

No Barriers in the New Millennium

Bill Miller

I am a 23-year-old ventilator user as a result of a spinal cord injury, which I incurred on August 23, 1997, just two days before I was to begin my senior year at the University of Florida. I tripped in my room and ended up a C-1/C-2 quadriplegic like Superman Christopher Reeve. Currently, I live at home in Leesburg, Florida, with my parents and older brother as my primary caregivers.

Despite the challenges my condition presents, I am proud to say that I have been out and about all over the state and beyond, proving that the ventilator, though it can make things more interesting, does not prevent or heavily hinder an active lifestyle.

Shortly after my accident, I developed pneumonia and it was touch and go for a while. When I stabilized, I was transferred to The Shepherd Center (a hospital specializing in spinal cord injuries – www.shepherd.org) in Atlanta, Georgia, where I was introduced to the In-Exsufflator (J.H. Emerson Co., Cambridge, Massachusetts – www.jhemerson.com).



Bill and Jamy

The In-Exsufflator is essential to vent-dependent health. As testimony I offer the fact that I have not had pneumonia – or any significant respiratory ailment whatsoever – since my initial hospitalization. My pulmonologist, Dr. Humberto Delgado, agrees that the In-Exsufflator has made a tremendous difference in my life.

Nondisabled individuals can easily cough up secretions, but ventilator users do not have the diaphragm control or ability to cough up respiratory ailments on their own. One

*"You can get better
or you can get bitter.
Better is a whole lot
more fun."*

solution is suctioning. Remove the air supply, then stick a plastic tube down through the airway and into the lungs and hope the tiny hole at the end of the catheter will find the problem and hold on to it as suction is applied to the other end.

It would be like eating mashed potatoes and gravy with a straw – while blindfolded. It would work fine with the gravy, but the potatoes? You must work quickly because you cannot breathe while doing this. With every miss you make, every stab you take trying to find the potatoes on the plate, you are causing trauma to your lungs and airway.



Suctioning is very uncomfortable. It gags you. It's invasive. It's traumatic. At best, it pulls out dribbles of "gravy," and it's not very efficient.

There had to be a better way. Fortunately, the experts at Shepherd knew about and used the In-Exsufflator which simulates the body's natural way of clearing secretions. The In-Exsufflator fills the lungs with air – a big, comfortable breath in – then, with the flip of a switch and an assist cough, pulls out the air and secretions (potatoes, gravy, and all) easily, effectively, and efficiently. This noninvasive procedure is over in seconds and relief is immediate. An added bonus is that family and friends can easily learn how to do it.

Though the In-Exsufflator is key, there are several more aspects to a happy and healthy life of vent-dependent independence that I will detail in the fall issue of *IVUN News*. If you cannot wait until then or wish to comment, please contact me at the address below or send an e-mail. ■

ADDRESS: Bill Miller, 9817 Fairway Circle,
Leesburg, FL (Florida) 34788
(MaxNWM@aol.com).

MiCASSA Is Back!

As part of a national "Campaign for Real Choice" in long-term care, rallies were held in Washington, DC, and around the USA in May and June to focus attention on the Medicaid Community Attendant Services & Supports Act (MiCASSA). MiCASSA was reintroduced in the 106th Congress in November 1999 by Senator Tom Harkin (D-Iowa) and Senator Arlen Specter (R-Pennsylvania) and designated S.1935. Recently, Danny Davis (D-Illinois) introduced MiCASSA in the House of Representatives as H.R. 4416.

MiCASSA (which had gained significant support in the 105th Congress as MiCASA) would reform Medicaid long-term care by ending the funding bias toward

nursing homes and other institutions. It would allow the money to follow the eligible individual who chooses to receive services in the community instead of forcing that person into an institution.

In 1998, Medicaid spent \$44 billion tax dollars on nursing homes and other institutions but only \$14 billion on home- and community-based services. The average yearly Medicaid expenditure for a person receiving services in a nursing home is \$23,225 compared with \$7,276 for community-based services.

