

# VENTILATOR-ASSISTED LIVING

SAINT LOUIS, MISSOURI

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## A Treehouse for Everyone

Peter von Buelow, designer and engineer, Ann Arbor, Michigan ([www.umich.edu/~tecamp](http://www.umich.edu/~tecamp))

The Craig VanLaanen Treehouse and Woodland Retreat at Trail's Edge Camp at the Fowler Center near Mayville, Michigan, was built for children needing to use ventilator assistance and often wheelchairs. Innovative in both its structural system and its development as a community-based volunteer effort, the 300-square-foot treehouse (22 ft. in the air) is supported by a structurally efficient branching column. All labor was donated, including design, analysis, fabrication and construction. The actual material cost of the entire facility was about \$88,000. The Treehouse was dedicated and enjoyed by campers during the 2004 camp.



"I feel just like Peter Pan. This is just unbelievable."  
CAMPER ANDY RANSOM

After the Trail's Edge Camp in 2002, the University of Michigan Hospital, along with camp director Mary Buschell, RRT, and her camp staff, met with faculty from the University's architecture program to discuss the feasibility of developing a structure that would allow children with limited mobility to experience the height and excitement of spending time in trees. Moving beyond compliance with the American with Disabilities Act and beyond modifying pedestrian-friendly design to meet the needs of the campers, the Treehouse team developed a structure that would allow all users to experience *super-mobility*, regardless of physical restrictions or limitations.

Super-mobility – or mobility beyond an individual's perceived capabilities – is made possible in the Treehouse through an array of body prosthetics, including harnesses, ropes, tracks and cradle-like seats. Everyone entering the Treehouse uses these prosthetics to be "launched" 22 feet into the air, leaving wheelchairs and other terrestrial implements behind.

Trail's Edge Camp's poor soil strength and the cantilevered load produced by the Treehouse prompted the team to design a structure that branched both upward and downward. The geometry of the Treehouse was also based on the restrictions of the site. Part of the structure is nestled among the branches of an existing maple tree, without disturbing either its canopy or root system. To avoid damage to the root system, the branching column's foundations had to be placed to the side of the maple's trunk, while the upper portion of the Treehouse is cantilevered through its branches.

The Treehouse was designed for a moist, woodland environment. The concrete footings raise both the Treehouse and the boardwalk structures clear of the damp earth. Even though the roof provides weather protection with a continuous rubberized membrane, exterior-grade materials were used throughout the structure.

**Trail's Edge Camp marks its 15th anniversary in June 2005.** During the upcoming camp, the inside of the Treehouse will be decorated – half by the boys and half by the girls, according to camp director Mary Buschell, RRT.

The lifting harness is designed to safely transport a person who may need spinal support or ventilator assistance. In this harness the visitor is lifted 22 feet vertically, through a hatch in the Treehouse floor. Once aloft, the visitor is transferred to the cradle chair. The cushioned cradle chairs, with adjustments for both backrest and footrest angles, are hung from an overhead track and allow the visitor to travel through the Treehouse and out to the observation deck on the far end. The way in which the chairs attach to the track allows them to swivel 360° for views in any direction. ●

