

VENTILATOR-ASSISTED LIVING

SAINT LOUIS, MISSOURI

WWW.POST-POLIO.ORG/IVUN

Vent Kids of Alabama Support Group

Kara Bishop, McCalla, Alabama (kbishop04@aol.com, www.ventkidsalabama.com)

My son Corey is 3 and he has used a ventilator since birth due to his premature arrival. His lungs had not developed and he had multiple problems. Corey stayed in the hospital for 11½ months before coming home for the first time. We were told (wrongly) he might only live three weeks. Coming home, experiencing normal everyday life and feeling the love of our family only made Corey thrive.

The Vent Kids support group, founded in October 2002 by myself and Marsha Wise, another mother with a child living at home with a ventilator, arose from our desire to be advocates for our children. Our prime goal is to spread awareness that our children are just like other kids and should be treated the same. We encourage families new to ventilator-assisted living to take their children and ventilators to the zoo, beach or favorite park, or to other fun-filled sporting events. In this simple way, we can help them give their children the high quality of life each deserves.



To contact other families, we received a list from Children's Hospital of Alabama in Birmingham of every child in their home ventilation program. We provide at least a quarterly newsletter and have support group meetings every few months. We always meet when a new family is going home for the first time and deliver a care package to the family. This is also a good opportunity for everyone to share experiences of how things are done at home. Our time together does not always focus on medical matters; sometimes we can just "be." Our two big events are our Christmas party and our camp.

Approximately 30 children in Alabama live at home with ventilators, with diagnoses ranging from Noonan's syndrome, spina bifida and dwarfism to Lee's syndrome and muscular dystrophy, along with prematurely born children whose lungs never had the proper chance to develop, and a 15-year-old with a high spinal cord injury.

All of the children have tracheostomies, except one who uses a mask only at night. Most of them use the LTV®950 (Pulmonetic Systems, Inc., www.pulmonetic.com) because of its size and portability. Some use the LP10 (Puritan Bennett, www.puritanbennett.com). Many of the families have nursing assistance either paid by their private insurance, Medicaid or Medicaid waiver. Some of the children attend school, accompanied by a nurse. Several of the children are involved in sports activities, from bowling and baseball to cheerleading.





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About 90 people attended our first Light the Way Camp this year in July at Children's Harbor in Alex City, Alabama, including 10 families with children (ages 2 to 15 years old) who use ventilators.

The facility offers an accessible swimming pool, lake with beach area, and comfortable air-conditioned cabins that are also wheelchair accessible. We asked for a sponsorship fee of \$75 per family. We did not want the families to bear any personal expense to attend the camp. Due to generous donations, all meals were provided for families and volunteers alike. Each family was responsible for the care of their child. We had a respiratory therapist, nurses and an occupational therapist available to help, but care was provided by the parents.

For many families, the weekend at camp served as their first overnight experience — a rare opportunity to relax and enjoy themselves in a supportive atmosphere. Ventilators alarming, suction machines roaring and people laughing were all beautiful sounds.

Keeping vents secured on strollers, wheelchairs or nearby floats at water's edge and circuits with PEEP valves flung over their shoulders, families enjoyed some well-

deserved fun in the sun. But the kids couldn't wait for the boat rides supplied by gracious volunteers. For many of our families, time spent one afternoon with VSA Arts of Alabama artist Bob McKenna and several VSA volunteers was a high note. An organization that introduces children and adults with disabilities to the arts, VSA brought many projects to keep the kids happily and artfully busy as they expressed themselves in a vivid way. With their help, our ventilator-assisted children created a gigantic painting on canvas that was auctioned off at a VSA fundraising event. A special luau ended the weekend on a festive note.

Both parents and children attending camp forged strong bonds and lasting friendships. All of our families want to live joyful, meaningful lives and to live them to the fullest — ventilator and all. ●

"Care of the child with a chronic tracheostomy"

by Janet Johnston, RN, CRNP, Scott H. Davis, MD, and James M. Sherman, MD, from the faculty of the Pediatric Pulmonary Centers (PPC) first appeared in the *American Journal of Respiratory and Critical Care Medicine*, published by the American Thoracic Society in 2000. Recently expanded into an educational program, it is available online: www.thoracic.org/ChildWithTracheostomy.asp

The PPC, funded by the Maternal Child Health Bureau of the Department of Health and Human Services, are interdisciplinary training programs within academic pediatric pulmonary programs (<http://mchneighborhood.ichp.edu>) to focus on children with chronic pulmonary conditions and their families. For more information and a CD, contact Janet Johnston: jjohnston@peds.uab.edu, 205-939-5499.

