical symptoms, I am alive today because of their diagnostic ignorance. Had they been more familiar with cases like mine, a variant form of limb girdle muscular dystrophy, and told me that in a few months I would need to use assisted ventilation fulltime, and had they been more informed about the transition to that particular lifestyle, I believe I would have written a living will with advanced directives that prohibited intubation.

If I had had time to consider the emotional, physical and financial burdens of vent life prior to my emergency intubation, I believe I would have allowed my body its natural death. It is, after all, the more practical option if one wants to avoid emotional, physical and financial burdens.

It takes guts to choose life with a ventilator. When my husband chose intubation for me, I was no longer conscious

when the doctor reached the ICU and intubated me in time to avoid brain damage. Assisted ventilation and blood transfusions saved my life and allowed me to return to full consciousness. At that point, I had to decide about a tracheostomy and long-term ventilator use. (No other options were given, except for the unspoken one of death.)

My one question for the doctors, including the doctor overseeing ethics at the hospital, was whether I had the right at any time to change my

mind after I agreed to try vent life. I learned that I did, and so I chose to work hard to rehabilitate as much as possible. Unlike "Million Dollar Baby" suggests, we do not have to ask someone else to commit murder or participate in euthanasia if we *do* find the lifestyle too hard to handle. We simply can exert our right to stop assisted ventilation, which will – for most of us full-time vent users – induce death fairly quickly.

Although the choice to live with a ventilator long-term has brought new limitations and routines and burdens and discomforts to our lives – of which we at times grow weary – I am grateful that my husband wanted me to live, no matter what. I am grateful that, with him, we create quality moments, both in our lives together and in my life independent of his. I am glad that we worked and continue to work at this. Each day proves all



Deshae E. Lott, PhD, teaches in the English Department at Louisiana State University in Shreveport.

Her husband, Jeffrey D. Sadow, PhD, is a political scientist and also a professor at LSUS.

Her Life: My Caregiving

Jeffrey D. Sadow, Bossier City, Louisiana (jsadow@pilot.lsus.edu)

Caregiving for a full-time ventilator user is expensive and potentially time-consuming, and those are its easier demands. As with so many activities in life, much of what goes on in caregiving revolves almost exclusively around time, energy and money.

While personal care tasks are specific for each individual, mine include transferring Deshae from bed to wheelchair to toilet to minivan, driving her to medical appointments, administering medicines orally and through a nebulizer or portacath several times a day, suctioning her airway multiple times daily, changing her trach tube as often as daily but more often weekly, using devices to simulate cardio-pulmonary therapy and coughing, assisting with range of motion physical therapies, all personal hygiene, dressing and grooming, and meals and feeding. Then there is the maintenance, cleaning, adjusting or otherwise tending medical equipment, including Deshae's most animated one, her service dog Ulina.

I am blessed with the strength and ability, because Deshae is petite and lightweight, to lift her without the assistance of another person or a lift (this fact may change as we both age). After much practice, I can flip up skirts, pull down underwear, etc., all while holding up Deshae midway in transfers from her wheelchair to the toilet and back. This avoids the need for catheterization and for adaptive clothing.

Another reason I can tend to Deshae on my own during transfers is that, at this time, she can spend short periods – about ten minutes – without using

the vent; if air quality is good and she lacks severe pneumonia, with effort, she can manage an hour or more.

So far no one is required to use an Ambu® bag during her disconnections from the vent or to hold the vent tubing to keep it connected to Deshae while I lift and move her. If she could not breathe for herself at these times, we would require more assistance.

Something else that helps reduce our need for outside assistance is that, with the trach cuff deflated or with the trach capped, Deshae can speak and greatly facilitate task direction and accomplishment. With her prodigious mental energy, she handles the business aspects of her health care.

Between that and her physical and pulmonary therapies, Deshae clocks nearly a full-time job on basic survival tasks. This is in addition to her work with LSUS.

Currently, I am Deshae's sole caregiver more than 140 hours a week. Many weeks we have 16-26 hours of help from a privately paid nurse; all four of Deshae's health insurance plans deny hourly home health coverage. Fortunately, my job is flexible and allows substantial opportunities for telecommuting, but Deshae needs another caregiver when I must work outside the home or perform routine tasks such as grocery shopping. As any primary caregiver knows, help from others, either paid or volunteered, is vital – you cannot do it alone.