### 2005 Camps for Ventilator-Assisted Children

- MARCH 19-25 VACC (Ventilator-Assisted Children's Center) Camp.** Miami, Florida. Contact Bela Florentin, VACC, Miami Children's Hospital, 305-662-8222, bela.florentin@mch.com, www.vaccamp.com.
- JUNE 4-10 Trail's Edge Camp, 15th Anniversary.** Mayville, Michigan. Contact Mary Buschell, RRT, C.S. Mott Children's Hospital, 734-763-2420, mdekeon@med.umich.edu, www.umich.edu/~tecamp.
- JUNE 5-11 Camp Pelican.** Lion's Camp, Leesville, Louisiana. Contact Cathy Allain, 985-764-0343, cathyallain@cox.net, www.camppelican.org.
- JUNE 15-19 Camp Inspiration at Double H Hole in the Woods Ranch.** Contact Tara Crandell, Admissions Coordinator, 518-696-5676, theranch@doublehranch.org, www.doublehranch.org.  
APPLICATION DEADLINE: APRIL 15.
- JUNE 18-24 CHAMP Camp.** Recreation Unlimited, Ashley, Ohio. Contact Dave Powell, 317-679-9062, admin@champcamp.org, www.champcamp.org.
- JUNE 26-30 Pennsylvania Vent Camp.** Camp Victory, Millville, Pennsylvania. Contact Lois Marshall, Pediatric Critical Care Department, 717-531-5337, lmarshall@psu.edu.
- JULY 3-8 Camp Inspiration.** Rocky Mountain Village, Empire, Colorado. Contact Monte Leidholm, RRT, The Children's Hospital, 303-837-2502, leidholm.monte@tchden.org.
- JULY 7-10 Light the Way Camp.** Children's Harbor, Alex City, Alabama. Contact Kara Bishop, karabishop@ventkidsofalabama.com, www.ventkidsofalabama.com, www.childrensharbor.com.
- JULY 12-17 Fresh Air Camp.** Hiram House Camp, Moreland Hills, Ohio. Contact Kathy Whitford, CNP, Cleveland Clinic Foundation, 216-721-7159, whitfok@ccf.org, www.freshaircamp.org.
- SEPTEMBER 1-4 SKIP Camp.** Seashore Methodist Assembly, Biloxi, Mississippi. Contact Judy Abney, SKIP of Louisiana, 985-649-0882.

## Extra Security During Emergencies

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

For people with neuromuscular weakness who rely on continuous ventilator support, a power failure or ventilator equipment failure can be a potential life-threatening event. Many ventilator users have little or no ability to call for help in the event of an emergency. Dependence upon ventilation support and lack of control in an emergency can cause great anxiety.

Although an electrical or ventilator failure may not be avoided, an emergency plan supported by a remote ventilator alarm system, a communication device, and an emergency electrical failure support system can provide security and safety during an emergency event.

Home mechanical ventilators have built-in preset high and low pressure alarms, apnea alarms that sound when not enough breaths are taken, and power failure alarms with backup internal ventilator battery support.

Low pressure and power failure alarms are essential, but they may not provide enough alarm sound to alert a caregiver in an adjacent room. For this reason, a remote pressure alarm system that sounds near the caregiver is an important security measure. Most home ventilators do not have remote alarm features, although an exception is the Achieva® (Puritan Bennett, www.puritanbennett.com) with cable lengths up to 100 feet.

There are a few stand-alone ventilator pressure alarms available on the market. The Pressure Alarm (Product No. 23001, Respironics, Inc., www.respironics.com) is a low pressure alarm system that can be used with any home ventilator.

This alarm can monitor a wide range of pressure from -99 to +99 cm H<sub>2</sub>O and can be used for both negative and positive pressure ventilators. The alarm is connected by an air line, up to 300 feet long, to a T-fitting in the ventilator tubing circuit. It can be powered by either battery or AC power.

Remote signaling devices provide security for the ventilator user as well as an audible signal close to the caregiver. There are few systems available on the market but Med Labs, Inc., a supplier of hospital remote call systems, also makes a home portable alarm system. E-Z Call™ (<http://members.aol.com/medlabsinc/ezcall.html>) is a sensitive “touch panel” that can be located anywhere on the bed so that it can be activated easily. E-Z Call™ is connected to a remote Med Labs PA-1 portable battery-powered alarm that alerts the caregiver.

Loss of power is an ever-present concern. *Everyone who depends upon mechanical ventilation should have some type of emergency power supply.* Most ventilators have an internal battery that will provide approximately only one hour of backup power in the event of an external power supply failure. An exception is the HT-50® (Newport Medical Instruments, www.ventilators.com) with an internal battery that will power the ventilator for at least eight hours when fully charged.

Emergency power lighting can alert a caregiver to a power failure and also provide an immediate light source. Stationary and portable emergency sources are plugged into power outlets

continued, page 5

# LIFE AS A TEENAGER ... WITH A VENTILATOR

Margaret Jo (MJ) Purk, Rye Brook, New York  
(tweetyroll88@aol.com, www.mjthesmaqueen.com)

People call me Margaret or Marg, MJ, Margaret Jo or even Miss Maggie. Now 17, I was born January 8, 1988, with spinal muscular atrophy (SMA) type I. The most severe type of SMA, it weakens all muscles, including those for breathing, eating, sitting unassisted and limits most of my functional movement.

