

IVUN News

My Quest for Ideal Ventilation

Julie Levine

On June 25, 1994, I received a telephone call from my neurosurgeon in New York City. (I had been living in New Jersey before moving to Southern California.) My MRI scan confirmed what I suspected – my brainstem tumor (ependymoma), which was removed eight years before, had returned. Two days later, my mother and I were on a plane to Manhattan. Recovery from my first surgery in 1986 at the age of 24 had been rapid. I walked out of the hospital in two weeks and after six months of outpatient physical therapy, I resumed my active life.

Anticipating the same quick recovery as before, I packed a suitcase for the hospital with a change of clothes, makeup, and a bathing suit, expecting to begin pool therapy immediately. I awoke in the hospital's ICU, looking up at my smiling neurosurgeon who was assuring me that the tumor was completely removed and would not bother me again. I was terrified and confused, for I could feel my body, but I could not move. After four weeks in intensive care with a breathing tube, I received a tracheostomy. My plans for my future were destroyed. I could not move and I could not breathe independently, due to aggressive surgery.

I returned to California via an air ambulance. The next six months were spent in five different rehabilitation facilities in California, futilely trying to do physical therapy and to be weaned from the ventilator simultaneously. I was exhausted and frustrated. No one understood

my condition. Instead I was given antidepressants which, needless to say, resulted in further debilitating my respiratory system. I did not fall into any textbook category. I was "upside down," with strong legs but an extremely weak upper body. I could not lift my shoulders and arms, but I could take steps if my upper body was supported.



Within four months, I was free of the ventilator during the day, requiring night ventilation only. Finally, after eighteen months of therapy and sheer persistence, my trach was removed. I was fine for a week, then I went into respiratory failure. I refused to be trached again. My pulmonologist agreed to try another means of ventilation and suggested bi-level positive airway pressure or BiPAP.

I have used the BiPAP® S/T system nocturnally for three years. I have tried every conceivable mask. The first year, I used hard plastic nasal masks which caused

skin breakdown and infections on the bridge of my nose and lip. Finally, I switched to the Monarch™ Mini Mask which minimized skin breakdown but leaked. To achieve optimal ventilation, it must be placed on the nose in just the right place. I had to use a chin-strap with the Monarch™ mask because I sleep with my mouth open. Being unable to move my arms, I cannot adjust the mask if it moves during the night. I recently developed pain and pressure buildup in my right ear which led to hearing loss in the ear and caused me to seek other methods of ventilation.

Luckily, my respiratory therapist, William Rivas, was willing to try every available noninvasive method to help me survive with the best and most comfortable ventilation. First we tried the Porta-Lung which did not work because my neck is curved from my surgery and could not clear the aperture. Then there was a trial with a full-length pneumosuit which caused severe back and hip pain. Somehow, after sleeping this way for two weeks, my abdominal muscles became stronger, thus improving my gait and helping to hold my head up.

The next attempt was with volume ventilation: the PLV®-100 with a lipseal. But the PLV®-100 did too much of the breathing for me. When I stopped using the PLV®-100 in the morning, I was extremely weak with tight muscles, making it very difficult to regain strength during the day. (My breathing muscles must have improved so much that when I did not use them, I lost strength.) And the lipseal proved too big for my mouth.

My current solution is to use BiPAP with the Monarch™ Mini Mask at night and the PLV®-100 during a short rest period in the afternoon. To keep my mouth closed – instead of a chinstrap with the Monarch™ – I had my dentist make a mouthpiece from a mold of my teeth. (I place a dab of Fixadent on it to prevent the mouthpiece from falling out). I lowered the BiPAP pressure to help my ears and had my ear doctor put a tube in my problem ear. Then, I had my dentist custom-make a lipseal with an attached molded inner tube to use with the PLV®-100.

Recently, my pulmonologist found that there was an increase in the amount of air flow, indicating that my lungs have expanded more and improved. My abdominal muscles are also stronger, so I no longer breathe with my neck muscles and am finally initiating my own coughs.

When adequately ventilated, I have the strength for physical therapy which I do every day for four to six hours. I devised a rudimentary system of pulleys which I use every day, along with an arm and a recumbent stationary bicycle. Twice a week, with the assistance of aides, I walk the width of a swimming pool for 10 laps.

