

## Living with ALS

Shoshanna Fahima, PhD, Tel Aviv, Israel, jjfahima@netvision.net.il

"My PhD is in neuro-physiology, and I have a Master's degree in the performing arts in historical wind instruments."

I began using a ventilator in 1997. During the night, I began to awaken from sleep feeling hungry for air and unable to initiate a breath. It was, needless to say, very frightening, so I went to my general practitioner and explained what was happening. She sent me to an excellent ENT doctor who referred me for polysomnography (sleep study). It revealed severe central and moderate obstructive sleep apnea. Subsequently, a CPAP unit was prescribed for sleep and daytime use when needed.

I was still experiencing breathing problems and about five or six months later, I was retested and prescribed a bilevel ventilator (VPAP® II ST). As time went on, I began experiencing weakness in my legs and started falling, which led to ankle sprains and eventually to a cracked knee and elbow. More testing followed, and a spinal fusion was done to correct scoliosis secondary to old severe scoliosis. However, my problems continued despite the surgery.

My neurosurgeon noticed signs of trouble and performed more extensive testing. In 2004, I was informed that I have ALS. I was shocked at the diagnosis, but deep inside I had a feeling that this was the cause of my problems with breathing, chewing and swallowing. I am a professional concert flutist and artist, but gradually have lost the ability to play flute and to draw. All four limbs are seriously affected now.

Currently I use the VPAP® III ST-A with total backup (spontaneous/timed) about twenty hours a day. Settings are: IPAP 20, EPAP 6.2, 10 BPM and IPAP max = 3. I use the Mirage® Achieva nasal mask at night and the

Mirage® Vista nasal mask during the day. When I sing in the choir, I use the Mirage® Swift nasal pillows. (See photo below.) All are ResMed products.

I have hydrotherapy and physiotherapy twice a week to maintain range of motion. Both the CoughAssist® and suctioning are used as needed. I eat

both liquid and ground food for proper nutrition. My respiratory functions are followed every four to six months at Tel Hashomer Hospital, a



teaching hospital affiliated with Tel Aviv University Medical School.

In the coming academic year, I plan to pursue MA and PhD degrees in rehabilitation psychology, since I cannot work in my present field. When the time comes for a tracheostomy, I will have it done in order to have a good quality of life. ▲

# Maximizing Your Support and Independence through Attendant Care

Laura Hershey, Denver, Colorado, Laura@cripcommentary.com



Photo courtesy Tom Olin

**“At night, I use a Respirationics BiPAP® S/T with a custom-molded nasal mask made by Wilma Breaux, RRT, at St. Paul University Hospital in Dallas, Texas. When I am in my wheelchair, I use a Puritan Bennett KnightStar® 330 with Nasal-Aire® nasal pillows by InnoMed Technologies.”**

**M**ore and more people with significant disabilities, including ventilator users, are living longer, healthier, independent lives in their communities. A key component to this success is personal care assistance, also called attendant services.

Some conditions that compromise respiratory function also impair mobility and arm and hand movement. Many ventilator users, therefore, require assistance with using a ventilator and interface. This is where the availability and quality of attendant support becomes critically important. An attendant can perform tasks such as readying the ventilator for use, changing and cleaning tubing and filters, applying a mask, cleaning and suctioning a tracheostomy, and troubleshooting when a ventilator malfunctions.

I have a neuromuscular disability, spinal muscular atrophy, that significantly limits my physical movement. I use bi-level ventilation support approximately 20 hours a day.

I rely on my attendants to put on and take off my nasal mask, periodically adjust the straps and tubing, thoroughly wash all the components, replace disposable parts, fill the portable liquid oxygen tank that bleeds O<sub>2</sub> into the tubing, charge the battery that powers the ventilators, and help when the mask slips off or the tubing comes apart or the cable gets disconnected.

This is all a normal, manageable part of my daily life, attributable to a dependable team of attendants whom I have hired and trained. There are six to eight attendants on my team, working various shifts for 10 to 16 hours a day. These workers are paid by Colorado Medicaid, under a program called Consumer Directed Attendant Support (CDAS).