John R. Bach, MD, started me with a bilevel when I was 8 years old, and I now rely on the LTV<sup>®</sup> 950 (Pulmonetic Systems, Inc., [www.pulmonetics.com](http://www.pulmonetics.com)), to support my weak breathing muscles. I use a mouthpiece during the day and the Mirage<sup>®</sup> Vista<sup>™</sup> (ResMed Corp., [www.resmed.com](http://www.resmed.com)) at night. I also use the CoughAssist<sup>™</sup> (J.H. Emerson Co., [www.coughassist.com](http://www.coughassist.com)) on a daily basis to help clear the secretions from my lungs. Then there are four nebulizer treatments daily along with The Vest<sup>®</sup> (Advanced Respiratory, [www.thevest.com](http://www.thevest.com)), which help to keep my lungs functioning “normally.”

A great team of physicians (Drs. Bach, Wendy Proskin, Josh Needleman and Colin Bethel) has helped me through several crises. Fortunately, they all follow Dr. Bach's protocol for noninvasive ventilation management.

Using a wheelchair and a ventilator does not mean I am unlike other teenagers. I enjoy reading and writing emails, watching television, playing computer games, making websites (I currently have six websites of my own), reading e-books, talking with friends on the phone or instant messaging, and making blankets for my organization, B4SMA, Blankets for SMA. I send a blanket to children

newly diagnosed with SMA. B4SMA is almost a year old, and I have sent approximately 60 blankets.

I also spend a great deal of time writing. I wrote an article for *Mary Beth's Beanie World for Kids*, March 1999 issue. I used to write a bi-monthly column for the WOW (Winners on Wheels) connection newsletter, and I was recently published in *Angel Times*, a quarterly newsletter for families of people with SMA. My first children's book was published last year; I am writing my second.

As a high school junior, my courses include physics, pre-calculus, American history and government, English, and I just completed a semester studying forensic science. I like most of my teachers, even though I was only in their classrooms nine days before becoming a home-schooled student.

My immune system isn't strong, and it seemed that every time I went out in the winter, I instantly caught a “bug.” To help prevent numerous pneumonias, I stay home. Now my teachers just send home the work they provide in school, and I complete it as I can.

In August 2006, I plan to attend an out-of-state college and to major in computer sciences. My caregiver, Brenda, who has been with me for several years, is going to college with me.

I don't talk with many of my peers from school. High school has changed a lot of the people I used to consider friends. It is also difficult to connect with them because I don't attend school on a regular basis. I have met many great people through the

Internet; some have become friends who will last a lifetime.

As I told a friend the other day, "My life is good. I am happy, though rarely healthy, and get to go just about any place I want to. I can't walk, I can't ride a bike, and I'll probably never be president. But with wonderful friends, supportive family, and God and my angels watching over me, I can do anything I set my mind to do." ●

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### Extra Security During Emergencies

continued from page 3

and activate when a power failure occurs. These are available from most hardware supply stores. Through the Internet, an Automatic Power Failure Lighting System, an emergency rechargeable power failure lighting (portable, desktop, wall) for up to four hours, and a Rechargeable Power Failure Flashlight that lights when power fails for up to one hour are available ([www.preparedness.com/powfailrecli.html](http://www.preparedness.com/powfailrecli.html)).

The alarm call signaling system and emergency lighting sources listed above are only examples of products that are available on the market. (Their inclusion here is not an endorsement.) A thorough search of this type of product on the Internet and an inquiry to a durable medical equipment supplier should provide more selections. Although these systems are not reimbursed by insurance, they are essential in providing security, safety and peace of mind, and are worth the out-of-pocket cost. ●

## Alcohol and Drugs: Dangerous and deadly for CCHS adolescents

The *CCHS Family Newsletter* (Fall/Winter 2004) featured an important warning on the dangers of drugs and alcohol for teenagers with congenital central hypoventilation syndrome (CCHS).

Mary Vanderlaan, founder of CCHS Family Network ([www.cchsnetwork.org](http://www.cchsnetwork.org)) and parent of a 16-year-old with CCHS, wrote that children with CCHS are growing into adolescence, and they are "... dealing with the normal issues of young adulthood: testing values, lifestyles, parental and social limits and more. It is not surprising then that we would see our children also trying to use alcohol or trying other controlled substances." Several deaths have occurred in young adults with CCHS due to alcohol and/or drugs, as well as several near-death experiences.