It has been five years since my surgery and I continue to forge ahead. I hope to eventually regain full body function and become independent again. If anyone has suggestions for improving and regaining shoulder and arm mobility, I would greatly appreciate receiving them. ■

ADDRESS: Julie Levine, 5 Monarch, Irvine, CA (California) 92604 (jmlpooks@fea.net).

Pneumobelt in Action

Tedde Scharf, MA

Tedde successfully converted from tracheostomy positive pressure ventilation to noninvasive ventilation (see IVUN News, Spring 1996). She has limb-girdle muscular dystrophy.

For those readers who are unfamiliar with what a pneumobelt or exsufflation belt looks like, it is a cotton corset-type belt about 12-14 inches wide with a front panel, a back panel, and adjustable, nylon connecting straps. The front panel has a pocket which holds an inflatable rubber bladder. The bladder has a tube at one end which connects to the flexible hose tubing from the ventilator (mine is a Respirationics PLV®-100).

Once strapped firmly around one's midsection just below the rib cage, the bladder fills with air from the ventilator and pushes up under the diaphragm thus forcing air out of the lungs. When the bladder deflates, the diaphragm lowers and air is pulled back into the lungs through the mouth and nose. I have learned to synchronize my breathing with the cycle of the pneumobelt.

Because it works with gravity, the pneumobelt is effective only in the upright position and cannot be used nocturnally unless one sleeps sitting up. It is not generally recommended for a person with moderate to severe scoliosis or lordosis. My pneumobelt was purchased by my insurance company and lasts for 18 months to two years. I generally keep a new belt on hand for backup.

In general, the pneumobelt is a great system. It is not obvious to

the naked eye, and it frees up my hands and mouth enabling me to work more effectively.

I use the pneumobelt about 16 hours per day, as well as mouth intermittent positive pressure (MIPPV) via a small mouthpiece held between my teeth while dressing, bathing, coughing, and doing lung expansion exercises. At night, I use a Lyon custom nasal mask which I have had since 1995. Ventilator settings such as tidal volume, BPM rate, and inspiratory rate are adjusted to increase volume for coughing and expansion exercises, but are decreased for sleeping (the pneumobelt settings are somewhere in between).

MIPPV is adequate backup to the pneumobelt. However, it interferes significantly with communication and related socialization skills. People have trouble understanding my speech with the mouthpiece so I tend to be more withdrawn. It is difficult to speak easily with a tube in one's mouth.

Due to weakened muscles following an accident last year, my vital capacity has dropped significantly and my speech is more difficult with the pneumobelt. Currently, I am working with a speech therapist at the University of Arizona regarding adjustments to tidal volume, BPM rate, and inspiratory rate for smoother speech delivery and better synchronization with breathing. Also, Arizona Rehabilitation Services is providing a portable speech enhancement system to help make my voice louder. I will be a rolling "bionic" woman with powerful speech output! ■

ADDRESS: Tedde Scharf, MA, Disability Resources for Students, Arizona State University, Matthews Center, Room 143, Tempe AZ (Arizona) 85287-3202 (tedde@asu.edu).

Sip Technology Instead of Tracheostomy

Joshua Benditt, MD

An alternative for tracheostomy for full-time ventilator users is a noninvasive system that delivers air through a mouthpiece (intermittent positive pressure ventilation or IPPV) instead of a tracheostomy. This mouthpiece or "sip" intermittent positive pressure ventilation (IPPV) has been used in some European countries for several years and in this country by John R. Bach, MD, at the University of Medicine and Dentistry of New Jersey. The University of Washington is the first medical center to offer this in the Northwest.

The mouthpiece is attached to standard ventilator tubing and positioned close to the face by a bracket on the wheelchair or bed frame. The individual turns toward the mouthpiece and grabs it with the lips, which triggers the ventilator to send a breath. (To avoid orthodontic problems that can develop with long-term use, some people have a custom acrylic mouthpiece made for them by a dentist.)