A vast improvement over the traditional home health agency-dominated attendant service delivery model, the CDAS program enables people with disabilities to manage their own attendants, includ-

ing budgeting, recruiting, hiring, negotiating terms, training, supervising, scheduling and, when necessary, terminating workers.

By having such a high degree of responsibility and authority for my support system, I can provide detailed training and oversight on the tasks that are most important to me, such as ventilator care. The CDAS program also fosters a greater sense of accountability among the attendants who come into my home because they recognize me as their boss, rather than reporting to a nurse or administrator.

Consumer-directed programs similar to CDAS are emerging in many states across the US. Ventilator users who do not have access to consumer direction, and who must operate within the constraints of strict nursing regulations and home health agency policies, often have a more difficult time managing their health and equipment.

Some states' nurse practice acts mandate that ventilator care must be performed by a registered nurse (RN) or by a certified nursing assistant (CNA) working under an RN's supervision. Such requirements, based on

**Personal Assistance Services (PAS)** are also known as long-term care (LTC), caregiving, attendant care, personal care services (PCS) or assistive care. While in some cases this assistance is formal (paid), the majority of this assistance takes the form of unpaid family or friends who give informal assistance. To find out about the programs in your state, contact the Center for Personal Assistance Services at the University of California, San Francisco, at [www.pascenter.org](http://www.pascenter.org).

a medical-model view of disability, treat people with disabilities as eternal patients in need of medical oversight. Sometimes such policies have the effect of denying ventilator users the level of care they need to maintain their independence. It's a Catch-22: ventilator care must be performed by a nurse, but home health agencies don't find it cost-effective to send nurses into someone's home every day. I've known people who ended up living in nursing homes as a result.

Tight medical regulation of attendant care is usually justified on the grounds of quality control. However, in a number of states, consumers and advocates have demonstrated convincingly that people living with long-term disabilities are quite capable of supervising the care they need.

Even if you live in a state with restrictive home care policies, you should assume as much responsibility as you can for managing your support services. Here are a few steps you can take.

■ **Learn all you can about your ventilator.** You might be able to get some training from your durable medical equipment company, although the quality of respiratory therapy personnel at these companies varies considerably. When you get a new device, ask questions and insist on complete answers. Search the Internet; you may be able to download your machine's clinical manual from the manufacturer's website. Study any information you can find about your ventilator's setup, your prescribed settings, cleaning and maintenance, power source issues such as cable connections and battery life, the meanings of different codes and alarms, and any issues involved with your interface.

■ **Translate your expertise into clear, easy-to-follow directions for others.**

Make a one-page list of instructions and post it near your equipment. Also, include a schedule for regular cleaning and changing of tubing and filters.

■ **Orient all of your personal assistants to your ventilator.** Explain the function of each part, how to attach the parts together, what might go wrong with each part, and how to fix things that do malfunction.

■ **Investigate the applicable regulations regarding in-home ventilator support in your state.** Depending on your location and your funding source for attendant services, these rules may come from your state or regional board of nursing, Medicaid or other publicly-funded program, your health insurance plan, and/or your particular home health agency. Of course, if you are paying your helpers privately, then you'll have few restrictions to worry about.

■ **If you're required to use a home care agency, push for as much autonomy and choice in your attendant services as possible.** Ask to interview new attendants before they are assigned to you. Offer to help with recruiting workers by posting ads in your neighborhood, your place of worship, local colleges, community centers, etc. This active involvement in the hiring process will give you more control over your services, and more respect from your service providers.

Whatever your attendant care arrangements, adopt the attitude that you are not only the client, but also the boss. You'll get best results if you become thoroughly knowledgeable about your ventilator needs and, within the regulatory limits, exercise the authority to get those needs met. ▲

## IVUN's New Medical Advisory Committee Shares Its Views

When IVUN was establishing its new Medical Advisory Committee, it looked for qualified health care professionals who supported the philosophy of independent living for users of home mechanical ventilation. Fifteen critically-thinking individuals, representing a wide range of specialization and experience in treating neuromuscular disorders, accepted the invitation.