Thomas Keens, MD, Children's Hospital, Los Angeles, and Ron Harper, MD, UCLA, commented on the dangers for CCHS adolescents. Because breathing is already compromised in CCHS, the use of alcohol and drugs can further depress brain function, including the part of the brain that controls breathing. Dr. Keen cautioned, "Excessive alcohol use can depress brain function enough that CCHS patients will stop breathing completely."

Dr. Harper noted that alcohol is also dangerous in people with obstructive sleep apnea. He suspects that alcohol induces a loss of muscle tone in both the upper airway and diaphragm muscles that "... results in a near-complete suppression/lack of activation of these muscles after even modest alcohol ingestion." The airway becomes completely blocked, and the individual cannot breathe.

Alcohol and drugs can be deadly for anyone with compromised breathing and weak diaphragms, particularly individuals with neuromuscular diseases. ●

# The Development of RespiteMatch.com

David Jayne, Rex, Georgia (David@RespiteMatch.com)

It was a beautiful spring afternoon seventeen years ago when I was seated on an examination table and the neurologist began to speak. "You have amyotrophic lateral sclerosis, ALS. You might have heard it referred to as Lou Gehrig's disease." Without raising my head I asked, "How long?" Void of hesitation, his reply rang in my head, "Three to five years." That marked the beginning of a journey of many changes and challenges.

As I declined into paralysis my dependence on others increased. I have hired many caregivers in my nearly two decades of disability, some fantastic, some horrible. Unfortunately, the horrible caregivers seem to leave the lasting impressions, but when your total existence depends on others and you are in need of a caregiver, the memory becomes short.

During the '90s, I became totally paralyzed, needed to use a ventilator full-time, and lost the ability to eat and speak. Living on a fixed income with increasing personal care needs made it more and more difficult to afford qualified caregivers. According to the government, I am wealthy and do not qualify for additional financial assistance, so all of my caregiver expense is out of pocket. I struggle to make ends meet, a catch-22 all too familiar to many Americans with a disability.

In my efforts to hire and afford caregivers capable of my care requirements, I have used every medium imaginable to locate qualified candidates: classified newspaper ads, personal referrals, nanny services, agencies, mailbox fliers, articles, church

bulletins, word of mouth, etc. Some methods have been more successful than others, but all have several drawbacks. The most common problem is the lack of information that can be easily accessed.

My caregiver of four years was leaving my employ early in 2004 to marry. I began looking for a replacement several months prior to her departure. I decided to use the Internet thinking it might be an excellent resource to find home health professionals.

To my disappointment, all I discovered on the Internet were a few classified-style ads scattered here and there on various sites. These postings were still lacking the detailed information needed to save time and make informed decisions to hire the appropriate candidate.

I have been an entrepreneur since childhood, and my wheels began turning. I thought if I, as an individual with a disability, experienced these frustrations, caregivers must wrestle with the same problems. The idea came to me of creating a platform much like a singles' website, but instead for home health professionals and "patients" in the home setting.

The plans for RespiteMatch.com began taking shape. I developed profiles that have the capability to be extremely detailed, containing many variables important to the patient/caregiver relationship. It is my desire to create one-stop shopping that will meet all home health needs and that will avoid the common home health pitfalls both patients and caregivers have endured.

Currently on [www.RespiteMatch.com](http://www.RespiteMatch.com), patients and caregivers can create detailed profiles with or without photographs (if provided) as members at no charge. They can add to their Favorites List, receive email notification when their profile has been added to another's Favorites List, and also view their personal MatchList generated by their requirements.

Subscribers to the RespiteMatch service (\$39 for 30 days; \$89 for 90 days; some additional fees for searches and surety bonds) receive all of the member benefits but have access to all of the contact information contained in the profiles, including the use of RespiteMatch's private email and email notification.

Subscribers can search by many criteria in addition to specific health skills that are required or possessed. Members can also search by location with GPS-powered zipcode searches.

Future services planned for subscribers include background checks, DMV checks, credit checks, employment verification, professional license verification, education verification, criminal and civil records checks, sex offender checks, reference verification, etc. Soon domestic workers' surety bonds will be available as well as home health products. ●

As founder of the National Coalition to Amend the Homebound Restriction (NCAHB), David Jayne prodded The Centers for Medicare & Medicaid Services (CMS) into conducting a two-year demonstration project called Home Health Independence Demonstration. It began in October 2004 in Massachusetts, Missouri, and Colorado, with a maximum of 15,000 Medicare beneficiaries (across all three states) eligible to participate.