From independent living to a nursing home ... and back?

Mark Boatman, Jamestown, North Dakota (nodakwheeler@yahoo.com, www.geocities.com/nodakwheeler)



In February 2003, I faced a decision that changed my life. I was in respiratory distress due to Duchenne muscular dystrophy, and I decided to get a tracheostomy and use a ventilator fulltime. Although the decision was a good one, it also came with new challenges.

At the age of 19 in 1994, I moved into my own apartment where I received 24-hour personal attendant care services. My attendants helped me with my personal care, including dressing, transfers with a Hoyer lift, eating and toileting. They also assisted me with cooking, grocery shopping, housekeeping and laundry. This was made possible by a home and community-based Medicaid waiver through the North Dakota Department of Human Services.

In 2000, I started experiencing morning headaches and was lethargic during the day. My physician prescribed bilevel ventilation (BiPAP® S/T with a nasal mask) to use at night. I slept better and had more day-time energy. Gradually I increased use of the BiPAP also during the day. I was aware that bilevel ventilation would only work for a few years and that eventually I would need 24-hour ventilation via a tracheostomy.

I was happy to live independently for nine years, and my attendant care arrangement worked well. In choosing a tracheostomy, I realized that I might lose my freedom and the independent lifestyle I valued so highly.

After getting the trach and ventilator, I went to a rehabilitation facility to recover and adjust to the changes in my life. But when it came time for discharge, I faced a difficult barrier:

finding a place to live. There were no programs in the community that would allow me to live in my own home as a ventilator user with a tracheostomy. In North Dakota, only nurses can provide tracheostomy and ventilator care, and the Medicaid waiver could not provide the amount of nursing hours I would need to live in the community.

The only housing option was a nursing home. There are two nursing homes in my hometown of Jamestown. One nursing home denied me admission because of the ventilator. Fortunately, the other nursing home accepted me because they had had experience with other residents who used ventilators. It was a victory for me to return to my hometown, however it was not the living arrangement that I preferred.

When I moved into the nursing home in March 2003, I adapted to life as best as I could. I became more comfortable with my ventilator and my new surroundings. Over the next several months I learned everything I could about my ventilator. My health improved; life stabilized. Last fall I decided to leave the nursing home and move back into an apartment in the community.

The battle to leave the nursing home has been very challenging. The Freedom Resource Center for Independent Living (CIL) and North Dakota Protection and Advocacy are assisting me. The Freedom CIL helped me file a civil

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To read a recent two-part article on Mark in the Jamestown Sun, visit: www.jamestownsun.com/main.asp?SectionID=31&ArticleID=18367&SubSectionID=98&FCID=99387&FCN=Mark%20Boatman

Ventilator Users in the Air

TRAVELING TO JAPAN

Adolf Ratzka and Audrey King, two long-term ventilator users, traveled to Japan in late June to participate in symposia sponsored by the Japanese Ventilator Users Network (JVUN). Adolf, head of the Independent Living Institute (adolf.ratzka@independentliving.org), traveled from Stockholm, Sweden, to Japan. Audrey, a disability rights activist and author, (king.aj@rogers.com) flew from Toronto, Canada, to Japan.



Which airline(s) did you fly?

ADOLF RATZKA: Finnair and All Nippon Airway.

AUDREY KING: Air Canada and All Nippon Airway.

How many hours was each leg of the trip? (not including check-in time, waiting for connecting flights, baggage, customs, etc.)

AR: 1 hour from Stockholm to Helsinki; 9½ hours from Helsinki to Osaka, 2 hours from Osaka to Sapporo.

AK: 4½ hours from Toronto to Vancouver; 12 hours from Vancouver to Osaka, 2 hours from Osaka to Sapporo (altogether 39 hours over 1½ days — three different airplanes; four different airports).

