

## The Research Fund: Final Report

# Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis

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The Research Fund grant in 2005 from International Ventilator Users Network allowed our team to investigate the effects of noninvasive ventilation in patients with neuromuscular disease and with relatively preserved pulmonary function.

We conducted a retrospective cohort study of patients with amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig's disease). Ninety-two patients were followed for a median of 3.5 years. We compared survival from time of diagnosis in subjects who started noninvasive positive pressure ventilation (NPPV) use when their forced vital capacity (FVC) was 65% of predicted (Early NPPV) with subjects who started NPPV when their FVC was  $\leq$  65% of predicted (Standard NPPV).

**"We concluded that survival from time of diagnosis was nearly one year longer in the Early group."**

There were 25 patients in the Early group and 67 in the Standard group. The two groups were similar except for pulmonary function. Patients used bilevel positive pressure units with backup rates and a variety of full face and nasal masks. All patients used NPPV for four or more hours per day.

Survival was significantly improved in the Early NPPV group. The median time from ALS diagnosis to death was 2.7 years in the Early NPPV group compared to 1.8 years in the Standard NPPV group. The risk of death remained significantly lower in the Early group after adjustment for potential confounding factors, including time from symptom onset to diagnosis, age, gender, presence of a gastrostomy tube, and bulbar onset.

We concluded that survival from time of diagnosis was nearly one year longer in the Early group. Until more definitive data is available from randomized trials, our findings suggest that clinicians should test for respiratory muscle impairment with supine FVC, maximal inspiratory pressure (MIP), sniff nasal pressure, and sniff transdiaphragmatic pressure, and encourage early use of NPPV.

### Q & A with Dr. Lechtzin

**Q: What impact will these results have for people with other neuromuscular conditions?**

**A:** While ALS progresses more rapidly than many other neuromuscular conditions, there is no reason to think our findings are specific to ALS. If

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NPPV works by resting fatigued muscles, improving compliance of the lungs and chest wall, and preventing elevated CO<sub>2</sub> levels, it should be effective earlier in other conditions, such as muscular dystrophy.

**Q: Can earlier use of NPPV benefit polio survivors? How would my physician and I decide when to start NPPV?**

**A:** This is a challenging question. The time to start NPPV in ALS is better defined than in other neuromuscular conditions, but even in ALS it is not clear-cut. My feeling is that until more definitive information is available, this question should be approached clinically on an individual basis.

If patients have evidence of respiratory muscle impairment and are symptomatic, NPPV will likely be beneficial. I do not think there is any absolute value of FVC or other pulmonary function test that will deter-

mine if any individual with post-polio syndrome or another neuromuscular condition will benefit from NPPV. However, if they have shortness of breath (dyspnea), need to sleep sitting up (orthopnea), fatigue, hypersomnolence, or difficulty sleeping, NPPV may be beneficial.

**Q: Is future research on early use of NPPV in ALS in the works?**

**A:** We have a randomized crossover study ongoing at Johns Hopkins in which individuals with FVC above 60% are evaluated. There is also an ongoing multicenter study of early NPPV led by Ed J. Kasarskis, MD, PhD, at the University of Kentucky.

**Q: Have you submitted the study results for publication?**

**A:** We have submitted a manuscript to *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders*. It is currently under review. ▲

### The Research Fund

- The Research Fund of Post-Polio Health International including International Ventilator Users Network was started by the estate of polio survivor and ventilator user Thomas Wallace Rogers of Moline, Illinois.
- Grants are awarded using the interest of the fund, which now exceeds \$500,000.
- Eight proposals from four countries, including the USA, were received in response to this year's call for proposals. Three were targeted at respiratory conditions; five at post-poliomyelitis.
- A Review Panel is currently evaluating the proposals for the next award of \$25,000 and will submit its recommendation to PHI's Board of Directors in December.

As you contemplate your end-of-the-year donations, please remember to support the educational and advocacy work of IVUN and The Research Fund.

*Reminder: The Pension Protection Act of 2006 offers tax benefits to individuals donating from their IRA accounts during 2006 and 2007. Consult your financial/tax advisor for details.*

# Pennsylvania Vent Camp at Camp Victory

Jack Freedman, West Chester, Pennsylvania, jackfreedman1@comcast.net

**T**his summer I went to Camp Victory, a vent camp near Scranton and Harrisburg in Pennsylvania. It was a long drive. It took five hours.