The project is studying the benefits and costs of allowing Medicare beneficiaries with severe, chronic conditions to be deemed homebound – for the purposes of remaining eligible for home health services – even though they leave home more than would be allowed under the existing Medicare rules.

The demonstration permits individuals who are eligible to leave home as often and as long as they like (except to work regularly in a paid position full-time or part-time outside the home) and still be considered homebound in order to receive Medicare home health services.

For more information and to check possible eligibility as a ventilator user, log on to: [www.cms.hhs.gov/researchers/demos/HHAPac10\\_8\\_04.pdf](http://www.cms.hhs.gov/researchers/demos/HHAPac10_8_04.pdf)

*Note: The letter is written to home health providers. The person with a disability is referred to as the "beneficiary."*

## **Amyotrophic Lateral Sclerosis (ALS)**

Extra Hands for ALS, a program in which high school and college students volunteer to provide non-medical assistance to individuals with ALS, is forming more groups across the USA: the most recent opened in the Dallas-Fort Worth area. Other locations are Saint Louis (home of founder Jack Orchard), Boston, Los Angeles and Orange County, San Francisco Bay area and Boise. ([www.extrahands.org](http://www.extrahands.org))

*A Manual for People Living With ALS*, Third Edition (2005), from the ALS Society of Canada ([www.als.ca](http://www.als.ca)) is available online and in print. More than 110 pages cover a range of topics about ALS, including breathing, swallowing, communication, end-of-life issues and advance care planning.

## **Muscular Dystrophy**

**Respiratory physicians for people with muscular dystrophy.** Physicians with an interest in the respiratory care of people with muscular dystrophy and neuromuscular weakness have agreed to have their contact information made available online for The Parent Project Muscular Dystrophy site ([www.parentprojectmd.org](http://www.parentprojectmd.org)). Most of these physicians require a referral from a primary care doctor. The site is maintained by Jonathan D. Finder, MD, Children's Hospital of Pittsburgh. ([www.pitt.edu/~finder/respdocMD.html](http://www.pitt.edu/~finder/respdocMD.html))

**Giving a Face to DMD**, a two-disc DVD, "Understanding the disease" and "Guidelines for care and management" is available for \$30 from The Parent Project Muscular Dystrophy. Contact [Kimberly@parentprojectmd.org](mailto:Kimberly@parentprojectmd.org) or call 201-944-9985.

## **Polio**

April 12, 2005 marks the 50th anniversary of the announcement of the success of the Salk vaccine. An exhibit at the Smithsonian's National Museum of American History, "Whatever Happened to Polio?" opens that day to tell the story of the polio epidemics in the United States, the development of the vaccine, the efforts to end polio transmission worldwide, and the influence of polio survivors on American society (<http://americanhistory.si.edu/polio>). An iron lung is included in the exhibit. Other commemorations are planned around the USA during April.

## **Spinal Muscular Atrophy (SMA)**

**International Alliance for SMA** ([www.iasma.net](http://www.iasma.net)) promotes international collaborative research efforts to ensure that there is coordinated research and to exchange information. Representatives will convene for the International SMA Research Group meeting during the FSMA Family and Professional conference in Philadelphia, Pennsylvania, June 23-25, 2005. ([www.fsma.org](http://www.fsma.org))



# Independent Living

Ines Gaudet, Rochester, Minnesota (inesita56@earthlink.net)

I am 48 and have used tracheostomy positive pressure ventilation since age 23. Currently I have a PLV®-102b volume ventilator at my bedside and an LTV® 950 on the back of my wheelchair. I usually have ventilator-free time for a four-hour stretch during the day and for two hours at night. I can often go a little longer without the ventilator if the need arises, but I find that the next day I may need to use it a little longer. Fatigue is a constant battle, and I have a lot of downtime each day.

I use a Bivona cuffed TTS™ (tight to the shaft) trach tube. Because of problems with frequent trach infections, I change my trach three times per week. I am suctioned a few times a day, but sometimes need to be suctioned up to as many as eight times a day. I have two suction machines, one of which is compact and portable.