Volunteers to help primary caregivers of vent users would be wonderful, but

continued, page 8

Deshae uses a Bivona TTS® cuffed trach tube (Portex, Inc., www.portex.com) and LTV® 950 ventilator (Pulmonetic Systems, Inc., www.pulmonetic.com). Previously she used a TBird® Legacy (VIASYS Healthcare, www.viasyshealthcare.com). The cuff is inflated when Deshae is sleeping or when inhaling nebulized medications. When the cuff is deflated, Deshae can speak. When the cuff is inflated, she holds a noisemaker to alert someone if there is a problem.

several factors deter people from volunteering. (And some of these apply to paid attendant/caregivers.) First, knowing someone's life potentially depends upon your reactions creates a high-pressure situation many refuse to accept. Second, some people may be uncomfortable dealing with the physical aspects of vent life, such as suctioning. Third, adequate training can take more time than people can give and may prove overwhelming. Fourth, people may be uncomfortable performing unpleasant tasks at another's behest—tasks that can require substantial time, energy and conscientiousness. Fifth, willing volunteers (Deshae's grandmother) themselves may be too frail to handle the physical demands of the task.

Finally, and perhaps most important, there is the absolute uncertainty about how controlled your life will be at any time by the needs of the vent user. While somebody is in your care, you never know when your life will be disrupted, while at the same time you know you cannot escape this without potentially risking the person's life.

Any number of things can intrude upon your lifestyle, without warning. This includes while you're sleeping; you must awake immediately and make the proper decisions to avoid or to reduce the severity of a crisis. Bluntly and understandably, most volunteers psychologically do not want to place themselves in this position for any extended period.

All of the above factors bring me to paid attendants/caregivers and money. To perhaps over-generalize: wealthy families can afford to pay large sums

out of pocket to obtain excellent care; poor and low-income families have all their needs paid for by the government and receive adequate or low to adequate care; and, for the rest, private insurance may be able to provide adequate care, but any gaps in coverage threaten to send such families into poverty (at which point they qualify for government coverage but often only if the primary caregiver divorces the spouse or quits his or her middle-class job).

Deshae and I fit into the last category. For others in a similar situation, I advise you to inform yourself fully about government programs and legal instruments (such as a special needs trust). For most middle-class Americans facing long-term vent life, it is largely up to you to seek the means to help yourself maintain even a semblance of your former quality of life.

Helpful information often is sparse and uncoordinated. Insurance companies wishing you weren't costing them far more than your premiums pay will have to be dragged kicking and screaming to fulfill their ends of the bargain. The incredible inefficiency of government-directed health care financing will frustrate you. But with much persistence and energy, you may be able to secure good quality care.

Given all of the drawbacks and demands and displeasures, why do I help my wife endure vent life? Because, for better or for worse, I will give all that I have to maintain the presence in my life of that "pearl of great price." ●

Vented and nonvented interfaces. A vented interface is designed with exhalation ports built into the mask so that it functions with a controlled leak to allow exhaled air to escape. Because of the continuous flow of air from either a CPAP unit or bilevel ventilator, the interface must have exhalation ports.

A non-vented interface has exhalation valves built in and is designed to work without a leak because the valve closes during inhalation and opens during exhalation. These interfaces are most often used with a volume-cycled or pressure support ventilator.

Headgear. Headgear, made of stretchy and/or breathable material, secures most interfaces. Strap-style headgear can provide from two to five point connections. Some straps are attached to nylon caps, satin bases or webbing. They feature sizing and securing adjustments using Velcro and/or buckle or clip mechanisms and attach to the mask by different types of clips or slits in the mask.

The more elastic models allow the individual to pull the mask on and off without having to manipulate clips – important for individuals with limited hand dexterity.

Breeze SleepGear™ is rigid plastic headgear that is secured like headphones but extends from the nose to the back of the head with sliding adjustments and straps for stability.

Interchangeable or proprietary headgears can work with various masks. Many headgears are designed to function with a specific interface. This is

a problem in the USA for Medicare reimbursement for accessories when a mask is not sold separately from the headgear because the headgear and mask replacement schedules do not coincide. Medicare allows a mask replacement every three months, but headgear replacement is every six months. Unfortunately, the headgear frequently wears out before the mask.

