

VENTILATOR-ASSISTED LIVING

FORMERLY IVUN NEWS

SAINT LOUIS, MISSOURI WWW.POST-POLIO.ORG/IVUN



Welcome to Ventilator-Assisted Living ... the new name for the newsletter of the International Ventilator Users Network (IVUN). It reflects a reorganization of the umbrella organization, Gazette International Networking Institute (GINI), which also has a new name, Post-Polio Health International (PHI).

The mission of Post-Polio Health International is "to enhance the lives and independence of polio survivors and home mechanical ventilator users by promoting education, networking, and advocacy among these individuals and health care providers."

The President of the PHI Board of Directors, Frederick M. Maynard, MD, stated, "Well-managed organizations periodically evaluate themselves to make sure they are fulfilling their mission. The Board undertook a strategic planning process to determine how our organization could more effectively meet the needs of the people we serve. We knew our founder, Gini Laurie, would have agreed."

Laurie's volunteer experiences in a polio respiratory ward in Cleveland, Ohio, in the 1950s led her to found the organization that, 45 years later, continues to work for and with ventilator users and polio survivors. "Historically, the first ventilator users were polio survivors who used iron lungs. Now, a growing number of people with a variety of conditions use home mechanical ventilation," said Maynard.

Throughout the strategic planning process, PHI reaffirmed its commitment to home mechanical ventilation users. Elements of the strategic plan include developing a membership structure to strengthen the organization's advocacy role in ventilator users' issues and forming alliances with other organizations that have compatible goals and philosophies to further PHI's mission.

Current newsletter subscribers are automatically members. (See membership form on page 11.)

"We ask our new members to encourage others - ventilator users, respiratory health professionals, ventilator equipment manufacturers and distributors - to join us," said Maynard. "By becoming members, they, too, can support our causes and contribute to the legacy of a truly unique organization." ☞

"Historically, the first ventilator users were polio survivors who used iron lungs. Now, a growing number of people with a variety of conditions use home mechanical ventilation." Frederick M. Maynard, MD Board President, PHI

GINI Is Now Post-Polio Health International

- OUR NAMES THROUGH THE YEARS
1960 International Iron Lung Polio Assistance, Inc.
1964 Iron Lung Polios and Multiplegics, Inc.
1970 Rehabilitation Gazette, Inc.
1983 Gazette International Networking Institute, Inc.
1985 Doing business as International Polio Network
1987 Doing business as International Ventilator Users Network
2003 Post-Polio Health International including International Ventilator Users Network

Getting Used to Noninvasive Bilevel Pressure Ventilation

Louie Boitano, MS, RRT, Northwest Assistive Breathing Center, Pulmonary Clinic, University of Washington, Seattle (boitano@u.washington.edu)

How noninvasive bilevel pressure ventilation (NBPV) is initially set up and started is pivotal to the success of acclimating to this therapy. Your pulmonologist prescribes the initial bilevel pressures – a higher pressure to support inspiration (breathing in) and a lower pressure for expiration (breathing out). Initial bilevel pressures should be set to enable you to acclimate to NBPV, after which the pressures can be adjusted to optimize your breathing support.

A progressive desensitization plan can help you more easily acclimate to NBPV. You can learn to use sensory stimuli to distract yourself and decrease your sensitivity to both the mask interface and the bilevel airflow.

Generally in our clinic, the initial inspiratory pressure is 8-9 cm H₂O and expiratory pressure is 4-5 cm H₂O. Starting with higher pressures may be counter-productive. Unfortunately, sleep studies may often recommend excessively high expiratory pressure. An insufficient difference between the inspiratory and expiratory pressures can make acclimation difficult and does not provide adequate support for people with respiratory muscle weakness.

A progressive desensitization plan can help you more easily acclimate to NBPV. You can learn to use sensory stimuli to distract yourself and decrease your sensitivity to both the mask interface and the bilevel airflow. The following four-step protocol is an example of a patient-directed progressive desensitization plan.

1 On initial setup, a respiratory therapist from the home care company supplying the bilevel pressure ventilator should show you a variety of interfaces to determine which interface is the best fitting and most comfortable for you. (Many people select nasal pillows that fit inside the nostrils because they cannot tolerate a nasal or facial mask.)