Which ventilator(s) did you take?

AR: Eole 3 volume ventilator (Saime, France, www.saime.fr)

AK: In flight, I used the LTV®950 (Pulmonetic Systems, Inc., USA, www.pulmonetic.com). On the ground, I used the LTV®950 in volume mode during the day when travelling, conveniently hanging on the back of my wheelchair. The PLV®-100 (Respironics Inc. USA, www.respironics.com), which is my usual ventilator, was provided for night use.

Were you able to plug directly into the airline's electrical system? If so, whom did you contact at the airlines?

AR: Finnair has a seat with a plug for their internal power supply but I did not inform them about my need of a ventilator.

AK: No and no. I asked different people at the Air Canada medical desk many times.

If you didn't plug in, what kind and brand of battery did you use?

AR: External 12V, 18 Ah standard battery.

AK: Four external LTV® Universal Power Supply batteries from Pulmonetic Systems, Inc. (Each lasts about 3½ hours.)

Did you use supplemental oxygen in flight?

AR: No, I have never tried it.

AK: Yes, I used a low flow via the LTV®950 (for the first time as a prophylactic measure because of the length of time in flight). The humidity provided was definitely an asset. I did not become sick or catch a cold as I have on previous flights.

Did the airline's transfer chair get you onto the plane and into your seat satisfactorily? Did your own wheelchair arrive in good condition?

AR: I travel by air about five to ten times a year and have developed my equipment accordingly. To better manage transfers between wheelchair, aisle chair, and seat, I designed a carrying cloth that I sit on with my ROHO cushion. The one-piece cloth is made of tough sailing material by a local sailmaker and extends from

Many ventilator users travel by air and use their ventilators in flight. Some may also need to use supplemental oxygen during the flight. It takes advance planning and critical attention to detail, but it can be done. Here are some recent travel experiences that include valuable tips to ensure a successful journey.

my knees up to the shoulder blades. It has two sets of carrying handles: one at my knees and one on my back up by the shoulders, with three Velcro straps across the front to secure me. This facilitates the job for the airline staff and makes transfers a breeze for me. My wheelchair arrived undamaged.

AK: For transfers, I also use a similar sling made of canvas by a sailmaker. It has loop handles at the back and at the knees, and a strap across my knees and chest so I won't slip off. I travel with a low-tech lightweight power chair that is small and easy to dismantle and reassemble. My attendant is responsible for packing it for the luggage hold and for reassembling it upon arrival. It was not damaged.

How long did you use the ventilator on each leg of the trip?

AR: All the time except when on the aisle chair when I breathed normally.

AK: I used the ventilator about two hours on the flight from Toronto to Vancouver, but not with oxygen. On the trans-Pacific flights, I used the ventilator with oxygen for about eight hours, off and on, with a mouthpiece. I am able to breathe on my own for about six to eight hours before getting too tired. I slept lightly with a nasal mask for about two hours, behind a blanket for privacy.

Who/what ventilator dealer or home care company in Japan helped with preparation, backup, repairs, emergencies, etc.?

AR: I travel with two ventilators that I make sure are in good condition for the trip, but only bring one ventilator onboard. In case it should fail, I have an emergency "ventilator" in my carry-on

case. It is not an Ambu® resuscitator bag (too expensive, too bulky when not in use, too cumbersome to use), but an ordinary foot air pump, carried in my backpack, similar to those used for inflating air mattresses. In an emergency I can connect my regular hose to the air pump, and my assistant can sit beside me using one foot at a time to pump air into the hose.

AK: Respironics in the US and Canada, and Fuji Respironics in Japan were great help in coordinating and providing backup units at all locations in Japan. They even helped with dead wheelchair batteries and found two connectors for which I have been searching. Many thanks to Monica Reid, Derek Glinzman and Danny Reisberg at Respironics. Special thanks to Angela King of Pulmonetic Systems, Inc. for her extra help with the LTV®950.

Additional Comments

AR: Most important for me is a good and experienced assistant whom I have trained and worked with for some time before the trip.