In order for people to use the sip IPPV, they must be able to breathe on their own for at least one to two hours in case of an emergency and they must be very motivated. While an individual with a tracheostomy does not have to think about breathing, the sip system requires the person to be conscious of every breath.

People who choose the sip IPPV system need to use an alternate system while sleeping, usually a nasal mask. Indeed, the transition to noninvasive ventilation from the trach begins with nasal ventilation at night with the trach temporarily plugged. It can take a while for people to become accustomed to the feeling of having air

pushed through the nose and still be able to sleep.

Once the individual can tolerate the night-time mask, the ventilator settings for day-time use are adjusted. The person is taught how to trigger a breath (using the mouthpiece), and the ventilator is set to be very sensitive to the point at which the person wants to take a breath. Comfort is very important for compliance. Too much air makes people feel light-headed, while too little can lead to panic or a sense of impending doom. Pulse oximeters and blood gas tests that monitor the oxygen saturation level of the arterial blood are used to measure how well someone is being ventilated. When the individual is properly ventilated noninvasively, the stoma is allowed to close and heal.

Javier Perez, C2 quad with a tracheostomy since 1990, spent two weeks in our hospital, practicing with sip IPPV, gradually increasing the time he spent using it. In between the practice sessions, Perez continued to receive ventilation through his trach. By discharge, Perez could use the sip technique continuously for 5-6 hours during the day, switching to nasal positive pressure ventilation for 7-8 hours during the night.

Cold weather, a chronic stuffy nose, and other health problems caused setbacks for Perez after he returned home, but he preferred the benefits of full-time noninvasive ventilation in reducing his risk of infection and in breathing air filtered through his mouth and nose. With the trach, he had been bothered by smoky or polluted air, but without the trach, he noticed the difference in the purer air.

The biggest challenge is integrating sip IPPV with activities of daily living such as eating, speaking, and driving a chin-controlled chair. "It is hard work for the individual. If you and I have a bad day, we can still breathe. If the patient has a bad day, he might not have enough stamina to breathe," according to respiratory therapist Marilyn Hilsen. However, noninvasive ventilation can have significant health and quality of life benefits and is a desirable alternative for certain people. ■

Adapted from an article in *Spinal Cord Injury Update*, Spring 1998. Reprinted with the permission of the Northwest Regional Spinal Cord Injury System, University of Washington, Department of Rehabilitation Medicine, Box 356490, Seattle WA (Washington) 98195 (206-685-3999; benditt@u.washington.edu).

International Ventilator Users Network (IVUN)

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Paediatric Home Ventilation in the United Kingdom

Dr. Robert Yates, a member of the UK Working Party on Paediatric Long-Term Ventilation, first wrote about long-term mechanical ventilation for children in the United Kingdom in *IVUN News*, Fall 1998. Dr. Yates updates the progress of his unit.

"We are steadily expanding and currently have 25 children on the books with only eight in hospital. Of these, at least two will be home by Christmas. We have a bid for a clinical nurse specialist and have written a regional document on the standards of care that a service should provide to persuade our purchasers to fund the gap between the current and desired situations. In addition, we have made inroads into linking with the adult services.

"Increasingly we are able to assess older children with neuromuscular conditions who are symptomatic from night-time hypoventilation. Bi-level positive airway pressure using the Breas® PV 102 machine has helped many of these children by improving their morning headaches, day-time sleepiness, and general well-being. I strongly suspect that the incidence of both hospital admissions and respiratory infections has been dramatically reduced in this population of children and await our audit figures with interest.

"Our next big battles are to try and have a fifth bed for reassessment, sleep studies, and respite, and to link Social Services and Housing with the Health Care package. This may happen through the development of a Continuing Care Group at a high level within Social Services and one or two key Health Authorities. It would also be nice to get some continuing medical education funded since at the moment there is none at all.

"As for the children I wrote about in *IVUN News* – Ian and Amanda are well and at home with their families supported by teams of carers, and Macauley will be finally discharged before Christmas."

ADDRESS: Dr. Robert Yates, Consultant in Paediatric and Intensive Care, Manchester Children's Hospitals, Pendlebury, Manchester M27 4HA England (Robert.Yates@man.ac.uk).