The bill must pass both the Senate and the House of Representatives and be signed by the President before it becomes law. The next step is to persuade the Senate Appropriations Committee to hold hearings. Please call, write, fax, or

e-mail Senators Harkin and Specter as well as your own senators to urge support for this vital bill. ■

The Honorable Arlen Specter,
Chairperson
Senate Appropriations Committee
SH-711 Hart Office Building
Washington, DC 20510-3802
202-224-4254 202-228-1229 fax
202-224-3442 TDD
senator_specter@specter.senate.gov

The Honorable Tom Harkin
SH-731 Hart Office Building
Washington, DC 20510-1502
202-224-3254 202-224-9369 fax
202-224-4633 TDD
tom_harkin@harkin.senate.gov

The progress of MiCASSA can be monitored on the ADAPT (American Disabled for Attendant Programs Today) Web site: www.adapt.org.

INTERNATIONAL VENTILATOR USERS NETWORK (IVUN)

IVUN News (ISSN 1066-534X)
Summer 2000 ■ Vol. 14, No. 2

IVUN News links ventilator users with each other and with health care professionals interested in mechanical ventilation and home care.

ISSUED IN: MARCH, JUNE, SEPTEMBER, DECEMBER

EDITOR: Judith Raymond Fischer
DESIGN/GRAPHICS: Sheryl R. Prater

International Ventilator Users Network (IVUN)

4207 Lindell Boulevard, #110
Saint Louis, MO (Missouri)
63108-2915 USA

314-534-0475 ■ 314-534-5070 fax
gini_intl@msn.com
www.post-polio.org/ivun.html

COORDINATED AND PUBLISHED BY:
Gazette International Networking
Institute (GINI)

Annual Subscription (US dollars only)
USA: \$17
Canada, Mexico, and Overseas surface: \$22
Overseas air: \$27

©Copyright 2000 by Gazette International
Networking Institute (GINI)

Permission to reprint portions must be obtained from the publisher.

IDEA: Individuals with Disabilities Education Act

IDEA is the federal law that supports special education and related services programming for children and youth with disabilities. It has its roots in a public law originally enacted in 1975 to establish grants to states for the education of children with disabilities. IDEA requires that a "free appropriate public education" be made available to children and youth with disabilities in mandated age ranges. The final regulations for the 1997 amendments to IDEA are currently guiding school systems as they design and implement special education and related services.

Federal, state, and local governments are obligated to share expenses for funding IDEA, with the federal government funding up to 40% of the average, per-pupil special education in public schools. Unfortunately, IDEA is one of the worst unfunded mandates. H.R. 4055, which

passed the House of Representatives in May 2000, would bring the funding level up to \$7 billion in 2001 and to \$15 billion in 2005 – finally reaching the 40% federal goal.

The National Information Center for Children and Youth with Disabilities (NICHCY) has prepared a thoroughly comprehensive guide to the IDEA. It – and many other excellent publications – is available online (www.nichcy.org) or by contacting NICHCY, P.O. Box 1492, Washington, DC 20013-1492 (800-695-0285; 202-884-8200; 202-884-8441 fax). First copies are free.

The National Campaign to Fully Fund IDEA is a national, nonpartisan, collaborative petition campaign designed to support efforts to secure increased funding for IDEA. The Web site is www.ncffi.org. ■

The Awesome Privilege of Living

Mark Warren

When I was in fifth grade in 1964, I remember writing a book report on Babe Ruth. One of the Babe's teammates was Lou Gehrig, and, after finishing my report on Ruth, I went to the school library and looked for a book about Gehrig. Gehrig played the game of baseball with humility and dignity. The personal qualities of consistency and dependability, along with extraordinary talent, are what made Gehrig a record-setter, and it is those qualities, along with humility and dignity, that I desire to emulate in my own life.

I attended Moorhead State University in Moorhead, Minnesota, where I studied biology, an interest initially sparked by my science teacher father. At MSU, I got involved with Campus Crusade for Christ, an interdenominational Christian organization, with chapters on nearly every campus in the country. This experience solidified my Christian commitment, and after graduating in 1976 with a BS in biology, I joined the full-time staff of Campus Crusade. I spent four years at Indiana State University, and three years at Illinois State University, where I met and fell in love with Susie. We were married in June 1983.

Soon after we were married, I planned to enter X-ray technology school in Bloomington, Illinois. As part of the admissions process, I needed to undergo a physical examination. During the exam I asked the doctor about some strange muscle twitching I had been noticing in both of my arms. I had also noticed a slight difficulty in speaking, and one day when it was raining, I tried to run to keep from getting soaked, but my legs just would not move. The doctor referred me to a neurologist, who, after a series of tests, confirmed

the diagnosis: amyotrophic lateral sclerosis (ALS). He said – in June 1984 – that I had three to five years to live.