If you do decide on a nasal or facial mask, try wearing the mask unconnected to the bilevel ventilator for 15-30 minutes at a time, at least once or twice a day while listening to music, reading, or watching TV so that you focus on something other than the interface. Do this for as many days as needed in order to become comfortable with the mask. If you are having difficulty with claustrophobia, simply hold the mask to your face for much shorter periods.

2 The next step is to attach the tubing (also referred to as the hose or circuit) from the bilevel ventilator to the mask and turn on the ventilator. Try using the system during the day for 15-30 minutes at a time, again while distracting yourself with music, reading, or television, to become comfortable with the airflow from the ventilator. You may want to connect the tubing to the mask slowly so that the airflow is not overwhelming. Adjust the mask and headgear to minimize annoying air leaks. (At first you may only be able to hold the mask, with airflow, to your face for short periods in order to begin acclimation.) This step should also be done more than once a day over several days to help you become comfortable with NBPV.

3 You may find that you feel comfortable enough to fall asleep during these day-time trials and use NBPV for day-time naps. The next step is to try falling asleep at night while using NBPV.

4 When you try NBPV at night, you should again progress according to your own comfort level. If you cannot fall asleep, do not frustrate yourself by continuing to use NBPV while lying awake. Simply try it again the next night, or go back to using it again only during the day. If you fall asleep for a time and awaken unable to fall asleep again, do not frustrate yourself lying awake, but start again the next night. Even a few hours of sleep with the support of NBPV can begin to help your sleep quality and day-time wakefulness.

With the support of your homecare respiratory therapist, a progressive desensitization plan can help you to successfully start and benefit from NBPV therapy. 

TAPES FROM

Conference on Children Who Are Medically Fragile

Audio cassettes are now available from the Ken-Crest conference March 31-April 2, 2003 (www.kencrest.org/medfrag/conf.html).

Individual cassettes are \$8 each and the complete set of 27 tapes is available for \$200.00 – plus shipping and handling. Order online or by mail from AudioVisual Communications, 435 Crooked Lane, King of Prussia, PA 19406 (www.audiovc.com).

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). Threats to “informed” advance directives for the severely physically challenged? *Arch Phys Med Rehabil*, 84 (4 Supplement 2), S23-8. (www.aapmr.org)

Baydur, A., & Kanel, G. (2003). Tracheobronchomalacia and tracheal hemorrhage in patients with Duchenne muscular dystrophy receiving long-term ventilation with uncuffed tracheostomies. *Chest*, 123, 1307-1311. (www.chestnet.org)

Douglas, S., & Daly, B.J. (2003). Caregivers of long-term ventilator patients: Physical and psychological outcomes. *Chest*, 123, 1073-1081.

MacDuff, A., & Grant, I.S. (2003). Critical care management of neuromuscular disease, including long-term ventilation. *Cur Op Crit Care*, 9(2), 106-112. (www.lwwonline.com)

Massie, C.A., & Hart, R.W. (2003). Clinical outcomes related to interface type in patients with obstructive sleep apnea/hypopnea syndrome who are using continuous positive airway pressure. *Chest*, 123, 1112-1118.

Oppenheimer, E.A. (2003). Treating respiratory failure in ALS: The details are becoming clearer. *J Neurol Sci*, 209, 1-4. (www.elsevier.com/locate/jns)

Severa, E., Sancho, J. Gomez-Merino, E., Briones, M.D., Vergara, P. Perez, D., & Marin, J. (2003). Non-invasive management of an acute chest infection for a patient with ALS. *J Neurol Sci*, 209, 111-113.

Trail, M. Nelson, N.D., Van, J.N., Appel, S.H., & Lai, E.C. (2003). A study comparing patients with amyotrophic lateral sclerosis and their caregivers on measures of quality of life, depression, and their attitudes toward treatment options. *J Neurol Sci*, 209, 79-85.

Adolescence: Transitioning from Pediatric to Adult Care

Howard B. Panitch, MD, and Cherie DeBrest, MSS, The Children's Hospital of Philadelphia
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"The goal of transitioning is not to remove parents from the team when the child reaches the age of majority, but to place the young adult in control of his or her health care needs ..."