Camp was from Sunday to Thursday. I did not bring shoes because it was summer. Mom and Dad brought medical equipment and taught the nurses how it worked. Two of my nurses were Ellen and Emily. Some of the helpers were Lori and Brian. Brian poked on my nose and made me laugh.

I cried Sunday and Monday nights because I missed my Mom and Dad, but not on Tuesday or Wednesday. I woke up at 7:00 am and had breakfast at 8:00 am every morning. I yelled, “Wake up, everybody its morning!” Sometimes I made Tarzan sounds to wake everybody up.

I liked to hang out in the activity room. One time I was pretending to eat chips and use two remotes while I was watching “Lilo and Stitch.” I had fun swimming in the pool with my respiratory therapist, Tomi. I swam with a float. We swam in the rain because it rained for three days! Kelly, a girl in a neighboring cabin, swam with me.

On Monday night, there was a talent show. My friend, Mason, and I hung out in the rain, having fun relaxing on the porch. I knocked over trash cans with my wheelchair. I had a good time.

We had a carnival in the cafeteria on Tuesday night, and I stayed up late. Kids were getting rides in a dog sled. I watched them. Emily helped me throw a ball at a throwing ball game as Ellen watched. I tried to hit the piñata but it was too hard for me. We had a big thunderstorm after the carnival. I was afraid of the storm, and I didn’t cry, but I felt like it.



The rain finally stopped on Wednesday. It was a beautiful day. We did lots of playing in the soccer fields. I tried to push the ball with my chair but it hurt my toes.

At night we had a luau. DJ Big Dog played music in the cafeteria but it was too loud for me. Stephanie (who took care of Mason) danced with me. We did the “Hokey Pokey” with Brian.

Thursday, another beautiful day, was when Mom and Dad and Cara picked me up. The pond outside had a fountain in it. I really liked that. I was happy. I want to go to camp every year! ▲

*To learn more about the Pennsylvania Vent Camp at Camp Victory ([www.campvictory.org](http://www.campvictory.org)), held annually the last week in June, go to [www.hmc.psu.edu/ventcamp](http://www.hmc.psu.edu/ventcamp).*

Jack is 11 years old and was diagnosed with spinal muscular atrophy (SMA) when he was 6 months old. He has a younger sister Cara, age 6. Jack uses BiPAP® S/T with ADAM™ nasal pillows interface at night and when he is ill. The CoughAssist® helps him clear airway secretions. Jack worked with his teachers at school on this story using REACH Interface Author™ onscreen keyboard ([www.ahf-net.com](http://www.ahf-net.com)) to write.

# IVUN Joins Those Studying Sexual Activity and Chronic Illness

Deshae E. Lott, PhD, Bossier City, Louisiana, deshaelott@hotmail.com

*“I am honored by and proud of respondents’ forthcoming reports, which offer hope and benefits to those who wish to keep reading.”*

The mysterious nature of the human body keeps us engaged scientifically as well as experientially. When our bodies veer from the norms, it offers us more to explore, which can be both exciting and challenging. Sexuality rests among those fascinating and complicated aspects of human existence.

Dr. Rosemary A. McInnes, Sex Therapist at the Australian Centre for Sexual Health in Sydney, argues that, “Relationship and sexual satisfaction are important boosters of quality of life, a crucial concern for patients who live with chronic illness. In a life restricted by illness, sex can be a powerful source of comfort, pleasure and intimacy, and an affirmation of gender when other gender roles have been stripped away. For patients with chronic illness and their partners, a satisfying sex life is one way of feeling ‘normal’ when so much else about their lives have changed.”

As true as this is, health care practitioners, families and even those of us who use vents don’t necessarily converse freely on just how those of us who use vents respond to our sexuality and act upon it, or how we might improve our abilities to act upon it. No physician, nurse, or physical, occupational or respiratory therapist, or social worker ever has approached the topic with me.

While dialogue about vent users’ sexuality may be lacking within the health care system, resistance to this type of dialogue rests among some of us vent users, too, not just society at large.

International Ventilator Users Network contacted me and proposed a study on this topic because new vent users periodically pose questions to the organization about the sex lives of other ventilator users. The opportunity to collect and then present information that might enhance others’ quality of life appealed to the teacher in me.

With my husband, I created a survey to find out about sexuality among my

fellow ventilator users. Many of you responded openly with intimate details. However, one vent user told me to mind my own business, that there was no place for such research, and that it invaded people’s privacy. Given how often we deal with being the object of others’ gazes, I relate to the desire for privacy when it comes to intimacies. I am honored by and proud of respondents’ forthcoming reports, which offer hope and benefits to those who wish to keep reading.