◆ More on this subject can be read in two excellent articles by Dr. Colin Wallis and Sister Elspeth Jardine at The Institute for Child Health and the Great Ormond Street Hospital for Children in London. The articles can be found on the British Medical Journal Publishing Group's Web site: www.bmjpg.com.

Jardine E, Wallis C. (1998) Core guidelines for the discharge home of the child on long-term assisted ventilation in the United Kingdom. *Thorax* 53:762-767.

Jardine E, O'Toole M, Paton JY, Wallis C. (1999) Current status of long-term ventilation in children in the United Kingdom: Questionnaire survey. *British Medical Journal* 318:295-299.

◆ **Voices and Choices. Young People Who Use Assisted Ventilation: their health, social care, and education** by Jane Noyes, 1999, London, The Stationery Office.

Jane Noyes, a senior lecturer in the department of nursing at the University of Salford, with support from the Joseph Rowntree Foundation, studied 18 ventilator-dependent children (ages 6-18) as well as their families. She presents their views on and experiences with: being in hospital, being discharged, living at home, starting or returning to school, growing up, and those unable to live at home. Noyes found that many articles in the UN Convention on the Rights of the Child (1989) had not been upheld or respected, and many basic needs were not met. Likewise, these young people did not receive full protection under the Chil-

dren Act (1989) and national standards of NHS care were not always provided.

While this book is intended for other young people who use ventilators, it should be mandatory reading for adults in both the private and public sectors. Noyes' excellent and wise study presents many issues and challenges for policy makers providing health, social, and education services for this growing population. Bibliography, appendices, and resource organizations are listed. (PDF files summarizing the main findings can be downloaded from www.jrf.org.uk by clicking on "read and download research summaries," then scrolling down to Voices and Choices.)

Voices and Choices. Young People Who Use Assisted Ventilation: their health, social care, and education, £12.50, order from The Stationery Office, Publications Centre, PO Box 276, London SW8 5DT England or online www.tso-online.co.uk. (All the monies from books sold will fund an additional printing.)

◆ **Voices and Choices of Children and Young People Who Use Assisted Ventilation: bibliography and analysis of the literature** by John Sudbery and Jane Noyes, 1999, The Joseph Rowntree Foundation and the University of Salford.

This volume contains the literature review and presents the context for the empirical research in *Voices and Choices*. It more fully explores the issues that arose during the study. John Sudbery is a lecturer in the department of social work, also at the University of Salford. These two books are incomplete without the other; both are comprehensive, extremely well-written, and fascinating.

Voices and Choices of Children and Young People Who Use Assisted Ventilation: bibliography and analysis of the literature, £6.50, order from the Institute for Health Research, University of Salford, Manchester M5 4WT England or j.noyes@salford.ac.uk. ■

CCHS: Are Nasal Masks Affecting Facial and Bite Alignment?

The *CCHS Family Newsletter* for April 1999, reported that some parents of CCHS children have noted that their children have similar orthodontia issues and/or "elongated jaws." Mary Vanderlaan, founder and director of the CCHS Family Network, uses the term "trach jaw" to describe the way children with tracheostomies lower their jaws to cover their trachs to talk more loudly and/or to cough, or to clear their airways. She hypothesizes that the effect might be to stimulate jaw growth over time. More study is needed to determine if a diagnosis of CCHS means the children have a proclivity toward a larger jaw or other facial anomaly.

As children with CCHS reach their teen years, some may need orthodontia and braces, as well as orthodontic headgear to pull out the mid-face. A new issue arises as more CCHS children make the transition to nasal ventilation: could a too-tight nasal mask also be working to push in the mid-face and/or exacerbate a misaligned bite?

Sung Min Park, MD, at Children's Hospital in San Diego, reported to a sleep disorders association meeting in 1995 on two cases of children with pseudoprognathism (the upper lip area appears pushed in while the jaw protrudes) after long-term use of nasal masks. One of the children had CCHS. While nasal masks and use of bi-level ventilation have psychosocial advantages over tracheostomy ventilation, they may cause disfigurement in growing children, according to Dr. Park. In these children, it appears that the anterior growth of the maxilla is restricted by pressure from the mask,

unlike the mandible which does not come into contact with the nasal mask and therefore develops normally.