Advances in medical care have resulted in an increased rate of survival of children with life-threatening conditions, many of whom have neuromuscular disease (NMD) and who may develop progressive respiratory muscle weakness. However, the weakness may not impair breathing until later adolescence.^{1,2}

These children will require chronic respiratory support, either part- or full-time, during adolescence or young adulthood. Teens who survive severe spinal cord injuries (the incidence of severe spinal cord injuries in children has two separate peaks, with the later one occurring in mid-adolescence in association with sports injuries and more risk-taking behavior³) will also require chronic respiratory support.

In our home ventilation program of more than 220 ventilator-assisted children, approximately 15% are over 16 years of age. More and more are reaching an age when they would traditionally seek medical care from internists or family practitioners. Paradoxically, they continue to be followed by pediatric sub-specialists in pediatric hospitals. The reasons for this are numerous and complex,⁴ and involve the children, their families, physicians, and health care systems.

Adolescence is about spontaneity, risk-taking, and asserting oneself among the peer group. As these teens try to become independent and separate emotionally from parents or other adult caregivers, their care can become more complex. Limitations in mobility necessitate assistance with transfers from bed to chair, more spe-

cialized equipment, and architectural changes around the home. The adolescent should be physically and emotionally pulling away from the parental safety net, but instead must remain squarely within it.

As the health status of older adolescents changes, they may feel particularly vulnerable and, therefore, unwilling to transfer trust in medical caregivers to a new health care team. Care needs also can become more complex because other body systems (i.e., cardiac, digestive, renal) may become involved and require the attention of additional sub-specialists.

Family attitudes towards the natural course of a child's illness may influence both parents and child. Families of ventilator-assisted adolescents may feel uncomfortable transitioning to adult programs. For example, expectations about survival of children with NMD into adulthood⁵ may be low enough that the families do not want to expend their efforts on meeting new health care providers at this late stage of the child's disease.

A paradigm shift occurs in the relationship between parent, child, and the pediatric and adult health care systems. Pediatricians are accustomed to considering a child as dependent, with health care decisions largely reliant upon parental influence. Internists view the patient as the decision-maker and the person who ultimately determines the medical course.

Adolescents who successfully take their college entrance tests may hesitate to answer questions during routine pulmonary office visits or defer

important decisions (such as when to shift from noninvasive mechanical ventilation to tracheostomy) to their parents. Adolescents who are passive participants in the exam room may assert themselves at home through nonadherence.

Some parents need to feel as if they are still ultimately in control, not over the adolescent, but over the disease process. The goal of transitioning is not to remove parents from the team when the child reaches the age of majority, but rather to place the young adult in control of his or her health care needs, with guidance provided by parents and the medical team.

Many of the diseases that result in respiratory insufficiency in later adolescence arise from childhood diseases about which internists are less familiar. Thus, these physicians may be unwilling to assume the care of patients for whom they have not received formal training and whose complex care requires the involvement of multiple sub-specialists.

An independent young adult who is learning how to advocate for herself/himself may not realize how much she/he relies on the accessibility and invaluable case management services provided by nurse practitioners and social workers. Issues with pharmacies, insurance, schools, or transportation may take hours or days to resolve. This amount of quality time is expensive, not well reimbursed, and difficult to obtain in the adult medical world.

The biggest obstacle to successful transitioning of ventilator-assisted adolescents involves insurance benefits.

Generally, ventilator-assisted children and adolescents are insured under their parents' commercial insurance as the primary payer. Medicaid in Pennsylvania is the secondary payer for hospitalizations, durable medical equipment and supplies, and up to 16 hours of skilled nursing care per day.

A cornerstone of home care for ventilator-assisted adolescents is the provision of skilled nurses so the family is able to live, work, sleep, and still have the mental energy to fight disease progression. Seventy-two percent of our adolescents receive skilled nursing care for part or all of the day. Families are trained in all aspects of care, but as care becomes more complex and the child becomes bigger physically, some assistance is mandatory.