For their first assignment, they were asked to respond to this question: **What are the major issues facing you as a health professional in treating/managing your patients who are users of home mechanical ventilation?** Here is a compilation of their responses.

**Bach** thought, "The answer is very simple ... it is the ignorance of the medical community. I get 5-10 calls and 20 emails a day to explain how to save ... patients I have never seen."

**Benditt** stated that, "For me, the predominant issue is obtaining the funding for patients to receive appropriate care in the home. Insurers and the government are unaware that for ventilator-assisted individuals an 'ounce of prevention' is truly worth a 'pound of (ICU) care.' We have the technologies available to help people live longer and with better quality of life but appropriate coverage is shrinking, not growing."

**Boitano** listed many challenges. "(1) The Medicare guidelines for timely initiation of noninvasive bilevel pressure ventilation are restrictive. (2) Payer support for mechanical ventilation and cough augmentation therapy is often difficult to obtain. The development of neuromuscular respiratory care guidelines, such as the ATS (American Thoracic Society) consensus statement on the respiratory care of DMD, should alleviate part of this problem. (3) Payer support for backup ventilators and backup power supply systems is poor. (4) Patients,

in general, are more mobile and require compact portable ventilators and power wheelchairs, but insurers are often resistant to supporting the newer generation of compact ventilators.

(5) There is a disconnect between wheelchair suppliers and homecare companies who supply ventilators, making the development of the complete setup both difficult and slow."

**Butka** reported that, "I have patients who need CoughAssist® units who cannot get coverage and inpatient respiratory therapists who just don't seem to 'get it' with regard to its benefits. The manufacturer and distributors of the CoughAssist® need to help get the message out by advertising, sponsoring meetings and educating homecare companies. Congress needs to pass Medicare guidelines that will allow separate billing for respiratory therapy visits to the home, just like for nursing and PT/OT visits. Lastly, I talk to many medical directors whose general attitude is, 'You want to do WHAT?' and 'Show me the literature'—of which there is not a lot that is not merely descriptive."

**Dikeman** reported that, "It is frustrating to see the lack of good homecare services. Insurance coverage is

so variable and patients really struggle to obtain the services they need.”

**Gay** saw the biggest issues ... “from the reimbursement standpoint—as competitive bidding and how to devise homecare service to vent users when there is no provision to do so. It would be nice to have a template for standards of care to deliver home ventilator care that is updated and accepted for reimbursement.”

**Hill** cited several major problems. “(1) Helping patients who seem to be under a constant onslaught from many sides get the services they need; getting services from homecare providers who are under severe financial pressure; and obtaining services from nursing agencies. (2) Lack of a coordinated system, standards of care and caregiver education. (3) Our current health care environment sees patients at home with chronic illnesses requiring labor intensive and expensive care as cost-cutting opportunities rather than as individuals deserving of adequate support provided through well-organized networks. Much of the battle will have to be fought at the political level.”

**Preutthipan** explained that, “In Thailand, there is no federal system to financially support ventilator-assisted patients. If the patients need ventilators, they have to be admitted to the hospital and stay forever.”

**Schwartz** felt “... the voice of big business loud and clear. The ability to gain access to the equipment and care has outdistanced the knowledge base of how to treat specific ‘off-the-beaten-path’ disorders.”

**Simonds** relayed these barriers from England: “A negative view of the outlook and prognosis in individuals with

## IVUN's Medical Advisory Committee

John R. Bach, MD, FCCP, University Hospital, Newark, New Jersey

Joshua Benditt, MD, FCCP, University of Washington Medical Center, Seattle, Washington

Louie J. Boitano, MS, RRT, RPFT, University of Washington Medical Center, Seattle, Washington

Brenda Jo Butka, MD, FCCP, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Selma H. Calmes, MD, Chairman & Professor, Olive View/UCLA Medical Center, Sylmar, California