The neurologist told me that ALS was also known as Lou Gehrig's disease, so my first stop was the university library to look up something about this disease I did not even know how to pronounce.



After telling Susie, we just held each other and cried. We told both our families and our pastor. I attended about a week of X-ray school, but found it impossible to concentrate and had to withdraw. During that whole week, I could not eat and had trouble sleeping. But I can honestly say that during that first week after learning I had ALS, I experienced love like never before, and that love has never abated. I never felt abandoned by God; His love became more real.

In the late summer of 1985, Susie and I moved to my hometown, Crookston, Minnesota, so I could be closer to my parents. I had a trach tube inserted in October 1988, during a three-week period that was mostly a blur to me. I went to the hospital to be evaluated for a trach, but went into a respiratory crisis, stopped breathing, and woke up with a trach tube. I had

already decided in favor of the trach and a ventilator, but thought I would be a little more aware of the actual event. I did not actually use the ventilator right away, because for some reason the doctors thought they would then have to try to wean me from it. We finally convinced them that I would never be able to be weaned, and I started using the LP6. (I now use the LP10.) During those three weeks, I fought through a bout with pneumonia and dealt with a difficult charge nurse and some ridiculous technicalities regarding who could care for me that resulted in Susie doing most of the care herself.

When I came home from the hospital, we were all faced with the immense challenge of an entire new lifestyle brought about by the ventilator. The most obvious thing everyone had to learn was how to do sterile trach suctioning. Fortunately, I have been mostly infection-free for the last 12 years, so our excellent staff of nurses and loving family got it right.

We also needed to learn the positioning techniques necessary for postural drainage, a treatment we do three times per day. We had to hire, schedule, and train new nurses for the additional care I required. Each person who performed any care for me had to learn how to communicate with me. I use what is known as an E-tran chart. It is a clear piece of plexiglass with stick-on letters and numbers applied to it. Through a series of simple eye movements, I converse and communicate my needs.

All the supplies related to the ventilator (suction kits, sterile water, etc.) as well as the ventilator itself, are supplied by a home health care company associated with the hospital where my tracheotomy was performed. They provide us with new trach tubes, and Susie has learned how to change them about every six months. We purchased an

CONTINUED ON PAGE 6

Ontario's Ventilator Equipment Pool

Regina Pizzuti, RRCP

In 1994, the Ontario Ministry of Health Assistive Devices Program (ADP) established the province-wide centralized Ventilator Equipment Pool (VEP) as the new model for equipment funding and distribution in an effort to maximize efficiencies and reduce escalating health care costs. I believe the Ontario model is unique because the equipment and service are provided free of charge to pediatric and adult clients, and eligibility criteria do not include the financial status of the client.

Operated on behalf of the ADP by the Kingston General Hospital in Ontario, Canada, the VEP model is based on several cost-saving concepts: recycling of equipment, bulk purchasing through a tendering process, and in-house equipment service and repair.

The ADP was established in 1982 by the Ontario provincial government. Its mandate is to provide funding assistance for the purchase of medical equipment and supplies to clients who meet the general eligibility criteria by obtaining a valid Ontario Health Card and by residing in the community or in a group home setting where the facility is the long-term residence. The applicant may also be required to meet medical eligibility criteria specific to each of the 12 categories of equipment/supplies funded by the ADP.

BACKGROUND

Prior to the VEP, hospitals granted special status by ADP served as "ventilator centres." On behalf of their clients, the ventilator centres purchased ventilators and adjunctive equipment, and were then reimbursed by ADP. Although some ventilator centres expressed an interest in recycling surplus equipment, there was confusion regarding responsibilities of ownership and sharing of service repair histories; equipment recycling was

virtually nonexistent. It was common practice for the ventilator centres to purchase new ventilators for every new applicant. Lack of a collective purchasing agreement meant each ventilator centre negotiated individually with the supplier of home ventilators. Cost of equipment maintenance was also a concern.

THE VENTILATOR EQUIPMENT POOL

The goals and objectives of the VEP were established by a steering committee comprised of physicians, health professionals, consumers, vendors, and government bureaucrats. Seven goals and objectives were identified by the VEP steering committee as follows:

- ◆ Reduce equipment costs through contracts to purchase and through more effective utilization of recycled equipment.
- ◆ Establish a facility to provide equipment maintenance and repair services.
- ◆ Make appropriate arrangements for equipment distribution.
- ◆ Offer in-home education services to experienced noninvasive ventilator users.
- ◆ Serve as a resource centre for consumers, community agencies, and health professionals.
- ◆ Establish an appropriate database to measure outcome.
- ◆ Provide ADP clients with direct access to equipment.