## The Survey Respondents and Their Self-Reported Sexual Activity

With the help of many of you who responded to my call, I present findings from our recent study about vent users and sexuality in the hopes that it will engage us all further in discussion about this important aspect of our health and quality of life. This study was conducted by an Internet poll.

Over the period of a month, 48 survey responses were gathered, resulting in 43 valid responses. While most respondents live in the United States,

**Meet Deshae:** Deshae E. Lott, PhD, teaches in the English Department of Louisiana State University in Shreveport, and her husband, Jeffrey D. Sadow, PhD, is a political scientist and professor at LSU. They authored “His Choice: My Life” and “Her Life: My Caregiving,” *Ventilator-Assisted Living* (Vol. 19, No. 3), Fall 2005.

multiple responses also hail from Canada, Great Britain, and Israel. And, via personal narrative, representation also comes from Japan.

The gender distribution is 51% female (all indicating they practiced sex heterosexually), with an average age of 48 and 15 years on ventilation (with four respondents indicating over 50 years using some form of mechanical ventilation to survive).

Over a third of the respondents live with the effects of polio, and almost as many live with some form of muscular dystrophy (MD). Most of the remainder, 14%, live with a spinal cord injury (SCI). The majority of respondents use ventilation almost or as many as 24 hours a day, but 30% report using it fewer than nine hours a day. Almost one quarter of those survey respondents who report sexual activity use a form of noninvasive mechanical ventilation (NMV).

#### **An array of sexual activity takes place among the sexually active group in our survey:**

- 82.1% report they engage in vaginal intercourse; most often the respondent utilizes positions of abled partner on top or the “spoon” position (the male entering the female from the rear while both lie on their sides).
- 88.0% report they receive oral intercourse.
- 44.2% report giving oral intercourse.
- 14.0% report having anal intercourse.
- 51.2% have their genitals stimulated by their partners in ways other than vaginal, oral and anal intercourse (for example, by genital touching).

- 51.2% stimulate their partner’s genitals in ways other than vaginal, oral and anal sex (for example, by partner-induced genital touching).

Although our respondents could name as many erogenous zones as they like, they cite the neck as the most common erogenous zone (13.1% of total responses), followed by breasts and testicles (9.8% each), and the clitoris and the penis (8.2% each).

Regarding sex without a partner involved, a quarter say they can still masturbate, and 14% still do. No one surveyed has a partner watch them while they masturbate; however, almost a third is at least sometimes in contact with a partner when the partner masturbates, and over a third watches their partner masturbate. Twenty-one percent of our respondents at least sometimes engage in simultaneous/mutual genital touching.

#### **Some differences noted in behaviors among our survey respondents include the following:**

- Older respondents and those with less daily time using ventilation are more likely to be sexually active.
- Women are more likely to receive oral intercourse.
- Those without feeling are more likely to give oral intercourse.
- Those with permanent catheters are more likely to receive oral intercourse (these catheter users also reported engaging in vaginal intercourse as well).
- Those with edema are more likely to be sexually active and to be stimulated by partners.

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### The most-often reported problems among our respondents for various kinds of sexual activity include:

- Vaginal intercourse: One-third indicated positioning; a quarter fatigue.
- Receiving oral intercourse: Almost half say fatigue; a third positioning.
- Other stimulation from partner: 30% say positioning; 20% say fatigue.
- Stimulate partner in other ways: three-fifths say they lack strength.
- Male masturbators report fatigue and erectile problems.

Although the sexual partners of a 52-year-old vent user with Duchenne muscular dystrophy (DMD) must be mindful of his circuitry and agreeable to a lack of spontaneity, they and he did not find these issues especially limiting. However, he shares, “I don’t have a sex life now mainly because I have considerable gastro-intestinal discomfort most of the time and don’t think it would be very pleasurable.” Another narrative respondent noted that as his diabetes medication causes erectile dysfunction, he no longer engages in sexual activity.

### Personal narratives also offer unforgettable examples of social ignorance and prejudice vent users must overcome for healthful sex lives.

Robert Mauro’s autobiography *Sucking Air, Doing Wheelies: Memoirs of a Fifties Polio Survivor* (2005), for example, details an encounter with a psychiatrist who exhorted that Mauro indeed *should* feel ashamed to use his vent in front of other people because doing so would be akin to “shitting” in their living rooms.