I never inform the airline or travel agency of my need to use a ventilator during the flight. That would raise a number of concerns, discussions and possible negative answers. Instead, I inform them of my needs for carry-on service and for my electric wheelchair. I have a medical statement that certifies that I am in excellent health and need to use a ventilator. This statement I would use only when nothing else helps. Because I am wheeled onboard in the aisle chair without my ventilator, the plane crew is not aware of my ventilation need. The ventilator and its external



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Japanese Ventilator U

Joan L. Headley, Executive Director, IVUN, Saint Louis, Missouri (v

I first met Kimiyo Sato from Sapporo City, Hokkaido, Japan, in Saint Louis, Missouri, in 1997 at our Seventh International Post-Polio and Independent Living Conference. She presented her experiences using a ventilator 24-hours a day via a tracheostomy due to muscular dystrophy. Kimiyo spent the first 20 years of her life in a hospital, but successfully moved to an apartment in 1990.

The second time I met Kimiyo was in the Sapporo Airport in June 2004. She and members of her talented staff greeted me and ventilator user Audrey King, Toronto, Canada, who came with

her friends and attendants Martha Lawrence and George Kokuryo, after our long 12-hour flights from North America.

Kimiyo, now the executive director of the Sapporo Center for Independent Living and the Japanese Ventilator Users Network (JVUN), was fulfilling a dream of organizing a conference to educate persons involved in Japan's disability movement, the medical and welfare specialists, and the general public in Japan. She wanted to raise awareness about the need for improved independent living for ventilator users. (In 2001, the Japanese Ministry of Health, Labor, and Welfare estimated there are 10,400 ventilator users.) JVUN also invited ventilator user Adolf Ratzka, PhD, from Sweden, and pulmonologist E.A. "Tony" Oppenheimer, MD, from Los Angeles, California.



Ventilator Users Network's Successful Symposia

ventinfo@post-polio.org)

JVUN organized three symposia in three different cities. We presented keynote speeches on specific topics, and then we all participated on panels with members of JVUN and advocates from several of Japan's independent living centers, the BakuBaku Club (for children who use ventilators), and the Japanese ALS Association.

Expanding the number of hours of personal assistance for ventilator users, providing more support for children with ventilators and their families, and educating the people of Japan to accept people with significant disabilities to live in the community were the major areas of concern.

During her presentation in Sapporo, Audrey King spoke about her years of travel with a ventilator to 17 countries — from luxurious places such as resort hotels in the Bermudas, Bahamas and

Barbados islands to the cold and windy floor of the North Sea. As a child of an army officer posted overseas, Audrey's love of travel was ignited by the frequent relocations to other countries. In a family where responsibility and self-reliance were the norm, Audrey extended the same organizational and planning skills to travel that she applied to her education and subsequent career.

While in Tokyo, Audrey signed numerous copies of the Japanese translation of her book, *There's Lint in Your Belly-button!* To view the pictorial diary of the trip Audrey wrote for children with disabilities, log on to <http://ablelink.org/public/audreysdiary/audreysdiary.htm>.

The second symposium at the National Olympics Memorial Youth Center in Tokyo featured Adolf Ratzka, founder and director of the Independent Living Institute (www.independentliving.org) in Stockholm, Sweden. He stated that as a ventilator user he needs medical assistance, a barrier-free environment and personal assistance. Adolf's presentation emphasized the concepts he has written extensively about regarding personal assistance. As a tireless international advocate, he supports a system based on lifestyle, not on medical need, such as the Swedish Personal Assistance Act of 1994, that allows him choice and control. He hires, he fires, he chooses who works for him and when.

Tony Oppenheimer, MD, who spoke in each city, presented an overview of home mechanical ventilation (HMV) based on his years of experience as



Kimiyo Sato



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For more information, contact JVUN at its new address, New Nango San Haitsu 1F, Minami 2-2, Nango-dori 14 Chome, Shiroishi-Ku, Sapporo-City, Hokkaido 003-0022, Japan (info@jvun.org, www.jvun.org).

the director of the HMV program at the Southern California Permanente Medical Group. Dr. Oppenheimer noted who could benefit from HMV, discussed when HMV should begin, emphasized the importance of patient/physician collaboration, and encouraged the ventilator users in the audience

They helped make it happen

Makoto Yamamoto, the liaison with the guest speakers and the translator of all conference materials, with Junko Konno, Vice President of CIL Sapporo.