The VEP currently has approximately 680 clients (about 100 pediatric) and has provided equipment and services to approximately 1,000 clients since the program's inception six years ago. Clients who meet the eligibility criteria and are approved for funding assistance receive equipment on loan from the VEP. There is no cost to the client for the equipment or services provided by the VEP.

Equipment supplied by the VEP includes mechanical ventilators, both primary and secondary (backup) systems where indicated, 12-volt battery and connecting cable for emergency power source, battery charger, heated respiratory humidifiers and brackets, humidifier chambers, nonheated humidifiers, ventilator circuits, PEEP valves, and bi-level pressure devices with backup rate. Clients must purchase masks, mouthpieces, and other supplies from ADP-registered respiratory vendors. The ADP provides some funding assistance for these items.

Equipment recycling is a successful element of the program. The objective is to realize cost-savings by not purchasing new equipment for every new applicant to the program. Vendor contracts ensure that when purchasing new equipment, the VEP receives the best pricing and long-term stability. All equipment, both new and recycled, must meet the VEP's quality assurance standards prior to its release for use by clients. As many as 40% of new clients have been accommodated with recycled equipment in previous years.

A centralized database helps direct the decision-making processes and helps track approximately 2,500 pieces of equipment for location and repair history. In-house service and repair of equipment adds up to additional cost-savings for the program because internal labor costs are lower in comparison to external service agencies.

An assessment process is in place to help identify mechanical problems prior to the client receiving a replacement ventilator from the VEP. This process consists of a telephone trouble-shooting service. Clients, family members, caregivers, and health professionals can access the trouble-shooting hotline 24 hours per day, seven days per week. Registered respiratory therapists with knowledge and expertise in home ventilation respond to the hotline. Many calls to the VEP are

resolved successfully and do not require replacement equipment.

The primary responsibility for education rests with the prescribing physician, and most often training for patients and caregivers is provided while the patient is in hospital. The VEP complements patient teaching by providing in-home education to clients using noninvasive ventilation. Recent education initiatives include a pressure verification program for users of bi-level pressure devices. Educational programs are developed by the VEP with emphasis on learning outcome objectives and an opportunity for clients to demonstrate a learned skill or technique.

The VEP model is a responsible approach to the spending of public dollars while providing ventilator-assisted persons with the necessary equipment to extend and promote their quality of life. ■

ADDRESS: Ventilator Equipment Pool, c/o Kingston General Hospital, 76 Stuart Street, Kingston, Ontario K7L 2V7 Canada (613-548-6156; 613-548-6157 fax; vep@kgh.kari.net).

HOME CARE VIDEO WIDELY DISTRIBUTED

Ventilator user Audrey King's video "From the ICU to Home: A Patient's Perspective" which she prepared for the Noninvasive Ventilation Conference in Orlando in 1999 has been very well received. Thanks to the CHEST Foundation for distributing the video to all pulmonary and critical care program directors in the United States to use in teaching their medical students, residents, and fellows and to keep as a resource in their library. The CHEST Foundation is the philanthropic arm of the American College of Chest Physicians (ACCP); chestfoundation@chestnet.org.

The 40-minute video is still available for \$25 postpaid. To order, call ACCP Member Services at 800-343-ACCP or 847-498-1400 or e-mail registration@chestnet.org.

Update: Daniel C. Vilaseca Dreischer



Daniel, now 32, has Duchenne muscular dystrophy.

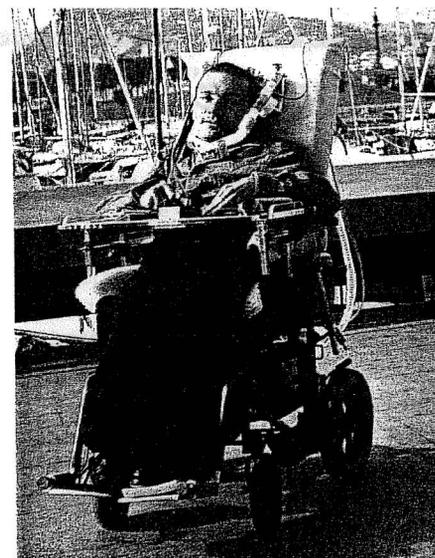
Since my article appeared in *IVUN News* in 1992, I have finished my law studies and am now busy with geography and history at the Open University which I find more difficult than law but more interesting. I am preparing myself for another English exam from Cambridge University. In addition to my studies, I enjoy my favorite hobbies of putting together jigsaw puzzles, reading, meeting friends, and playing chess. Barcelona now has taxis adapted for wheelchair users, and I can use them to go out to visit the centre of the city, the beach, or the museums.