Karen Dikeman, MA, CCC-SLP, Silvercrest Center for Nursing & Rehabilitation, Jamaica, New York

Peter C. Gay, MD, FCCP, Mayo Clinic/Rochester, Rochester, Minnesota

Diana Guth, BA, RRT, Home Respiratory Care, Los Angeles, California

Nicholas S. Hill, MD, FCCP, Tufts-New England Medical Center, Boston, Massachusetts

Virginia Simson Nelson, MD, MPH, University of Michigan Health System, Ann Arbor, Michigan

Aroonwan Preutthipan, MD, FCCP, Ramathibodi Hospital, Mahidol University, Bangkok, Thailand

Jesper Qvist, MD, The Neuroscience Centre, Copenhagen, Denmark

Oscar A. Schwartz, MD, FCCP, FAASM, Advantage Pulmonary & Sleep Medicine, Saint Louis, Missouri

Anita K. Simonds, MD, FRCP, Royal Brompton & Harefield NHS Trust, London, England

John A. Widder, BA, CRT, Los Niños Hospital, Phoenix, Arizona

severe neuromuscular disease held by the public and health care professionals who are not routinely involved in their care, an assumption that one plan of medical management suits all, and a constant struggle to get funding—for research and ventilatory equipment.”

**Widder** identified many challenges. “(1) Getting insurance companies to understand that we no longer use 1990s technology. (2) Dealing with discharge planners who want the patient to go home ‘tomorrow’. (3) Getting paid appropriately for the services we provide, such as training which is paramount to living in the home. (5) Providing the correct amount of humidity. (6) Explaining that battery life is dependent on the type of ventilation used, the rate, the pressure, etc., and the number of alarms that may occur, and that a ‘nine-hour battery’ is an advertisement, not a reality.” ▲

## Enjoying the Arts: Expect the Unexpected

Tedde Scharf, Tempe, Arizona, Tedde@asu.edu



Last fall, I participated in the annual Leadership Exchange in Arts and Disability (LEAD) Conference in Scottsdale, Arizona, hosted by the John F. Kennedy Center for the Performing Arts. It was a gathering of professionals who work in the performing arts, theatres, galleries and other creative venues. I participated in a workshop panel entitled, “Expect the Unexpected.”

The “unexpected” can be surprisingly rewarding. On a cold December day in 1956, I remember standing in line with my family at New York City’s Radio City Music Hall to see the Rockettes. An usher saw my difficulty in walking and ushered all of us to a side door ahead of a long line of customers. A similar incident happened at the 1964 New York World’s Fair when an usher guided my whole family (parents, siblings, aunts, uncles and cousins) out of line to view Michelangelo’s “Pieta” from a quiet side room. I was using a wheelchair.

I have limb-girdle muscular dystrophy and, in 1988, had respiratory failure caused by a flu bug or pneumonia and weak diaphragm muscles. As a result, I was trached. In 1995, I switched to noninvasive ventilation using an exsufflation (pneumobelt) belt (Respironics, Inc.) and various mouthpieces. Over the years, I have used different ventilators and currently use the LTV®950 (Pulmonetic Systems) because it is compact, lightweight and fits my active lifestyle. Recently, I retired after 30 years in higher education and am presently consulting and grantwriting.

As a child, my mother, a professional cellist, took me to concerts, and I literally grew up backstage meeting the famous performers of the 1950s and 1960s. This instilled a love of classical music, symphony, theatre and the arts, and I love being “on-the-go.”

During the last eighteen years, my attendance at concerts by string quartets, soloists and small music ensembles has generated a few unusual experiences. There’s no escaping the similarity to Darth Vader as the ventilator

inhales with a baritone whoosh and exhales in a swish. Most users are accustomed to the sound and tune it out. However, it is annoying to some people in an audience who can’t dismiss the repetitive sounds.