Chinstraps. These are effective with people who leak slightly out of the mouth or lips, but they will not really keep someone's jaw closed because the jaw is strong. They should be adjusted to fit snugly under the lower lip for a "stiff lower lip" to eliminate air leaks. Some are merely small patches of fabric or donut holes that cup the chin. They are secured with stretchy Velcro fabric on top of the head. Other chinstrap/head attachment configurations offer more stability. A wide post-facelift style band (Design Veronique, also distributed by Resironics) is also an effective chinstrap.

Other considerations. A few interface systems provide a clear line of vision, making it possible to wear glasses. Some interfaces have quick disconnects from the tubing so that the individual can use the bathroom quickly without having also to remove the interface – an important consideration for people with limited dexterity or hand strength. Alternating interfaces to relieve pressure points is advisable, using one during the day and another type while sleeping. Alternating is also beneficial during respiratory tract infections. ●

Hypoventilation? Obstructive Sleep Apnea?

continued from page 2

neuromuscular disorder, absence of chronic obstructive pulmonary disease (COPD) or if present it does not significantly contribute to the individual's respiratory limitations, and one of the following test results:

- ◆ FVC <50% of predicted,
- ◆ MIP <60 cm H₂O,
- ◆ PaCO₂ arterial blood gas >45 mm Hg,
- ◆ Nocturnal SpO₂ (oxygen saturation) <88% for five continuous minutes while asleep.

Obstructive sleep apnea (OSA).

Apnea is the cessation of airflow for more than 10 seconds. OSA occurs when tissues in the throat collapse, intermittently blocking airflow during sleep. Snoring is often a major indicator of OSA, but not always.

A sleep study (polysomnogram test or PSGT) is primarily used to determine and design treatment for individuals with OSA. A sleep study is not absolutely necessary for the diagnosis in people with neuromuscular disorders but it may be helpful when first introducing the bilevel treatment.

The main breathing problem is almost always hypoventilation, although people with neuromuscular disorders early on may also have undiagnosed OSA. Most sleep labs are not equipped to measure CO₂ levels, and therefore cannot diagnose hypoventilation.

The standard treatment for OSA is continuous positive airway pressure (CPAP) to help keep the airway open or a bilevel unit without a backup rate. ●

EQUIPMENT

Respironics, Inc., announces the release of its new **PLV® Continuum™**. The Continuum is a smaller, lighter (20 lbs.) version of the PLV®-100, but it can also provide pressure support and pressure control. Peak inspiratory pressure is 99 cm H₂O.

It can also be used with children weighing more than 5 kg. (www.respironics.com)

A future issue of *Ventilator-Assisted Living* will include comments by ventilator users who are transitioning to the Continuum.



His Choice: My Life

continued from page 6

that much more precious, if all the more difficult.

If assisted ventilation is almost certainly an inescapable part of your future or that of someone for whom you care, I encourage trying a vent. If you have progressive disease, you can start with noninvasive ventilation to forestall respiratory failure and possible emergency tracheostomy.

Before you dismiss the option to continue living, give assisted ventilation a chance. No matter what complications vent life brings, you and your caregivers can create beauty and purpose in such living. ●

INTERNATIONAL VENTILATOR USERS NETWORK

AN AFFILIATE OF



MEMBERSHIP OPPORTUNITIES

International and USA membership levels are the same.
(US dollars only)

\$15 Supporter

Access to home mechanical ventilation information at www.post-polio.org/ivun
Access to www.post-polio.org
Networking opportunities
Information about relevant events
Support of Post-Polio Health International's educational, research, and advocacy efforts
Opportunities to participate in research
100% tax-deductible

\$25 Subscriber

All of the benefits of Supporter, AND ...

Quarterly 12-page newsletter of your choice:
Ventilator-Assisted Living OR Post-Polio Health
100% tax-deductible

\$45 Subscriber Plus

All of the benefits of Subscriber, AND ...

Both quarterly newsletters:
Ventilator-Assisted Living AND Post-Polio Health
100% tax-deductible

\$75 Contributor

All of the benefits of Subscriber Plus, AND ...