My life changed a lot after I obtained a computer and found a way of adapting a track ball mouse to a Jelly Bean switch (AbleNet, Inc., Minneapolis, Minnesota; 612-379-0956). I use Dragon Dictate in Spanish, English, and German. I am very pleased with these advances, but unfortunately the English program does not work very well. Like most computer users, I would like to throw the computer out of the window sometimes.

When I read that ventilator users in other countries, i.e., the USA,

Denmark, Holland, can employ attendants, I become envious. In my case, the caregiving is performed by my parents and friends every day of the year. I think it is not fair for me to depend entirely on the good will of people around me.

I still have difficulty in switching over from the Siemens ventilator to a portable home ventilator, such as the Breas 402. Perhaps the reason is that the air pressure is created by a piston system that is not very flexible and does not adapt to all of the person's respiratory needs. After breathing three hours with a portable machine, I have problems with bronchial phlegm. This does not happen with the Siemens. I find that volume ventilators are too aggressive for me. I use the portable one when I go out for a few hours, but when I return home,



I am glad to go back to using the gentler Siemens.

IVUN News is a very useful publication. I have personally made new penfriends through it. It helps to know that other people live with a ventilator and manage their life as well as possible. ■

ADDRESS: Daniel C. Vilaseca Dreischer, C/Elisa 17, E-08023 Barcelona, Spain.

excellent Schuco suction machine manufactured by Allied Healthcare Products, Inc. (www.alliedhpi.com). Susie's dad built a wheelchair ramp on the front of our home, and my dad bought us a van equipped with a Crow River wheelchair lift. My life with a ventilator has truly been a team effort.

Susie works full-time as a special education teacher and our insurance coverage is very good, paying 100% for nursing care. A day nurse and a night nurse provide care every day, an evening nurse comes three times per week, and Susie provides about 60 hours of care per week.

Music, reading, and writing are the things with which I occupy myself most days. I enjoy reading the newspaper, magazines, letters from friends, and about a chapter a day in the Bible. I have a DynaVox 3100 (www.dynavoxsys.com/),

which is probably the best augmentative communication device on the market today. I received it through an ALS augmentative communication program at Courage Center, supported by funds from Kent Hrbek and the Minnesota ALS Association.

I activate the DynaVox by means of a P-switch and a sensor pad which is precisely taped to my temple. When I gently clench my teeth, the DynaVox begins a scanning pattern through which I select letters and type documents.

The DynaVox has given me back the ability to write, and it gives me infrared control of the TV, VCR, receiver, and CD player. And best of all, with the voice synthesizer (I sound like Stephen Hawking), I can tell Susie I love her!

ALS has deprived me of the ability to eat, to breathe, to speak normally, and all the other things we gen-

erally associate with living. But I do not base my identity on what I can or cannot do. Sometimes people ask me how I maintain my faith in light of my circumstances. My answer to that question is based on love – the love of God revealed in the Bible, and the love given to me by all the wonderful people in my own family and Susie's family. I seldom have to battle discouragement because there is so much love around me.

I have never regretted my decision to use a ventilator because I have lived 12 wonderful years that I would not have otherwise. I realize that I am totally dependent upon a machine and upon others for my very life (which sometimes can be frustrating) but those times are far outweighed by the awesome privilege of living. ■

ADDRESS: Mark and Susan Warren,
533 Summit Avenue, Crookston MN
(Minnesota) 56716 (Swarren@rrv.net).

Potpourri

Pediatric Tracheostomy

Home Care Guide by Cynthia M. Bissell, RN, with foreword by Michael A. Rothschild, MD, is an excellent 66-page, spiral-bound resource, published in response to numerous requests for a hard copy of Aaron's Tracheostomy Page on the Web. Even though it is advertised as a pediatric guide, the book is extremely useful for adults.