Another male with the effects of polio, age 66 and a 24/7 vent user for 22 years, conveys that during his teenage

years his home-school teacher suggested they skip the part in the textbook about sexual education but later would insist they cover the section on driver’s education, when the student had no intentions or means of driving. Of his teacher, he writes, “He probably thought, like many people do, that if a person is disabled they lose any interest in sexual matters.”

An inherent sense of inertia exists in any social bias, and the way to engage a momentum for change is for those of us with disabilities to recognize ignorance as ignorance without second-guessing ourselves for being sexual beings. We must work with researchers in the health care professions to raise social consciousness.

### So how can we begin the innovation, the transformation in cultural awareness about sexuality and vent users?

We begin by shaping our personal lives, to the degree we can among those of us who can, in ways that allow for free expression and edification.

A 62-year-old male polio survivor who has used a vent for 45 years gives us a good start, “My view is that the ability to love and to be close to and intimate with another person is the result of one’s psychological makeup and not of one’s physique.”

A 49-year-old female with limb girdle muscular dystrophy (LGMD) and a vent user for 18 years proposes, “I think the most important [factor] is the partner’s knowledge about mechanical ventilation and his attitude to it.”

Mauro eloquently sums up his philosophy after a lifetime of personal experiences and observations: “The best couples, the couples who had been together for years, were the most

Those of you who responded have provided us with information that will aid in further educating health care professionals and fellow vent users. A more complete report on these findings can be seen at [www.post-polio.org/ivun/val\\_20-4lottreport.pdf](http://www.post-polio.org/ivun/val_20-4lottreport.pdf)

creative. They were the ones willing to explore the possibilities, to make compromises, to take the time to work things out – in bed and out of bed. They found ways to please each other. Satisfaction was not guaranteed, yet they worked together to achieve it.” Such couples, he states, nurtured their relationship by nurturing one another.

While these attitudes might sound deceptively easy or simple, they are places for us to begin increasing cultural understanding: learn to love ourselves as we are and know we’re lovable as sexual beings; help our partners learn about our needs and feel good about providing for those needs; nurture our partners and enjoy with them the adventure of being an innovator when it comes to sex and exploring the involved bodies.

Among those of us who still engage in sexual activities, despite complications and limitations, we do face challenges. As stated earlier, many report difficulties with to positioning, fatigue, and energy to sustain stimulation or arousal. Those of you who shared more via narrative elaborate on these matters. The same LGMD person quoted above also tells us that “sometimes my husband complained, needing more time and being more careful than before without the ventilator.”

Indeed, we have to slow down. Like most everything else in our lives, sex takes more time. Mauro’s book acknowledges how challenging it can be when partners vastly vary from one another in energy levels, activities considered fun, and physical ability. If his lover lies upon his chest during or after intercourse, he struggles to breathe.

A wife writing of her sexual activity with her vent-dependent late hus-

band, who had Charcot-Marie-Tooth, explains, “He could not tolerate any weight on his stomach or chest as this restricted his breathing further so we had to adopt a head-to-toe position ... [to] achieve penetration.” Moreover, his face mask made kissing difficult.

Similarly, Mauro’s mouthpiece interferes with kissing and oral sex to some degree; just like one survey respondent – a 41-year-old male with DMD who uses a vent 24/7 – Mauro must pause for air during these activities. Those individuals answering our survey and sending us personal narratives more often than not tend to find ways to work with their physical limitations as they engage in sexual activities. But this is no small task. So, just how do we manage to “do it”?

### Survey Respondents’ Means of Enhancing Their Sexual Activities

Indeed, we are “doing it.” The how part testifies to our determination and creativity. One survey respondent, a 50-year-old female with the effects of polio who uses a vent 24/7, repeatedly answers that the solution to problems in her sex life is “try to be more creative.”

In a personal narrative, a 59-year-old male polio survivor who has used a vent 24/7 since 1989 and has been in a committed relationship since 1997 shares that they explored ideas from the *Kama Sutra* and adult videos. He continues, “We laughed and had a ball finding a way to enjoy intercourse and oral sex. ... Too often people see someone using a vent and ... have no idea how sexy we are and how we can share sex with someone we love.

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Love finds a way. You just need to be patient, experiment, and as my mom once said (in another context), ‘If at first you don’t succeed, try, try, again.’ And it is so much fun to try, try again.”