About five years ago, during a solo musician’s performance at a university theatre, a fellow patron of the arts stood up during intermission, turned around, pointed a long, bony finger at me in the back of the auditorium, and said loudly, “YOU should not be allowed in this theatre!” Gasps and indignant comments were heard all across the audience. Out in the hallway, I was surrounded by sympathetic music students who insisted that I stay for the rest of the concert. I did, but sat between two sets of closed entrance doors where I could hear the music, but where my ventilator was muffled. A large group of students sat on the floor around me.

The following week, the Dean of the Music College called to apologize and asked if I would work with his staff to find a way to ensure the comfort of

all patrons who attended concerts. We looked into numerous options including access to the mechanical room at the back of the auditorium where I could view the performance on a small TV screen and listen through speakers. We explored ways to muffle the ventilator's sounds with padded covers which, unfortunately, caused it to overheat.

A similar incident involved a larger theatre and a visiting string quartet. In this case, the wheelchair accessible seating was level with and close to the stage with a low carpeted wall behind the area which should have been a nice sound barrier. Not so! During the first half of the performance, the musicians kept looking around the room in annoyance. After intermission, before they started playing, the first violinist apologized for the extremely bad acoustics and noisy air-conditioning system in the brand new, state-of-the-art building. I realized he was hearing the breathing of my ventilator as it reflected off the wall behind me.

Over the years, acceptance has been more common than rejection. I've attended Broadway productions, concerts, symphonies and small music ensembles in a variety of theatre settings without any complaints from the audience or the performers.

I steer clear of recitals with one or two performers in small recital halls and select 'noisy' musical performances in medium-sized venues. I've never had any additional complaints and no one (with any authority) has ever asked me to leave a concert.

One of the most memorable concerts was a solo performance by world famous violinist, Itzhak Perlman, at

LEAD invited representatives from IVUN to participate in a focus group with managers of venues around the country to discuss ways to assure unfettered access to plays, symphonies, etc., for users of home mechanical ventilation. Quiet is expected but some patrons are disturbed by the sound of portable ventilators. The group discussed the following.

- Most often patrons who complain about the "noise" are satisfied when given an explanation, i.e., "the lady uses a ventilator because she has ALS."
- Venues have a policy about the unacceptability of noise from cell phones, loud talking, etc. This policy should be expanded to include an explanation as to what noise is acceptable.
- Most ventilator users are conscientious patrons and are willing to work with management by calling ahead, helping to find the "best" seat, etc.
- Some ventilator users think their ventilator is distracting and do not even attempt to go to places that expect quiet.
- Under no circumstances should any alterations of a "noisy" device be made, because it is medical equipment that has been prescribed by a physician.
- In most cases, managers of venues change the seats of the complaining patrons. However, this can be very difficult if there is a full house.

#### Other suggestions include:

- Offer the person who complains the opportunity to wear an Assistive Listening Device (ALD) to block out environmental noise and improve his/her audio.
- Provide ventilator users with a closed room with sound piped-in and a large viewing window similar to space provided in some churches for families with small children.
- Provide a sound-proof box just for the ventilator. Is this possible with the need for air and the accumulation of heat?

the Frank Lloyd Wright Gammage Auditorium in Tempe. Mr. Perlman invited a group of Arizona State University students and staff with disabilities to sit on the stage while he played. Thrilled, I sat in my wheelchair with the ventilator puffing steadily ... not more than ten feet behind him. Afterwards, he spent two hours individually greeting us.

In any situation, a positive attitude, a sense of humor and flexibility are the keys to acceptance and coping with the unexpected. The surprises and rewards are beyond one's expectations.

continued, page 8

## Enjoying the Arts: International Experiences

### Sheila Keogh, Toronto, Canada

“My husband and I attend theatre and concerts on a fairly regularly basis. I take my PLV®-100 and have never encountered a complaint from anyone. I just wheel it in on a small luggage carrier and tuck it behind my wheelchair and say nothing. I run the tube under my clothing so it is fairly hidden except for a little piece of tubing holding the mouthpiece near my face. (I use an off-the-shelf mouthpiece from Medigas and when they told me they couldn't get them anymore, I bought up the last box of 14.) My vent is quite quiet except for the odd beep from the low pressure.”