This project was made possible in part by a grant from the Massachusetts Department of Mental Retardation, Region II, and with the help of several parent and professional experts. The guide is available for purchase online at www.twinenterprises.com or by sending a check or money order to: Tracheostomy Guide, Twin Enterprises, Inc., P.O. Box 150, Grafton, MA (Massachusetts) 01519. Cost is \$12 each, plus \$3 shipping and handling. Proceeds

from all sales go to printing additional copies for families in need.

Cynthia Bissell has also set up www.tracheostomy.com, another exceptional resource.

Respiratory care videos from The Muscular Dystrophy Association (MDA).

MDA has completed a two-year project resulting in the production of two 25-minute educational videotapes that address decision-making regarding ventilator use in people with neuromuscular diseases and conditions. Both John Bach, MD, and Tony Oppenheimer, MD, contributed.

"Breath of Life" is directed toward health professionals, while "Breathe Easy" is geared for individuals and families. The videos are available by calling the local MDA office or by contacting MDA headquarters, 3300 E. Sunrise Drive, Tucson, AZ (Arizona) 85718-3208 (800-572-1717; www.mdaua.org/video/breatheeasy.html).

Medicaid waivers permit states flexibility to work outside federal and state regulatory requirements so that people with special health care needs receive health care but avoid institutionalization. Without waivers, children and adults would either go without health care (due to their health condition or financial situation) or would be institutionalized in order to qualify for Medicaid.

The most common waiver, better known as the Katie Beckett waiver, is the Home and Community-Based Services [1915(c)] program waiver. There is also the research and demonstration waiver [1115].

The Family Voices Web site (www.familyvoices.org/katiebec.html) explains the waivers. The Health Care Financing Administration (HCFA), which administers Medicaid, details the complete waiver information and process on the Web page: www.hcfa.gov/medicaid/hpg1.htm. ■

New Masks and Equipment

Ultra Mirage™ has been added to ResMed's nasal mask product line. The mask offers forehead support that can be adjusted using only one hand, quick release straps for headgear, a soft silicone membrane covering the cushion, 360° of elbow rotation, and a quick release swivel to disconnect the mask from tubing. A specially designed airflow vent controls exhaled airflow with minimum noise. It is available in three sizes. Contact your home health care dealer or ResMed (www.resmed.com). ResMed has offices in the USA (800-424-0737), England, France, Germany, Australia, and Singapore.

Simplicity™ is the new nasal mask from Respirationics. It is a very small nasal mask that fits on the lower portion of the nose, thus eliminating irritation on the bridge of the nose and airflow to the eyes. It also has a built-in port for quiet exhalation airflow and full 360° swivel. Simplicity™ is available in two mask sizes. Contact your home health care dealer or Respirationics (800-345-6443; www.respirationics.com). Respirationics has offices in Europe, Australia, and Hong Kong.

DeVilbiss® Serenity™ Nasal CPAP Mask is new from Sunrise Medical. The Serenity™ features a forehead rest and adjusts front to back and up and down so that one size can accommodate a wide range of people. It also has an adjustable exhalation port. Contact your local home health care dealer or Sunrise Medical (888-333-2572; www.sunrisemedicalonline.com).

Hans Rudolph Inc. presents a new nasal CPAP mask with three sealing surfaces to choose from: a soft silicone rubber mask flange; the Ultimate Seal™ gel; or the Comfort Seal™ foam. It is available in three sizes. Contact Hans Rudolph (800-456-6695; www.rudolphkc.com).

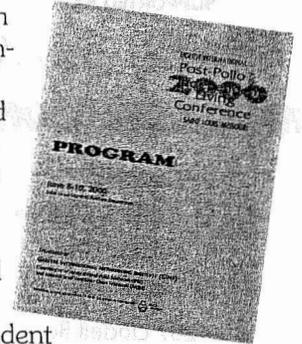
New CPAP units are available from both Bird and ResMed. Bird offers the **Alura®** (contact your local home health dealer or Bird through Thermo Respiratory Alternate Care, 800-328-4139; www.thermoresp.com). ResMed introduces the **S6™** series in lightweight, plus, or elite styles to replace its line of Sullivan® V CPAP units. Contact ResMed (800-424-0737; www.resmed.com).

iVent201™ is a portable computer-controlled PC-based ventilator from VersaMed. iVent201™ offers both volume and pressure support by a self-contained turbine flow generator. Weight is 24 lbs. with battery. The iVent201™ can display pressure and flow waveforms, and pressure, volume, and flow loops. Contact VersaMed, Inc., Route 4 East, Fort Lee, NJ (New Jersey) 07024 (800-475-9239; www.versamed.com).