Switching to a full face mask, using some of the newer and lighter masks, or using nasal pillows may help avoid this problem. In each case, however, the mask must be fitted to each child carefully. As mask technology develops and masks do not leak as much, the effects of the mask on facial development may be minimized. Nevertheless, this is an issue that deserves special attention from parents and caregivers. ■

For more information, contact Mary Vanderlaan, CCHS Family Network, 71 Maple Street, Oneonta, NY (New York) 13820 (807-432-8872; vanderlaanm@hartwick.edu).

Pseudomonas aeruginosa

Linda Egar writes, "As a 57-year-old woman ventilator user due to muscular dystrophy, I have had a problem with phlegm since my tracheostomy 17 years ago. At first I thought it was 'normal' because of the trach, but recently, after sputum cultures grew *Pseudomonas aeruginosa*, I learned that I have a chronic bacterial infection very resistant to antibiotics. My doctor is suggesting that I learn to live with this, but it makes my life very uncomfortable, and I am afraid that the longer the infection

remains, the more serious it will become. If anyone has had any success in managing this infection, please contact me at 639 Island View Drive, Santa Barbara, CA (California) 93109 or MSTRI@impulse.net. ■

EDITOR'S NOTE: There is a Web site on the subject - www.pseudomonas.com.

Respironics Introduces New Customer Service System

Many ventilator users have received letters from Respironics advising them of a new system for customer service, distribution, and repair. The former Customer Satisfaction Centers are being phased out gradually, and a new centralized distribution warehouse in Youngwood, Pennsylvania, will take over. Respironics is also using a nationwide network of trained mobile respiratory technicians in association with a local homecare dealer to handle same-day service. Ventilator users should call their homecare dealers or Respironics' main customer service number, 800-345-6443, for assistance. Respironics still guarantees 24-hour, 7-day emergency support and is promising a quicker turn-around time for repairs. Time will tell whether this new system is more beneficial to ventilator users. ■

WANTED: Ventilator-Dependent Children to Adopt

Gary and Nora Edgar of Benton Harbor, Michigan, are looking for children to adopt who are ventilator-dependent. They have a five-year-old adopted daughter with a rare myopathy who needed 24-hour ventilator use for the first three and a half years of her life, but who now uses the ventilator only during the night. They also are foster parents to a three-year-old boy with tracheomalacia who was recently trached.

Please contact the Edgars at 699 Riverview Drive, Benton Harbor, MI (Michigan) 49022 (816-925-0401; neaaskmi@aol.com).

"Laptop" Ventilator Highly Rated

Barbara Rogers, BA

Every once in a while a product comes along that is a quantum leap above anything else in the marketplace – Pulmonetic Systems' new LTV™ "laptop" ventilators are just such a product.

Pulmonetic Systems, Inc., (Colton, California) manufactures three models of the LTV™ ventilator. The LTV900™ is probably the model that most people who use volume ventilators at home would choose. It offers a wide variety of modes and features, including volume control, pressure support, assist control, SIMV and CPAP modes, and variable flow triggering. The LTV1000™ is the "top of the line" model which provides all that the LTV900™ does, plus a pressure control mode and an internal oxygen blender (for high-flow oxygen needs). The third model, the LTV950™, has a pressure control mode like the LTV1000™, but not an internal oxygen blender.

When I first tried it, I selected the LTV900™ model, thinking it had a pressure control mode, similar to the old Puritan-Bennett Maxivent. (As someone with severe scoliosis, I had been using the Maxivent for nine years with nasal pillows as the interface.) As I was being set up on it, I realized it had pressure support but not pressure control, and I prefer the ability to set the rate of breaths. Because I had the machine at home, I decided to try the volume ventilation mode. I was immediately struck by how much smoother and less "harsh" this ventilator is than the other volume ventilators I had experienced. (Although, I was not really comfortable using any of those because they all seemed very "harsh" to me in the

breaths they delivered, I believe I could comfortably use *this* ventilator in the volume mode if it was all that was available.) I then had a trial with the LTV1000™ using the pressure control mode I was used to – and I loved it.