### Shoshanna Fahima, Tel Aviv, Israel

“I sing in an all women's choir while using a ventilator. The only comments I hear are 'keep up the good work' and 'more power to you.' I use ResMed's Mirage® Swift nasal pillows and the VPAP® III ST-A when I sing.”

### John R. McFarlane, Senior Partner, McCON Services (consultants on disability and occupational health), Ireland

“The real question is whether the person in the wheelchair can access the auditorium in the first place. Unlike the Americans with Disabilities Act (ADA) in the United States, there is no equivalent for privately owned buildings in Ireland. The disability legislation that was passed here in 2005 only placed duty on publicly, i.e. state-owned facilities and then not for another 10+ years. There have been incidents in the last four years (until an Equality Bill came into force covering gender, race, age, disability) of people in wheelchairs being turned away because they constituted the old hoary one of 'a fire hazard.'

“Now the owners have the right to refuse entrance to anyone they believe could cause a disturbance. I have trawled through all my contacts here regarding ventilator use, and can find no case where entry has been refused or complaint made. Whether that is because no one has tried or not, I do not know.

“I have spoken with several theatres and the National Concert Hall, and their attitude was, 'No problem, but could we have prior notice by the ventilator user so we can ensure their comfort and enjoyment of the event?' I was also asked in one instance if the person would need a secure power supply in case of electrical failure or need a backup unit.”

## Enjoying the Arts: Your Suggestions

Managers of venues in the US have asked ventilator users for their additional comments and suggestions. Please forward them to Betty Siegel, Director of Accessibility, The John F. Kennedy Center for the Performing Arts ([access@kennedy-center.org](mailto:access@kennedy-center.org)).

Siegel is looking for a ventilator user in the DC area who would be interested in serving on a panel during the 2006 LEAD conference, which will be held August 4-6 at the Kennedy Center in Washington, DC. ([www.kennedy-center.org/accessibility](http://www.kennedy-center.org/accessibility); 202-416-8727) ▲

## Update on the Ventilator Users' Medical Emergency (VUME) Project

To: IVUN Members

Fr: Virginia (Ginny) Brickley, Leader, VUME Project

**GOAL** The project's goal is to assist ventilator users, their support persons (personal care attendants, family members and friends) and the health professionals who would treat them to perform their respective roles during a medical emergency with fewer complications, increased confidence, and more successful outcomes.

**PROGRESS** In May, we distributed questionnaires to ventilator users and their support persons. A steady stream of responses arrived from ventilator users themselves, but not from attendants, family members or support persons.

**TRENDS** The data in the responses have been amazingly consistent, informative and sobering. Emerging themes include absence of written documentation by users about their condition, medications and equipment; lack of knowledge among health care professionals about neurological conditions and their impact on respiration; and the need for improved access to specialists via the Internet, such as the availability of well-researched comments provided by the late A.E. "Tony" Oppenheimer, MD. Many ventilator users expressed wide-ranging fears about surviving an emergency situation, particularly regarding anesthesia and oxygen use.

**NEXT STEP** We are now preparing a questionnaire for health care professionals, using the information gained from users and their attendants and family members.

An important part of this step is reaching the many professionals who would interact with ventilator users in an emergency situation (power failure, traffic accident, heart attack, etc.). It is critical that we reach health care professionals who can contribute by describing challenges they face when treating ventilator users and/or by suggesting solutions for those challenges.

We are asking ventilator users to recommend health care professionals to receive the questionnaire designed for them. Contact me with their name(s), address(es) and phone number(s) and advise if we may use your name when contacting them.

If you are such a professional and want to be involved in this project, please contact me or Joan L. Headley at [ventinfo@post-polio.org](mailto:ventinfo@post-polio.org). More details are posted on [www.post-polio.org](http://www.post-polio.org). ▲

THE VUME Project is funded  
by the Christopher Reeve  
Foundation.