Ventilator battery backup with built-in charger and inverter is available from Home Health Depot. Each unit is handmade by Lenny Habif. Although tested for up to 36 hours with a bi-level unit, the battery's recommended use is limited to 20 hours and it recharges overnight. A 100 amp/hr battery can be made. The battery backup weighs 63 lbs. and comes with a cart. A ventilator tray is also available. Cost is \$1,500 plus shipping. Contact Home Health Depot, 2154-A Pacific Coast Highway, Lomita, CA (California) 90717 (800-811-2257; 310-891-1954; www.homehealthdepot.com). ■

Post-polio Breathing Information in GINI Conference Program Book

The program book containing the abstracts and papers from the speakers at GINI's Eighth International Post-Polio and Independent Living Conference, June 8-10, is available for purchase.



More than 360 pages, the spiral-bound book contains useful information for polio survivors on all aspects of the late effects of polio, including breathing problems and the cardiopulmonary aspects (Peter Gay, MD, Mayo Clinic, and Rupert Mayuga, MD, Northwestern University), anesthesia for polio survivors (Selma Calmes, MD, Olive View/UCLA Medical Center), tracheostomy (E.A. Oppenheimer, MD, Kaiser Permanente), and the sleep bladder connection (University of Alabama-Birmingham researchers).

Health care programs for Danish polio survivors who are also ventilator users were presented by Lotte Mortensen, Matron, Institutionen for Respirationspatienter in Copenhagen, and Grethe Nyholm, RNP, Respiratory Centre East, Rigshospitalet, also in Copenhagen.

The book is \$27 postpaid and can be ordered from GINI, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915 USA; 314-534-0475; 314-534-5070 fax; gini_intl@msn.com; www.post-polio.org. ■

Calendar

2000

August 30-September 3. European Respiratory Society (ERS) Annual Meeting. Florence, Italy. Contact ERS, 1 Boulevard de Grancy, CH-1006 Lausanne, Switzerland (www.ersnet.org).

October 5-6. Ninth Annual Conference: Children with Special Health Care Needs. New Orleans, Louisiana. Contact Dorothy Page, FNP, MSN, National Association of Pediatric Home and Community Care (508-856-1908; 508-856-2609 fax; dorothy.page@banyan.ummed.edu).

October 7-10. American Association for Respiratory Care (AARC) Annual Meeting. Cincinnati, Ohio. Contact AARC (972-243-2272; www.aarc.org).

October 10-11. Rehabilitation Approaches for the Tracheostomized and Ventilator Dependent Population with Mary F. Mason, MS, CCC-SLP. Berger Health Systems, Columbus, Ohio. Course fee \$285 (50% discount for family members or caregivers). 11 contact hours or 1.1 ASHA CEUs. Contact Professional Marketing Seminars (800-223-5766; www.speechpaths.com).

October 22-26. American College of Chest Physicians (ACCP) Annual Meeting. San Francisco, California. Contact ACCP (847-498-1400; www.chestnet.org).

2001

February 26-28. Children Who Are Medically Complex or Technology Dependent: "Growth Through Transitions." Philadelphia, Pennsylvania. Contact Ken-Crest Services, Inc. (215-844-4620, ext. 134; kencrest@kencrest.org; www.kencrest.org/medfrag/conf.html).

March 7-9. 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; BrigitteHautier_JIVD@compuserve.com; www.jivd-france.com).

Non-profit Org.
U.S. Postage
PAID
Permit No. 210
Jefferson City, MO

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915 USA

**International
Networking
Institute
Gazette**

MIcASSA and IDEA	2
ALS	3
Ventilator Equipment Pool	4
New Equipment	7

INSIDE THIS ISSUE ...

IvUN News Online
www.post-polio.org/ivun.html
will access the IvUN home
page directly. Selected articles
from current and back issues
are online, as well as the latest
IvUN Resource Directory.

MALLINCKRODT
RESPIRONICS
Always Thinking™
SPONSORED BY
SUPPORTED BY
Passy-Muir Co.

IvUN NEWS
SUMMER 2000 ■ Vol. 14, No. 2