When commercial insurance coverage ends, either because of circumstances or because the child becomes too old to remain under the parents' policy (depending on student status), Medicaid becomes the sole provider for all health care needs. It does not include provisions for shift care nursing delivered in the home for anyone, whether 21 or older. Medicaid deems that someone with a medical condition meeting the criteria for requiring 24-hour skilled care should be in a nursing home environment. (Nick Dupree challenged Medicaid in Alabama on this and won – www.nicksrusade.com.)

Transitioning of ventilator-assisted adolescents and young adults represents a process that, despite many obstacles, remains a worthy and important goal. ☞

References

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4. Schidlow, D.V., & Fiel, S.B. (1990). Life beyond pediatrics. Transition of chronically ill adolescents from pediatric to adult health care systems. *Med Clin North Am*; 74(5), 1113-20.
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DMD Pioneers

Jeff McAllister (Jeff@DMDpioneers.org/www.JeffSpace.net/NIVnews)

Diagnosed with Duchenne muscular dystrophy (DMD) in 1983 at the age of 6, I later learned that my decreasing lung capacity (at age 15) meant I would need some sort of assisted ventilation. There were two options: to undergo a tracheotomy or to wear a nasal mask at night. The physician obviously preferred the tracheotomy; I obviously preferred the noninvasive method. The physician insisted that a tracheotomy was the best choice, but finally the physician said, "I have to respect your decision."

Fortunately, I connected with John R. Bach, MD, a leading proponent of noninvasive ventilation in the USA. He recommended that I obtain a pulse oximeter to periodically check the oxygen saturation levels in my blood. He also recommended that I obtain the CoughAssist™ for secretion removal during respiratory infections to prevent them from worsening and turning into pneumonia. Currently I use mouth intermittent positive pressure ventilation via a mouthpiece and LTV™ 900 ventilator (both attached to my wheelchair) during the day. At night, I use SleepNet's Phantom® mask and PLV®-100 ventilator.

People with Duchenne muscular dystrophy (DMD) are often told that living beyond their 20s is unlikely or that a cure is right around the corner. The problem is that these statements lead people to think that there is no need to plan ahead or to deal with real life situations.

After 19 years of living with DMD, I realized that not enough information is available. There are some resources – occasional articles in *Quest* (the magazine of the Muscular Dystrophy Association), a few email lists and message board posts, and even a website (www.DMDOptions.com). Several of the email lists deal with muscular dystrophy in general, but these lists focus on parents of children with muscular dystrophy. Issues affecting adults with DMD include respiratory care, cardiac health, and sexuality; they are not usually issues that parents wish to discuss.

In the summer of 2001 I started an email list specifically geared towards adults (16 years and older) with DMD. It is called DMD Pioneers – pioneers because we are exceeding the life expectancies projected for us and literally pioneering the idea of living a long,

healthy life with DMD. (<http://groups.yahoo.com/group/dmdpioneers>)

Our website's Living with DMD (www.DMDPioneers.org) includes "Prolonged Survival" – respiratory care, cardiac health, nutrition, etc.; "Day-to-Day" – activities of daily living from attendant care to clothing; and "Quality of Life" – employment, higher education, volunteerism, relationships, assistive technology, etc. The interactive weekly chat room and message board are popular. Parents of younger children with DMD communicate directly with adults with DMD. The ground rules are that nothing is taboo and people are free to speak their minds.

DMD Pioneers (the organization) is a diverse and international group of people who strive not to be statistics. Ages range from teenagers to one adult who is in his 40s. The number of those using invasive ventilation and those using noninvasive ventilation is about evenly split. Our goal is very simple: to educate people about DMD and to promote "Prolonged Survival" – our belief that anyone diagnosed with DMD has the potential to become a DMD Pioneer. ☞

Editor's note: A recent article discussed a group of individuals with DMD in Newcastle, England, who had been followed from 1967-2002. "Survival in Duchenne muscular dystrophy: Improvements in life expectancy since 1967 and the impact of home nocturnal ventilation" by Michelle Eagle, Simon V. Baudouin, Colin Chandler, David R. Giddings, Robert Bullock, and Kate Bushby. (*Neuromuscular Disorders*, 2002, 12(10), 926-929.)