To reach Ginny Brickley:  
146 Geneva Avenue  
Elmhurst, IL 60126  
or  
630-833-0602  
or  
[virginia-brickley@comcast.net](mailto:virginia-brickley@comcast.net)  
or  
[ventinfo@post-polio.org](mailto:ventinfo@post-polio.org)

**Respiratory Management Following Spinal Cord Injury: A clinical practice guideline for health-care professionals** (©2005) contains recommendations for the acute phase of SCI that can also be applicable to anyone with SCI experiencing respiratory problems. Recommendations include prevention and treatment of atelectasis and pneumonia, tracheostomy, PEEP, medications, diaphragmatic pacing, dysphagia and aspiration, psychosocial assessment and discharge planning.

Produced by the Consortium for Spinal Cord Medicine, chaired by Kenneth Parsons, MD, the guideline provides a valuable discussion of weaning from the ventilator and when long-term use is indicated. Clinical protocols from Craig Hospital in Colorado are appended. Available in PDF format (\$3) or hard copy (Publ. #2900-179, \$19.95 plus \$3 shipping/handling) from Paralyzed Veterans of America, 888-860-7244, [www.pva.org/pvastore](http://www.pva.org/pvastore). ▲



Sitta Sang-rod with respiratory nurse Thitida Chaisupamongkollarp.

## Ventilator Donation to Thai Hospital

Aroonwan Preutthipan, MD, Ramathibodi Hospital, Mahidol University, Bangkok, Thailand, raapt@mahidol.ac.th

Sitta Sang-rod is now 11 years old. He has inoperable congenital heart disease. His left diaphragm is paralyzed due to phrenic nerve injuries from one of his heart surgeries. Sitta used a Puritan Bennett 2801 ventilator donated by Walgreen Health Initiatives for five years, but in 2005, Sitta had a leak around his trach which caused a false alarm. Sitta was readmitted to the hospital and switched to a PLV®-100 (Respironics, Inc.) ventilator, a donation from Post-Polio Health International and the family of Lew Gumerman. (The 2801 ventilator was sent out for maintenance.) Sitta is currently doing well. He uses the ventilator only during the night; he can breathe spontaneously through his tracheotomy without ventilator support during the day.

## Registries

■ The **ALS Registry Act**, introduced in Congress last year (H.R. 4033/S. 135), would authorize the Centers for Disease Control and Prevention to create and maintain a nationwide registry of people with ALS. The ALS registry would bring together existing collection and surveillance entities, maintain information over time, and track the progress of people with ALS, helping researchers to determine causes and potential treatment. For the legislative status of the act, go to [www.alsa.org/policy](http://www.alsa.org/policy) and click on "Legislative Priorities."

■ The **International Spinal Muscular Atrophy Registry** helps researchers gain statistical data to benefit others with SMA. The registry is coordinated by the Department of Medical and Molecular Genetics at Indiana University. To participate, contact Connie Garland at Indiana University, 317-274-5745, [cjgarlan@iupui.edu](mailto:cjgarlan@iupui.edu). Registry forms are available online: [www.iupui.edu/~medgen/hereditary/sma.html](http://www.iupui.edu/~medgen/hereditary/sma.html).

## Calendar 2006

**JULY 2-7. Eleventh International Congress on Neuromuscular Disorders.** Istanbul, Turkey. Contact [icnmd2006@flaptour.com.tr](mailto:icnmd2006@flaptour.com.tr) or visit [www.icnmd2006istanbul.org](http://www.icnmd2006istanbul.org).

**JULY 13-16. Parent Project for Muscular Dystrophy (PPMD) 2006 Annual Conference.** Cincinnati, Ohio. Contact PPMD, 800-714-KIDS, 513-425-9907 fax, [www.parentprojectmd.org](http://www.parentprojectmd.org).

**JULY 14-15. Families of Spinal Muscular Atrophy (FSMA) Families and Professionals Conference 2006.** San Diego, California. Contact FSMA, 800-886-1762, 847-367-7623 fax, [www.fsma.org](http://www.fsma.org).