I finally chose the LTV950™ and found it to be extremely "user-friendly." I like its many options and variables, and the fact that it is easy to adjust. I especially like the continuous readouts which are very helpful when adjusting the settings to ensure that the necessary pressure is maintained.

The circuitry is similar to what I was accustomed to, and I use the same headgear and nasal pillows. At first, I found the exhalation valve in a position that was a bit uncomfortable, but I was able to adjust it without much difficulty. Connecting the circuitry is very easy and the individual hoses are basically size-proofed so they are not readily confused. The LTV™ is much quieter than the Maxivent. The lightweight and slim features of the LTV™ make it easy to move about for use in different rooms of my home.

As Director of Breethezy, a respiratory education, recovery and support program based in New York City, I travel a good deal. Before the LTV™, I used a bi-level pressure unit for travel. Although easier to transport than the Maxivent, the bi-level does not have the capability of the higher pressures that I need. Taking the trial LTV1000™ on the road with me, I found it extremely easy to handle – I put it in my laptop computer case and off I go. I appreciate the discreetness of this ventilator in being able to carry it on board an airplane like I (and so many others)

carry a laptop computer. In hotels, it is easily set up on night tables. I feel more like a high tech traveler now than a traveling medical show!

I presently rent my equipment so that changing ventilators is not a problem from the insurance end. The monthly rental reimbursement is the same for any ventilator in the specific DME category; it is not tied to the actual purchase price of the ventilator. I just switched home care companies and am fortunate that my new company sees the quality of life benefit this new ventilator offers its users and is willing to make the initial investment in purchasing the LTV™. (I highly recommend respiratory therapist Bill Simonds and Low Surgical and Medical Supply, 718-352-4063, to any ventilator user in the NYC metropolitan area. They make me feel safe.)

On a scale of 1 to 10, I would not hesitate to give the new laptop ventilators from Pulmonetic Systems a very solid 10. I hope that more home care companies and insurers will see the very definite therapeutic and quality of life advantage this innovative new ventilator offers its users and that they will step up to the plate to provide them. I also hope that physicians, seeing these benefits, will request them for their patients and that ventilator users will exercise whatever power they have as consumers to get them for themselves – even if it means shopping around for a new home care company. It is *our* lives and *our* quality of life. ■

ADDRESS: Barbara Rogers, Director, Breethezy, 850 Amsterdam Avenue, Suite 9A, New York, NY (New York) 10025 (212-666-2210; 212-666-0642 fax; Breethezy@aol.com; www.breethezy.com).

EDITOR'S NOTE: Breethezy, a national respiratory education, recovery, and support program offers presentations and workshops to bring the patient's perspective to the clinical community. Breethezy also works directly with ventilator users and families to help achieve successful outcomes with mechanical ventilation.

Atrostim® Phrenic Nerve Stimulator (the Finnish system) is again available in the United States. The new representative is Michael Londo, President, Lifestream Medical Corporation, in Orlando, Florida. Londo has a daughter with CCHS who uses the system. His phone is 407-445-0864 (407-290-5581 fax; mlondo1@aol.com).

www.lougehrigsdisease.net is an excellent new Web site for ALS started by Doug Eshelman. It is extremely thorough as well as being easy to use.

www.pca-hha.com assists people in finding personal care attendants and home care nurses. The Personal Care Aid Connection was created by Scott Duffy, C5-6 quad. ■

CALENDAR

2000

APRIL 1-7. Ventilator-Assisted Children's Center (VACC) Camp, Miami, Florida. Contact Bela Florentin, VACC, 3200 S.W. 60th Court, Suite 203, Miami, FL (Florida) 33155-4076 (305-662-8380 ext. 4610, 305-662-VACC [8222], or 305-663-8417 fax). Deadline for overnight campers is January 15, 2000.

JUNE 8-10. Eighth International Post-Polio and Independent Living Conference, Saint Louis Marriott Pavilion Downtown, Saint Louis, Missouri. Contact GINI, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63105-2915 (314-534-0475, 314-534-5070 fax, gini_intl@msn.com, www.post-polio.org).