Reading documents or watching films with sexual content can give us ideas which we can try and modify for our unique situations. But what, specifically, are we trying? Over a quarter of our survey respondents say they use some kind of sexual aid, with over a third saying they use vibrators, and almost a third using lotions or lubricants including Astroglide and massage oil.

When offering solutions for enhancing sexual activities during intercourse, respondents recommended rest and repositioning. Male masturbators say to try accessing stimulating sensory input (such as pictures, films, etc.) and to rest during the process.

Positioning, rest and sensory input all enhance the quality of our sexual experiences by and large. Besides using pillows, we adjust our positions by having sex in various venues: on kitchen tables, sofas and commodes, (which allow for height adjustments), as well as on shower seats, in wheelchairs, in van seats, and, of course, in bed. Stabilizing the ventilator tubing so that it does not move too much while moving into the right position, or sustaining a position, ranks among a number of respondents’ pre-sex preparations.

To a lesser degree, other planning on our part improves our performance. Some respondents use Viagra, and another reported shaving her clitoral area to enhance stimulation.

One wife writes, “We had to turn up the respiration speed on the vent to

cope with his exertion.” His normal rate was 11-12 bpm, but we increased the rate to 15-18 bpm prior to commencing sexual activity in order to avoid the need for interruption.

A 49-year-old with LGMD similarly notes that sexual intercourse proves easier for her when her vent is set on the assist control mode: “An assist control mode makes [me] feel comfortable. I could take as many breaths as I needed.” These results suggest that it could be incredibly helpful to vent users if the appropriate medical personnel advised them, their partners, and their caregivers on safe adjustments to ventilator settings when engaging in sexual activities.

Another way around logistical problems is recruiting able-bodied persons beyond our partners to help with the processes. The taboo of voyeurism and our own inner resistance to impositions on the intimacy we share with a partner make it hard for us to request outside assistance. But some people bravely do just that, embracing it as a means to greater sexual fulfillment, and adjusting their comfort thresholds accordingly.

A 52-year-old with DMD, for example, requested positioning help from personal care attendants with his two long-term relationships. A 33-year-old survey respondent with SMA who’s needed a vent 24/7 for 20 years reports that, “My partner’s head is resting on my stomach in bed. My penis is placed in her mouth by an assistant. Her head is moved by an assistant until I have an orgasm.” And a 27-year-old female with SMA who for seven years has required up to 16 hours daily using the vent writes that when she and her partner have sex,

“We have to usually go to a hotel and get a suite so our nurses/aides can be in the livingroom if we need assistance. We use pillows to aid in positioning. Make sure his tubing is attached to his trach securely. I make sure my trach ties are secure.”

### Health Professionals' Tips for Enhancing Vent Users' Sexual Experiences

Health care providers, too, have begun to offer safe logistical advice on sexual activity. McInnes suggests that medical practitioners remind persons with disabilities that “sexual activity doesn't require a partner” and to “try different things.”

In “Sexual Health and Chronic Illness” *Clinics and Family Practice* (2004), licensed clinical social worker Patricia M. Lenahan, suggests ways for us to cultivate more positive sex lives. She urges us to understand it's a myth that sex is necessary harmful to one's health and may cause illnesses, that it weakens the potency of therapeutic drugs and treatments, or that alcohol and drugs improve sexual performance. She also wants us to know that communication issues and degree of affection between partners plays a key role in level of satisfaction; she implores us to “identify communication issues that may affect sexual behaviors” and to “experiment with positional changes to ease breathing difficulties.”

She advises couples “to adjust their sexual positions so the patient can assume a less active position” and “feel less closed in.” She registers facts that our survey respondents also give as their reality: the need to time sexual activity for when we are least fatigued and to “acknowledge that rest periods may be needed” during sex.

In John R. Bach and Joan L. Bardach's chapter “Neuromuscular Diseases” in *Sexual Function in People with Disability and Chronic Illness: A Health Professional's Guide* (1997), they reveal that of “the major issues that concern quality of life and life satisfaction in severely disabled ventilator users, the only issue in which the majority of subjects reported dissatisfaction was their sex lives.” They encourage physical and occupational therapists to discuss sexual positions and contraceptive devices, and to give specific suggestions about them and the use of lubricants, vibrators or even surgery to eliminate contractures interfering with sexual positions.