Resource Directory for Ventilator-Assisted Living
Post-Polio Directory
Discounts on special publications such as
Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors
Discounts on meetings sponsored by
Post-Polio Health International
100% tax-deductible

\$125 Sustainer

All of the benefits of Contributor, AND ...

One additional complimentary Subscriber
Membership subscription for another person designated by the Sustainer or to a person who has expressed financial need to PHI
\$100 is tax-deductible.

Use the form below to join today!

If you are a current member, give this form to a friend, family member, or health professional.

INTERNATIONAL VENTILATOR USERS NETWORK

AN AFFILIATE OF



Name _____

Institution _____

Address _____

City _____

State/Province _____

Zip/Postal Code _____

Country _____

Phone _____
(area/country code) Fax _____
(area/country code)

Email _____

PAYMENT OPTIONS

- Enclosed is my check made payable to Post-Polio Health International. (US dollars only)
 OR, charge my: VISA MasterCard Discover

Card # _____

Exp. date _____

Name on card _____

Signature _____

MEMBERSHIP APPLICATION

MEMBERSHIP LEVEL

- Supporter, \$15** (No newsletter is included)
 Subscriber, \$25 Choose either newsletter:
 Ventilator-Assisted Living OR Post-Polio Health
 Subscriber Plus, \$45
 Contributor, \$75
 Sustainer, \$125 ...

Please send the additional subscription of
 Ventilator-Assisted Living OR Post-Polio Health

TO: Name _____

Address _____

City, State/Province _____

Country _____ Zip/Postal Code _____

Or, donate the complimentary subscription to person selected by Post-Polio Health International.

Other \$ _____

Send to:

POST-POLIO HEALTH INTERNATIONAL
4207 Lindell Blvd., #110, Saint Louis, MO 63108-2915 USA
314-534-5070 fax

The mission of International Ventilator Users Network, an affiliate of Post-Polio Health International ... is to enhance the lives and independence of home mechanical ventilator users through education, advocacy, research and networking.

Calendar

DECEMBER 3-6

AARC's 51st International Respiratory Congress.

San Antonio, Texas. Contact American Association for Respiratory Care, 972-243-2272, www.aarc.org.

Travel

The Federal Aviation Administration under the U.S. Department of Transportation released a Special Federal Aviation Regulation (SFAR) approving the use of portable oxygen concentrator devices brought onboard commercial aircraft by passengers, effective August 11, 2005. The only devices pre-approved for use now are the Inogen One (www.inogen.net, <http://oxygentogo.com>) and Lifestyle (www.airsep.com). Each airline is currently revising its policy.

For the complete SFAR, go to "Use of Certain Portable Oxygen Concentrator Devices Onboard Aircraft," Docket No.: FAA 2004-18596; SFAR No. 106, RIN 2120-A130. (<http://dms.dot.gov/search/document.cfm?documentid=339107&docketid=18596>)

IN THIS ISSUE ...

Hypoventilation? Obstructive Sleep Apnea?
Different Tests, Different Treatment

Swedish Respiratory Unit for Ventilator-Assisted Children

Masks, Part II: Noninvasive Interfaces

His Choice: My Life
Her Life: My Caregiving

VENTILATOR-ASSISTED LIVING

SAINT LOUIS, MISSOURI USA

ISSN 1066-534X

VOLUME 19, No. 3

FALL 2005

Issued Quarterly

EDITOR

Judith R. Fischer, MSLS

GRAPHIC DESIGN

Sheryl Rudy

EXECUTIVE DIRECTOR

Joan L. Headley, MS

©Copyright 2005 by Post-Polio Health International.

Permission to reprint must be obtained from Post-Polio Health International.

How to contact IVUN ...

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915 USA
www.post-polio.org/ivun
ventinfo@post-polio.org
314-534-0475, 314-534-5070 fax

Sponsored in part by

Passy-Muir Inc.



RESMED

Supported in part by

EMERSON

NON-PROFIT ORG.
U.S. POSTAGE
PAID
PERMIT NO. 210
JEFFERSON CITY, MO

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 LINDELL BOULEVARD, #110
SAINT LOUIS, MO 63108-2915 USA