**AUGUST 2-6. ALS Nursing ... For the Americas 2006.** Chicago, Illinois. Contact Jennifer L. Armstrong, RN, BSN, 312-695-5886, 312-695-3166 fax, [jarmstrong@nmff.org](mailto:jarmstrong@nmff.org), [www.lesturnerals.org](http://www.lesturnerals.org).

# Join IVUN!

Support International Ventilator Users Network's educational, research, advocacy and networking mission.

## \$15 SUPPORTER

- Access to [www.post-polio.org/ivun](http://www.post-polio.org/ivun) and [www.post-polio.org](http://www.post-polio.org)
- Networking opportunities
- Information about relevant events
- Opportunities to participate in research

ALL MEMBERSHIPS 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*

## \$45 SUBSCRIBER PLUS ... All of the benefits of Subscriber, AND ...

- Both quarterly newsletters: *Ventilator-Assisted Living* AND *Post-Polio Health*

## \$75 CONTRIBUTOR ... All of the benefits of Subscriber Plus, AND ...

- *Resource Directory for Ventilator-Assisted Living* and *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

## \$125 SUSTAINER ... All of the benefits of Contributor, AND ...

- One additional complimentary Subscriber Membership for another person designated by the Sustainer or to a person who has expressed financial need.

## Membership Application

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

Name \_\_\_\_\_

Institution/Support Group \_\_\_\_\_

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 # \_\_\_\_\_

Name on card \_\_\_\_\_ Exp. date \_\_\_\_\_

Signature \_\_\_\_\_

### Membership Level

- Supporter, \$15**
- Subscriber, \$25**  
 *Ventilator-Assisted Living* OR  *Post-Polio Health*
- Subscriber Plus, \$45**
- Contributor, \$75**
- Sustainer, \$125** I am designating this person for the additional Subscriber Membership. Please send:  
 *Ventilator-Assisted Living* OR  *Post-Polio Health*
- Name \_\_\_\_\_
- Address \_\_\_\_\_
- City, State/Province \_\_\_\_\_
- Country \_\_\_\_\_ Zip/Postal Code \_\_\_\_\_
- Or, donate this complimentary Subscriber Membership to person selected by International Ventilator Users Network.

Send to:

**POST-POLIO HEALTH**  
INTERNATIONAL

4207 Lindell Blvd., #110  
Saint Louis, MO 63108-2915 USA  
314-534-5070 fax

VL 20/2

**INSIDE THIS ISSUE**

- 1 Living with ALS
- 4 IVUN's New Medical Advisory Committee Shares Its Views
- 6 Enjoying the Arts: Expect the Unexpected

*International Ventilator Users Network's mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.*

©2006 Post-Polio Health International (PHI).  
Permission to reprint must be obtained from Post-Polio Health International (PHI).

ISSN 1066-5331

Editor: Joan L. Headley,  
editor@post-polio.org

Designer: Sheryl R. Rudy,  
webmaster@post-polio.org

Contributing Editors:  
Judith R. Fischer, MSLS,  
and Sandra Stuban, RN.

**How to contact IVUN**

**International Ventilator Users Network**

An affiliate of Post-Polio Health International (PHI)

4207 Lindell Blvd., #110

Saint Louis, MO 63108-2915 USA

314-534-0475, 314-534-5070 fax

ventinfo@post-polio.org

**REMINDER: THE RESEARCH FUND PROPOSAL DEADLINE**

**What?** Call for Proposals for The Research Fund

**Who should apply?** Researchers investigating the late effects of poliomyelitis and/or neuromuscular respiratory disease. The Fund's priorities are to provide funds to initiate new research; to continue notable projects; to combine with other resources to complete research into post-poliomyelitis and neuromuscular respiratory research.

**How much?** \$25,000 for 2007

**Deadline for Phase 1:** August 1, 2006 (Applicants will be notified by September 1, 2006, if accepted for Phase 2.)

**Deadline for Phase 2:** November 1, 2006

**Criteria and Procedures:** Available on [www.post-polio.org](http://www.post-polio.org) or by calling 314-534-0475.

IVUN is sponsored in part by



IVUN is supported in part by



POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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

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