I highly recommend those of us requiring ventilation look at the complete fact-filled article “Chronic Illness and Sexual Functioning” in *American Family Physician* by Margaret R.H. Nusbaum, DO, MPH, University of North Carolina at Chapel Hill School of Medicine, and her colleagues, Carol Hamilton, EdD, PA-C, Emory University School of Medicine, and Patricia Lehahan, LCSW, University of California, Irvine, College of Medicine. (See [www.aafp.org/afp/20030115/347.html](http://www.aafp.org/afp/20030115/347.html) or contact IVUN.)

It's up to us to explain our disappointments with as well as our gratitude for health care professionals' efforts in the hopes that we thereby make the realities of living with a disability a little easier for those who follow us, as well as ourselves. Those of you who responded to my call for this piece may count yourselves among the movers and shakers in the sexual revolution for vent users. Here's to our greater sexual fulfillment! ▲

## Letter to the Editor

## DPS System Article Clarified

Kenneth Aron, Vice President, Sales & Marketing, Avery Biomedical Devices ([www.averybiomedical.com](http://www.averybiomedical.com)) took issue with some statements in “The Latest Facts about the Diaphragm Pacing Stimulation (DPS) System” published in *Ventilator-Assisted Living* (Vol. 20, No. 3), Fall 2005.

**Re: The historical role of Avery**

“The first practical application of diaphragm pacing was made by the renowned cardiothoracic surgeon, William W.L. Glenn, MD, at Yale University in the 1960s. The first commercial distribution of the device that resulted from that research was made by Avery Laboratories in the early 1970s. William Dobelle, PhD, purchased Avery Labs from Roger Avery in the 1980s and continued the development of the technology until his passing in 2004.”

**Re: The definition of surgery**

“My primary problem with the article is in the sentence, ‘The Avery system requires surgical, rather laparoscopic implantation of the electrodes directly on the phrenic nerve and utilizes an antenna.’ There is an obvious flaw in the logic of this sentence as any laparoscopic procedure is fundamentally a surgical procedure. The implication ... is an attempt to convince prospective patients that phrenic nerve pacing is fundamentally risky. The fact is that phrenic nerve pacing can be accomplished by a number of surgical techniques, including thoracoscopic and cervical approaches that have comparably low morbidity to the DPS experiment.”

Aron points out that “the investigational device exemption for the Atrotech phrenic nerve stimulator was withdrawn by the FDA in November 2005.” ▲

## Calendar

**JANUARY 27-28, 2007. ALSA Clinical Conference. Will Rogers Institute Respiratory Symposium.** Newport Beach, California. Newport Beach Marriott Hotel and Spa. Contact ALSA, 800-782-4747, [www.alsa.org/community/conference.cfm](http://www.alsa.org/community/conference.cfm).

**MARCH 31-APRIL 6, 2007. Ventilator-Assisted Children’s Center (VACC) Camp.** Miami, Florida. Applications will be accepted through December 29, 2006. Visit [www.vaccamp.com](http://www.vaccamp.com) or contact VACC program coordinator, Bela Florentin (305-662-8222).

**JUNE 22-24, 2007. Noninvasive and Home Mechanical Ventilation: ICU and Beyond 2007.** Montreal, Quebec, Canada. This is a major conference (alternating every two years between Lyon, France, and the USA) devoted to all aspects of mechanical ventilation. The emphasis is on the use of noninvasive mechanical ventilation in many settings (ICU or home), long-term or short-term use. Conference planners include Nick Hill, MD; Barry Make, MD; and Josh Benditt, MD. Contact American College of Chest Physicians, 800-343-2227, [www.chestnet.org](http://www.chestnet.org).

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*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.*

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## IVUN's 2007 Resource Directory for Ventilator-Assisted Living® is now online.

The *Resource Directory for Ventilator-Assisted Living* has been the premier resource for hooking into the world of home mechanical ventilation since 1989. To download your copy, go to [www.post-polio.org/ivun/VentDIR.pdf](http://www.post-polio.org/ivun/VentDIR.pdf).

### Are you in it? Should you be?

The 32-page *Directory* lists **Health Professionals, Ventilator Equipment and Aids**, including the manufacturers' contact information, and **Organizations, Associations and Foundations**.

And **Listserve**s for ventilator users. Let us know at [ventinfo@post-polio.org](mailto:ventinfo@post-polio.org) if your favorite one is not listed.

**Facilities with Long-Term Ventilator Units** is one of the most frequently accessed sections of the *Directory*. Help us build the list by sending the names of facilities that offer weaning and/or preparation for going home with a ventilator. ▲

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