My vocal cords are paralyzed, so I speak in a whisper. I have lived independently in an apartment in Rochester, Minnesota, since 1983, with the aid of personal care attendants (PCAs) who are with me 24/7 (paid through a state program). I have seven PCAs currently and one substitute. I use a local home health agency for my care, but write all my own ads for attendants and interview, hire, schedule and fire them.

The PLV®-102b and the LTV® 950 each have an internal battery that provides about 45-90 minutes of backup power. Each has external battery backup also, vital in power outages. I am still somewhat new to the LTV® 950, but love its size and portability. It's especially useful on road trips. The local utility



*Ines and Tucker*

company keeps my name on a list of consumers on life support, and in case of an extended outage will notify me about how soon power will be restored.

I purposely left my diagnosis for last, because

it's not concrete. For the sake of labels and insurance forms, my internist writes a diagnosis of post-infectious encephalomyelitis. I had influenza at age 13 with subsequent seventh nerve palsy, some generalized weakness and weakness of my vocal cords.

At age 23, I developed an array of neurological problems (again after a bout with the flu) that ultimately became life-threatening, left me tetraplegic and unable to breathe on my own. I have weakness in all four extremities, but can walk a little. I use an electric wheelchair (Permobil) with a high back, reclining mechanism, ventilator tray and batteries. ●

#### **Equipment:**

##### **PLV®-102b**

Respironics, Inc.  
800-345-6443, [www.respironics.com](http://www.respironics.com)

##### **LTV® 950**

Pulmonetic Systems, Inc.  
866-752-1438, [www.pulmonetic.com](http://www.pulmonetic.com)

##### **Bivona TTS™**

Portex, Inc.  
800-258-5361, [www.portex.com](http://www.portex.com)

## IVUN EQUIPMENT EXCHANGE: PLV-100s Donated

IVUN received donations of five PLV®-100 volume ventilators that were no longer needed. These ventilators have found homes in Israel, Turkey, Thailand and Mexico. Many thanks to Mrs. Lewis Gumerman and an anonymous donor for their generosity.

Surang Chiemchanya, MD, wrote, "On behalf of the Department of Pediatrics, Ramathibodi Hospital [Bangkok, Thailand], I would like to express my sincere appreciation and gratitude for your kindness in donating a mechanical ventilator ... for our underprivileged children. ... Your donation will further encourage Dr. Aroonwan Preutthipan and her team to keep on helping the technology-dependent children to go back home efficiently and safely."

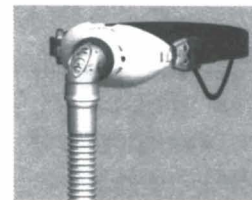
Other ventilatory equipment and aids continue to be successfully "exchanged" through the IVUN Equipment Exchange. If you are trying to locate a specific piece of equipment or have equipment that you no longer need or use and would like to donate it, please contact IVUN, 314-534-0475, [ventinfo@post-polio.org](mailto:ventinfo@post-polio.org), [www.post-polio.org/netwkg\\_ivun.html](http://www.post-polio.org/netwkg_ivun.html). ●

## AN ORAL MASK ALTERNATIVE: The Oracle

Gene Love, polio survivor,  
Charlotte, North Carolina ([truloves@earthlink.net](mailto:truloves@earthlink.net))

After I was hospitalized for a stomach disorder, I was discharged and advised to use the ventilator when I rested in the daytime. I am alone during the day, and my weak arms and shoulders make it difficult to attach the Mirage® nasal mask (ResMed, [www.resmed.com](http://www.resmed.com)) I use at night with the LP6 (Puritan Bennett, [www.puritanbennett.com](http://www.puritanbennett.com)). I did not want to employ someone to do this for me.

My respiratory therapist remembered seeing information about the Oracle™



(Fisher & Paykel Healthcare, [www.fphcare.com](http://www.fphcare.com)) and suggested that it might work for me. It has been a good solution,

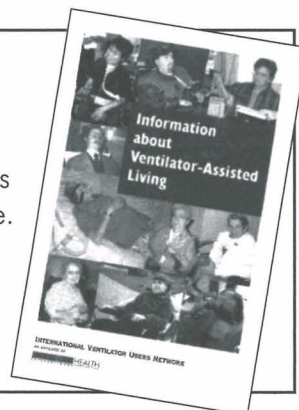
and I have been using it since then with my BiPAP® Synchrony (Respironics, [www.respironics.com](http://www.respironics.com)) for short rests during the day.