Happily Using Bilevel Pressure Ventilation

John Molini (Kmolini@saonet.ucla.edu)

As a polio survivor (1951 at age 8), I have used a bilevel ventilation system for more than a decade. I was first introduced to bilevel pressure ventilators by my home care respiratory therapist, Diana Guth, RRT (diana@hrcsleep.com). Initially, she told me that there was a machine on the market that would lower my high carbon dioxide levels and enable me to sleep better so I would have more strength and endurance during the day.

My first reaction was whom do I see about this unit, the Easter Bunny or the Tooth Fairy? Diana said neither, but I would have to see Adrian Williams, MD, FRCP, (now in London) at UCLA Medical Center in Los Angeles. Dr. Williams arranged for a two-night sleep study there to confirm my underventilation. The first night I did not use anything to help my breathing. The second night I used the BiPAP® S/T (Respironics, www.respironics.com) with nasal pillows, and I dreamt for the first time in years. That was in 1991, and I have used a bilevel ventilator with ADAM nasal pillows (Puritan Bennett, www.puritanbennett.com) ever since.

I used the BiPAP® S/T exclusively for about seven years until it needed a complete overhaul. Diana then introduced me to the VPAP® II ST (ResMed, www.resmed.com), a more mobile, smaller, quieter, lighter unit, and the filters did not need to be changed as often. When it was being evaluated for a repair, I tried the Respironics BiPAP® Synchrony™, but I preferred the VPAP.

I now use a newer VPAP version: the VPAP® II ST-A (A for alarms, although I have disconnected them). It is also

lightweight and quiet, but the settings are easier to adjust than the older model. My settings now are 22 inspiratory, 4 expiratory.

I recently recovered from a serious case of bronchitis. My oxygen levels fell, but my carbon dioxide levels remained normal. I believe that without the use of the ventilator, I probably would have needed to be hospitalized. Bilevel pressure ventilation works well for me. ☺

Potpourri

Equipment problems. To check whether problems, malfunctions, or failures have been reported for ventilatory equipment in the USA, go to the FDA website: www.accessdata.fda.gov, click on Medical Devices, and then scroll down to MAUDE. The search is by the name of the manufacturer and the name of the equipment. However, this site only provides the reports: these have not been investigated or confirmed. Ventilator users can also access this site to report problems (a form is provided) they are having with equipment. Thanks to Lisa Kiessling, CCHS Family Network, for advising about this website.

Living With ALS, a set of six manuals from The ALS Association, first published in 1997 and recently updated, is available online: www.alsa.org.

To access the manuals online, you must obtain a user name and password, easily done by registering on the website. The manuals include:

- | | |
|-----------|---|
| Manual #1 | What's It All About? |
| Manual #2 | Coping With Change |
| Manual #3 | Managing Your Symptoms and Treatment |
| Manual #4 | Functioning When Your Mobility Is Affected |
| Manual #5 | Adjusting to Swallowing and Speaking Difficulties |
| Manual #6 | Adapting to Breathing Problems |

Home Mechanical Ventilation in the Netherlands

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Home mechanical ventilation (HMV) started in the Netherlands at the end of the '60s, when the first centre for HMV was established in Groningen. A decade later a similar centre was founded in Utrecht, followed by centres in Rotterdam and Maastricht. Each centre is based within university medical centres and serves clearly defined regions with approximately four million inhabitants each. Together with the Dutch organization, Vereniging Spierziekten Nederland, the centres have established a platform for combined research, external contacts, and development of guidelines and teaching materials.

Currently, the Utrecht Centre for HMV supports a total of 465 patients (35 children) with neuromuscular diseases (64%), chest wall deformities (20%), pulmonary disorders (12%), and various other problems (4%). Most of them (61%) use noninvasive ventilation – this percentage is still growing. Roughly half are ventilated at night only, and approximately 15% are ventilated more or less continuously, either by invasive ventilation or by a combination of nasal ventilation at night and mouth-piece ventilation during the day.

Our team consists of three full-time medical specialists in respiratory home care (including myself), seven intensive care nurses specialized in HMV, three secretaries, a technician and two assistants, and a dietician.