Takahiro Hanada, Vice-Director of JVUN, who uses a ventilator 24-hours-a-day via a tracheostomy. JVUN has published his story, "Cannula is like a pierced earring" (available from JVUN).



Naoki Okamoto, the organizer of the symposia program.

Naohito Tomita, JVUN staff member who uses BiPAP at night because of muscular dystrophy.



to monitor their own breathing status by periodically using an incentive spirometer to measure vital capacity, peak flow meter to measure peak flow and peak cough flow, and, if financially possible, an oximeter to measure oxygen saturation levels in the blood.

In Osaka, I discussed the independent living philosophy and the importance of adhering to it when meeting the needs of home mechanical ventilator users. Independent living does not mean "doing everything by oneself," but it does require that ventilator users be involved in all decisions that affect their lives.

By reviewing the stages of being a ventilator user — facing the situation and learning the life — I commented on the importance of personal choice, of connecting with knowledgeable health professionals and related services, and of finding peer support and personal assistance.

I concluded by encouraging all to "live the life" and not be afraid to seek experiences that make life, with or without disability, complete. As Mark Twain said, "Keep away from people who try to belittle your ambitions. Small people always do that, but the really great make you feel that you, too, can become great."

Kimiyo's dream was fulfilled because more than 1,000 people attended the three symposia. Many activities were videotaped and JVUN has produced a tape that will be used to further educate the community on living life with a ventilator outside an institution. ●

New Interfaces: Nasal Pillows

Ventilator-Assisted Living (Spring 2004, Vol. 18, No. 1), described ResMed's ComfortLite™ nasal pillows system. Several other interface manufacturers have developed their own nasal pillows products that are now on the market. Many ventilator users who cannot get accustomed to a nasal or facial mask prefer to use nasal pillows. Puritan Bennett was the first company to develop the nasal pillows system, called ADAM® (Airway Delivery And Management).

Interfaces should be fitted by a respiratory therapist experienced in noninvasive ventilation in the home. Unfortunately, the level of reimbursement (in the US) to home health care dealers for the interfaces and the respiratory care involved in fitting and monitoring them prohibits many dealers from offering a wide range of choices to their clients/consumers.



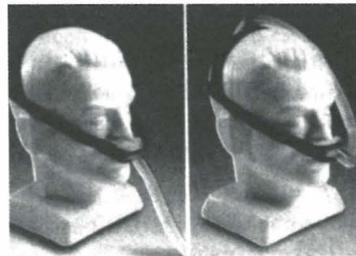
Mirage® Swift™ nasal pillows system is ResMed's (800-424-0737, www.resmed.com) new product in the nasal pillows market. It weighs only 2.5 oz and offers four interchangeable tubing positions (up, down, left, or right) for flexibility and comfort while the individual is sleeping. There are three sizes of pillows (S, M, L). A carry bag also includes an educational CD, quick-fit guide and user instructions.

Breeze™ SleepGear™ with nasal pillows from Puritan Bennett (800-635-5267, www.puritanbennett.com) has been redesigned, thanks to consumer feedback. The hose guide is improved and made of stronger material. A new clip has been added for greater flexibility in positioning the head straps, the cradle pad has thicker padding, and the swivel has a cuff to make it easier to disconnect.



SNAPP system from Tiara Medical Systems, Inc. (800-582-7458, www.tiaramed.com) stands for Soft Nasal Accessory for Positive Pressure. Its design resembles that of a soft bellows, with swivel elbows on each side. Tubing either goes over the head or below the chin. The two-strap headgear can be donned by a person with limited hand use.

LYRA Interface system from VIASYS Healthcare (800-231-2466, www.viasyshealthcare.com) is their answer to nasal pillows. The LYRA offers two positions for the tubing, either over the head or below the chin, 360° swivel, extra-long tubing, EasyStrap headgear, and four sizes of pillows.