2001

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

Assisted Living for Ventilator Users

Madonna Rehabilitation Hospital in Lincoln, Nebraska, is taking applications for a new assisted living facility (scheduled to open in the winter of 1999) for young adults with complex disabilities or who use ventilators. The program is designed to allow these individuals to direct their own care in a more independent setting. A special contract through the Medicaid Waiver program in Nebraska is funding this project.

With capacity for eight residents, the building allows each person his or her own bedroom with attached bath. Common areas include a living room, dining area, and kitchen. Personal care assistants will be available around the clock, but residents will be responsible for training them and for directing their own health care. ■

For more information, contact Susan Lonn, Director of Community Services, Madonna Rehabilitation Hospital, 5401 South Street, Lincoln, NE (Nebraska) 68506 (402-483-9573; Slonn@madonna.org) or check the Web site: www.madonna.org/assistliv.htm.

More on Air Travel for Ventilator Users

Alitalia's policies concerning ventilator use on-board, according to Professore Giorgio Ricciardi Tenore, Medical Director for Alitalia Airlines, in an interview printed in the quarterly magazine of Unione Italiana Lotta alla Distrofia Muscolare (UILDm), November 1998, are condensed below:

- ◆ Each person with medical needs must fill out an international medical form "MEDIF," obtained at travel agencies and Alitalia's booking offices. Other information is available from Servizio Medicina Alitalia, Largo Forlanini, 5, 00050 Fiumicino Aeroporto, Roma, Italia (+39 6 65632660).
- ◆ The ventilator must be electromagnetically compatible with flight apparatus and approved by the Registro Aeronautico Italiano (RAI), Via Villa Ricotti n, 42, 00161 Roma, Italia (+39 6 44185).
- ◆ Ventilator users who need to lie down during the journey can use a stretcher fitted to some of the seats.
- ◆ No electrical hookup is permitted on-board. Only a dry battery is accepted and some types of lithium batteries.
- ◆ If the ventilator must occupy a seat, then a ticket must be purchased for the ventilator.
- ◆ If suction equipment must be used on-board, it must be approved by RAI.

For additional information, contact Liana Garini, Respircare, Via Valenza 5, 20144 Milano, Italy (respicare@tigem.it).

THE GINI RESEARCH FUND WAS ESTABLISHED in 1995 by the Board of Directors of Gazette International Networking Institute (GINI). A generous bequest from Thomas Wallace Rogers provided the impetus for this fund's creation. Thomas Wallace Rogers contracted polio at age 19 and was paralyzed from the neck down. With breathing assistance from a rocking bed, Rogers pursued an education and worked as a financial planner and investment advisor. His financial contribution acknowledged the importance of GINI's work and challenged GINI to promote research in addition to its exemplary educational endeavors.



For
Post-polio myelitis
and
Neuromuscular
Respiratory
Research

THE GINI RESEARCH FUND SUPPORTS the work of researchers and clinicians investigating the late effects of poliomyelitis and/or neuromuscular respiratory disease through **one** of two grants:

The Thomas Wallace Rogers Memorial Respiratory Research Grant to study the cause and treatment of neuromuscular respiratory insufficiency and the effects of long-term mechanical ventilation;

The Post-Poliomyelitis Research Grant to study the cause(s), treatment, and management of the late effects of polio.

THE GINI RESEARCH FUND WILL AWARD ITS FIRST GRANT IN THE YEAR 2000.

The postmarked deadline for Phase 1 is March 1, 2000. Applicants will be notified by May 15, 2000. The post-marked deadline for Phase 2 is July 1, 2000. Applicants will be notified by October 15, 2000.

- ◆ One grant for a maximum of \$20,000 is available.
- ◆ A review panel of research experts, health care professionals, and persons with disabilities will select an award recipient.
- ◆ The GINI Board of Directors will approve the panel's recommendation.

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IVUN Resource Directory 1999/2000 is an excellent networking tool for health professionals and both long-term and new ventilator users. Sections include health professionals, ventilator users, equipment and aids, and organizations. Cost (postpaid) is \$5 USA; \$6 Canada, Mexico, and overseas air. (US funds only)

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