Candidates for HMV, who are often presented during multidisciplinary consults at a rehabilitation centre or referred by rehabilitation physicians or neurologists, are first visited at

home or invited to the hospital for an extensive discussion about the pros and cons of HMV for their specific situation. Consequences for (future) care are discussed, and candidates and their relatives are asked to think it all over before an appointment is made in the outpatient department.

In the outpatient department, a diagnosis of nocturnal hypoventilation can only be suspected because patients are seen during the daytime. Suspicion is based primarily on the patient's history/complaints, blood gas analysis (capillary) and lung function. Patients are then referred to the specialized respiratory unit – located within the Groot Klimmendaal Rehabilitation Centre in Arnhem – for confirmation of nocturnal hypoventilation by nocturnal blood gas analysis (either capillary or arterial), end-tidal CO₂ measurement, pulse oximetry, and observation of sleep during one to four nights.

In most patients, noninvasive HMV is only initiated (the day after confirmation of nocturnal hypoventilation) when PCO₂ is 50-55mm Hg, and the amount and severity of the patient's complaints taken into account. Interfaces are nasal or facial masks (about 75% commercially made) or mouthpieces. Generally, pressure-targeted ventilators, like the Breas 403 or BiPAP®, are used for this purpose. The PLV®-100 is used less frequently in noninvasive ventilation. There is a tendency to postpone invasive ventilation as much as possible, but now and then tracheostomies are needed (particularly in ALS).

In ALS, noninvasive ventilation is only started when there are complaints and

PCO₂ is >45mm Hg. Without complaints, noninvasive ventilation in ALS is usually advised when PCO₂ is 55-60mm Hg.

The respiratory unit combines specialized HMV care and rehabilitation for both children and adults with chest wall deformities and neuromuscular diseases in very comfortable surroundings. Since the unit was opened six years ago as an alternative to the intensive care unit (ICU) in our hospital, which was considered the worst place to be for HMV users, nearly 95% of all (future) HMV users are referred to this specialized eight-bed unit. The physician on call from the Utrecht Centre for HMV visits the unit twice a week and communicates daily on all HMV-related issues.

Under supervision of one of our nurses, patients are discharged from the respiratory unit to their home (67%), congregate living (28%), or nursing home (5%). Children are usually cared for by their parents and relatives, and only in special circumstances is professional home care needed. However, as more and more of our HMV users get older (some with Duchenne muscular dystrophy are in their 30s and 40s), home care by elderly parents becomes more difficult. Caregivers, school personnel, taxi drivers, and volunteers in HMV care, receive extensive instruction, particularly about suctioning (the use of the CoughAssist™ is not yet routine) and cannula care.

An individual with an income of less than \$35,000 is eligible for the National Health System (NHS). Individuals with higher incomes have private insurance. The insurance companies of the NHS contract with the HMV centre and reimburse for the ventilator, mask, tubing, and supplies; ventilator maintenance and repair; and home visits by the HMV's nurses, physicians, and technicians (about \$10,000 per year).

Home care companies are independent and sell ventilators to the four HMV centres; a very small percentage sells

to insurance companies who supply ventilators to their clients, but this does not include maintenance of the equipment or medical care and followup from an HMV centre.

Nurses and/or attendants who provide care in the home are paid by insurance companies up to about \$300 per day or are subsidized by the town in which they live. Many people with neuromuscular diseases who use HMV benefit from the latter system which amounts to \$50,000–\$150,000 per year. From this money, people can buy care for themselves and even pay a relative or friend. Full 24-hour home care by medical personnel is almost never reimbursed by either method and is hard to obtain due to a shortage of personnel. The lack of nursing and/or attendant care personnel, unfortunately, forces some HMV users to move to congregate living or nursing home.

At least twice a year, the effectiveness of the ventilation is checked by a full night of pulse oximetry and capnometry in the home setting. In addition, all HMV users are routinely visited at home one to four times per year by one of our nurses. Additional home visits are made, when needed, to repair a custom-made nasal mask or to adjust the ventilator settings. Once a month consultation is available with an ear-nose-throat surgeon from our hospital for tracheostomy-related problems.

Our centre offers permanent accessibility and continuous availability. If needed, ventilators are replaced within two hours. Because of the small size of our country, we are able to deliver continuous care from the Centre's nurses and physicians specialized in HMV to the home, where most HMV users are able to stay satisfactorily for a long time. ☺



Roanne and her nasal mask.