New Equipment

VPAP® III ST-A, the latest model in ResMed's (www.resmed.com) VPAP® III bilevel ventilator series, provides a pressure range of 3-30 cm H₂O and an optional integrated humidifier. It also features Vsync™, an automated leak compensation algorithm. New and improved alarms include power failure, over pressure, over use, fault, low/high pressure, low minute ventilation, and a new nonvented circuit alarm that responds to nonvented mask connection problems. Small and compact, it weighs 5 lbs.

rights complaint against the North Dakota Department of Human Services for not providing my care in “the most integrated setting” as mandated by the 1999 Supreme Court “Olmstead” decision. I am awaiting a decision on the complaint from the US Department of Justice.

Respiratory care and Duchenne muscular dystrophy

The American Thoracic Society recently published “Respiratory Care of the Patient with Duchenne Muscular Dystrophy, ATS Consensus Statement” in its *American Journal of Respiratory and Critical Care Medicine*, August 15, 2004, 170, 456-465. The statement is available online: American Thoracic Society (www.atsjournals.org) and The Parent Project for Muscular Dystrophy (www.parentprojectmd.org). Jonathan Finder, MD, Children’s Hospital of Pittsburgh, University of Pittsburgh, chaired the ATS consensus committee that drafted the statement.

I continue to advocate in any way I can for home- and community-based care on both the state and federal levels. Proposed legislation in the form of MiCASSA (www.adapt.org) and the Money Follows the Person initiative (www.cms.hhs.gov/states/letters/smd081704.pdf) would greatly reduce the current Medicaid bias toward institutional care. My website (www.geocities.com/nodakwheeler) links to other resources advocating for living independently and not in an institution.

Only when more money is put into home- and community-based programs will all people with disabilities really have a choice of where they want to live. Our elected officials need to know that the current system is not working and that changes must be made. ●

Traveling to Japan continued from page 5

battery are carried in an unobtrusive bag. As the rest of the passengers embark and command the cabin crew’s attention, I hook up the hose (an elegant 8 mm translucent hose – no ICU-looking circuit) without a mouthpiece. The only question I might get asked by the crew, when the plane is in the air and they discover the hose in my mouth, is whether it is oxygen.

Over the years I have traveled to most continents and my policy of never mentioning the ventilator beforehand nor asking for special treatment because of my ventilator has worked out fine.

AK: Knowing your attendant well is absolutely crucial because there is more stress, unpredictability and fatigue when you travel. Also you are more physically

dependent when you are out of your familiar environment that has been set up especially for you. I cannot over-emphasize the importance of research and planning. You must know how your equipment works and how to reassemble or readjust it if settings get altered (basic troubleshooting). This includes packing basic fix-it-yourself tools such as tape and scissors and back-up bits and pieces.

You also need to locate resources at your destination. I always carry a doctor’s letter, but only produce it when and if challenged. The right blend of gratitude, respect and appreciation for those who truly help you along the way (and there are many such folks) is essential, as well as strong assertiveness when you absolutely must have things provided in the way they need to be provided. ●

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

Calendar

DECEMBER 4-7, 2004. 50th International Respiratory Congress, American Association for Respiratory Care, New Orleans, Louisiana. Contact AARC, 972-243-2272, info@aacrc.org, www.aarc.org.

APRIL 8-9, 2005. 10th International Conference on Home Ventilation, Journées Internationales de Ventilation à Domicile (JIVD), Lyon, France. Contact Brigitte Hautier, +33 4 78 39 08 43, +33 4 78 39 58 63 fax, Brigitte.Hautier@free.fr, www.jivd-france.com.

JUNE 2-4, 2005. Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: Strategies for Living Well, Saint Louis, Missouri. Contact IVUN, 314-534-0475, ventinfo@post-polio.org, www.post-polio.org/ivun.

IVUN Census

IVUN is collecting information from ventilator users, particularly what kinds and brands of ventilators and interfaces they use. By completing an IVUN Census, ventilator users can help IVUN better connect ventilator users when medical or equipment problems arise or when new users need information and support.

If you haven't filled out a census, please go to www.post-polio.org/ivun/ivun_census.html or write IVUN, 4207 Lindell Boulevard, #110, Saint Louis, MO 63108 USA.

Thank you ... your cooperation is appreciated.

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HOW TO CONTACT US ...

INTERNATIONAL VENTILATOR USERS NETWORK

AN AFFILIATE OF

POST-POLIO HEALTH
INTERNATIONAL

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915 USA
www.post-polio.org/ivun
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