It took a great deal of practice but I am able to put the Oracle on by myself, after placing one side of it into my mouth and then, with one hand, pushing it in the rest of the way with a light bamboo backscratcher. The advantages are that it seals almost perfectly, no headgear is needed, and I can wear my eyeglasses with it. The disadvantages are that it tends to dry the mouth, but it can be used with a humidifier. Of course, I can't talk with it in my mouth. ●

### Information about Ventilator-Assisted Living

(Second Edition) is a 16-page brochure, available in print or online. Single copies in print are free; bulk pricing is available.

Contact IVUN (314-534-0475, [ventinfo@post-polio.org](mailto:ventinfo@post-polio.org)), or find it online at [www.post-polio.org/ivun](http://www.post-polio.org/ivun).



# INTERNATIONAL VENTILATOR USERS NETWORK

AN AFFILIATE OF



# MEMBERSHIP OPPORTUNITIES

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

## \$15 Supporter

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

## \$25 Subscriber

### All of the benefits of Supporter, AND ...

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

## \$45 Subscriber Plus

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

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

## \$75 Contributor

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

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

## \$125 Sustainer

### All of the benefits of Contributor, AND ...

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

**Use the form below to join today!**  
If you are a current member, give this form to a friend, family member, or health professional.

# INTERNATIONAL VENTILATOR USERS NETWORK

AN AFFILIATE OF



# MEMBERSHIP APPLICATION

Name \_\_\_\_\_  
 Institution \_\_\_\_\_  
 Address \_\_\_\_\_  
 City \_\_\_\_\_  
 State/Province \_\_\_\_\_  
 Zip/Postal Code \_\_\_\_\_  
 Country \_\_\_\_\_  
 Phone \_\_\_\_\_ Fax \_\_\_\_\_  
(area/country code) (area/country code)  
 Email \_\_\_\_\_

## PAYMENT OPTIONS

- Enclosed is my check made payable to Post-Polio Health International. (US dollars only)
- OR, charge my:  VISA  MasterCard  Discover
- Card # \_\_\_\_\_
- Exp. date \_\_\_\_\_
- Name on card \_\_\_\_\_
- Signature \_\_\_\_\_

## MEMBERSHIP LEVEL

- Supporter, \$15** (No newsletter is included)
- Subscriber, \$25** Choose either newsletter:
  - Ventilator-Assisted Living* OR  *Post-Polio Health*
- Subscriber Plus, \$45**
- Contributor, \$75**
- Sustainer, \$125 ...**
  - Please send the additional subscription of
  - Ventilator-Assisted Living* OR  *Post-Polio Health*
  - TO: Name \_\_\_\_\_
  - Address \_\_\_\_\_
  - \_\_\_\_\_
  - City, State/Province \_\_\_\_\_
  - Country \_\_\_\_\_ Zip/Postal Code \_\_\_\_\_
  - Or, donate the complimentary subscription to person selected by Post-Polio Health International.
- Other \$** \_\_\_\_\_

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

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

## Calendar

**JUNE 2-4 Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: STRATEGIES FOR LIVING WELL.**

Marriott Saint Louis Downtown, Saint Louis, Missouri. [www.post-polio.org](http://www.post-polio.org), 314-534-0475.

For polio survivors, ventilator users, families and friends, health professionals, organizations and companies.

Thursday opens with an 11:30 am luncheon, followed by afternoon and twilight sessions. Friday offers 24 diverse sessions. Saturday has 17 more presentations, concluding at 4:30 pm.

**JUNE 23-25 FSMA Family and Professional Conference.** Philadelphia Marriott Downtown, Philadelphia, Pennsylvania. [www.fsma.org](http://www.fsma.org), 800-886-1762.

**JULY 7-10 The Parent Project MD Annual Conference.** Westin Hotel, Cincinnati, Ohio. [www.parentprojectmd.org](http://www.parentprojectmd.org), 800-714-KIDS.

### IN THIS ISSUE ...

A Treehouse for Everyone

Extra Security During Emergencies

Life as a Teenager ... with a Ventilator

The Development of RespiteMatch.com

Independent Living

**POST-POLIO HEALTH**  
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 LINDELL BOULEVARD, #110  
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