Letters to the Editor

From Adolf Ratzka, PhD, respiratory polio survivor, Director, Institute for Independent Living, Sweden (ratzka@independentliving.org)

“Regarding *IVUN News*, ... it is USA-centered in legislation and institutional framework. For information on personal assistance in Sweden, one of the better programs in Europe, you are free to browse our website (www.independentliving.org/libauth.html) and look for articles, many of which I wrote.

“Looking at myself, I find that my interests have widened from ventilators (still the core) to elimination, seating and posture, energy, osteoporosis, heating through clothing, bedding and shoes, weight loss and pressure sore prevention – in short, a whole list of secondary issues that surface as primary problems. It would be interesting reading how other people are trying to cope with these problems.

“Also, it is necessary to stay ahead of the development of these problems, since it does take time to experiment and to come to a (temporary) solution. Learning from peers might shorten the time it takes to get ready for the next problem before it really becomes a problem.” ☞

Clarification

Robert A. Hoover, MD, PhD, the Medical Director of DMERC Region D, requested that a clarification be published regarding the article “Reimbursement for Ventilator Equipment: How It Works” in *IVUN News*, Spring 2003, Vol. 17(1).

The article stated, “The DMERCs notify interested parties through announcements in the Federal Register (www.access.gpo.gov/su_docs/aces/aces140.html) and on the CMS website (<http://cms.hhs.gov/providerupdate>).” Dr. Hoover responded, “Policies are posted on each DMERC’s website and distributed to clinical organizations like the American Thoracic Society, NAMDRC, AARC, individual practitioners, state medical and DME societies, trade publications, and beneficiary groups.”

Dr. Hoover also informed IVUN that the policy on the CoughAssist™ (one of the examples presented in the article) was made public on June 1, 2003, and the effective date is October 1, 2003. (www.cignamedicare.com/dmerc/lmrp) ☞

Ninth International Conference on Noninvasive Ventilation: “From the ICU to Home”

October 23-25, 2003, Caribe Royale Resort Suites, Orlando, Florida

Sponsored by American College of Chest Physicians (ACCP)
In cooperation with National Jewish Medical and Research Center &
International Ventilator Users Network (IVUN)

Take advantage of this excellent opportunity to see and try the latest ventilator equipment and masks, meet the medical experts on long-term use of mechanical ventilation at home, attend ventilator user sessions with IVUN’s own Larry Becker, Linda Bieniek, Laura Hershey, David Jayne, Audrey King, Bill Miller, and Barbara Rogers, and network with respiratory health professionals.

For complete program information, go to www.chestnet.org. Register until August 29 at a reduced rate. For hotel information, contact the Caribe Royale (800-323-8300, www.cariberoyale.com) and ask for the group rate for “ACCP Noninvasive Ventilation.”

See you there!

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THE MISSION OF POST-POLIO HEALTH INTERNATIONAL, including International Ventilator Users Network ... is to enhance the lives and independence of polio survivors and home mechanical ventilator users by promoting education, networking, and advocacy among these individuals and health care providers.

HOW TO CONTACT US ...

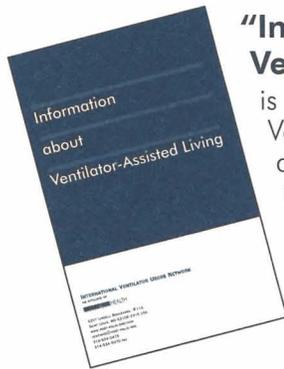
INTERNATIONAL VENTILATOR USERS NETWORK

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Questions about your membership and our services ...
An application for \$500 towards purchasing a scooter ...
Justine Craig-Meyer at ventinfo@post-polio.org



"Information about Ventilator-Assisted Living"

is a new 12-page brochure from International Ventilator Users Network (IVUN). It is an introduction to mechanical/assisted ventilation: what is it? who uses it? what types of ventilators? what types of interfaces? and more.

If you would like a free copy mailed to you, please contact Justine Craig-Meyer, ventinfo@post-polio.org.

VENTILATOR-ASSISTED LIVING

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