

Crafting in Cardboard

Lille Troelstrup, Program Coordinator, Adaptive Design Association, Inc.,
New York City, lille@adaptivedesign.org

Located in Manhattan's Garment District, our non-profit organization, Adaptive Design Association, Inc., serves all of New York City. We design and build customized equipment for children with special needs, as well as offer training to make our concepts and techniques available to communities all around the world.

One of the most unique features of Adaptive Design's equipment is that it is mainly fabricated out of corrugated cardboard. We order the cardboard from a family-owned carton manufacturing company in Long Island City and use up to 300 4' x 8' sheets a year to make everything from easels to forward-tilt chairs to activity tables. Though cardboard isn't the only material that we use, it proves to be amazingly useful and practical. Not only is it inexpensive, lightweight, and easy to alter, but it also supports up to 1100 lbs. per square inch when constructed properly.

Our equipment is edged to seal the corrugation, and painted so that it looks inviting and child-friendly. The kids themselves participate in decisions about color and motifs.

The key element in Adaptive Design's creations is that each one is tailored to the individual needs of the user. Positioning is usually the first consideration when dealing with our young clients. When addressing needs like ventilators, feeding tubes and pulse oxygen monitors, additional consideration is necessary but we've found imaginative solutions for varying situations.

The projects range in price depending on the number of site visits, and equipment development and preparation time. Unfortunately, much of the equipment goes unpaid, and we are currently exploring ways to receive Medicaid reimbursement.

Keithan, for instance, who needs to use a ventilator, lived in an intensive care facility, and after meals he had to be propped up to prevent aspiration. The bumpers and pillows that the nurses used didn't furnish the solid support that he needed.

Using tri-wall cardboard, a utility knife, and a T-square, staff from Adaptive Design fabricated a crib chair on the spot, which provided him with firm back support and was angled slightly backward to prevent his tipping forward. It was the first time that Keithan could watch what was going on around him. The chair cost about \$240.

Owen's world has largely been his bedroom, where his schooling, therapy and family time take place. His spinal muscular atrophy makes moving him precarious because his pulse oxygen

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Keithan in his crib chair
Photo property of Adaptive Design Association



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

Designer: Sheryl R. Rudy
webmaster@ventusers.org

Special thanks ...

Judith R. Fischer, Diana Guth,
Audrey King, Adolf Ratzka,
Lille Troelstrup

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How to contact IVUN

International Ventilator Users Network (IVUN)

An affiliate of Post-Polio Health International (PHI)

4207 Lindell Blvd., #110

Saint Louis, MO 63108-2930 USA

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

info@ventusers.org

www.ventusers.org

To be sure you receive email updates from PHI and IVUN, set your spam filters to allow messages from info@post-polio.org

Inside this Issue ...

Pages 1 and 3

Crafting in Cardboard by Lille Troelstrup features the creative solutions Adaptive Design Association (ADA), a New York based non-profit, offers children with disabilities and their parents. Want to know more? Connect with Troelstrup, who is a great ambassador for ADA.

Pages 4 and 5

The article, **Ventilator Users and Meditation** by Adolf Ratzka, PhD, Stockholm, Sweden, is not only an informative piece about meditation and its benefits, but a reminder that ventilator users can be very active and enjoy life. This fact is often lost when we focus only on the medical and the mechanical.

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Experienced pulmonologists Drs. Lechtzin and Benditt share their views on **Bilevel or volume-cycled ventilation?**, a question often discussed by ventilator users.

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This issue's advocacy page provides **updates on the ADA, the UN Convention on the Rights of Persons with Disabilities, and the Homebound Demonstration Project** fought for by ventilator user David Jayne.

Pages 8-9

New products, information for veterans, good news about Take Charge, Not Chances, and honoring Dr. Forrest Bird are part of Judith R. Fischer's **From Around the Network**. IVUN continues to receive questions about interfaces and page 9 includes another "My Favorite Mask." Take a few minutes and send details about your favorite mask to info@ventusers.org.

Page 10

It's time to think about 2009. Check out the dates and places and attend a meeting to learn more about home mechanical ventilation.

Pages 11 and 12

Post-Polio Health International selected its fifth Research Fund recipient this fall. Remember the funds are also available for research into respiratory issues related to neuromuscular disease. Next call for proposals: fall of 2009.

We wish our sponsors, supporters and Members a peaceful holiday season and good wishes for 2009.

—Joan L. Headley, Executive Director

Crafting in Cardboard

continued from page 1



Owen in his wheeled reclining seat
Photo property of Adaptive Design Association

monitors, feeding tubes and oxygen feed need to accompany him. Adaptive Design devised a wheeled reclining seat with rear storage so he could be taken around the house and have more contact with his family.

Notches were cut into the headrest and storage space to provide channeling for Owen's tubing. To accommodate the unique contours of his back, Adaptive Design created a seat cushion with multiple compartments, each containing adjustable amounts of beanbag filler.

This was the third version of Owen's chair and necessitated multiple visits to his home, as well as office visits

Adaptive Design serves the five boroughs of New York City directly in order to meet the clients in person and conduct site visits for true customization. The organization serves other New York areas by offering monthly courses in cardboard carpentry and adaptive design to therapists, teachers and parents. It encourages Master's degree programs in occupational and physical therapy to integrate hands-on design fabrication into the curricula. www.adaptivedesign.org



The back of Owen's special seat
Photo property of Adaptive Design Association

with his parents. The total cost amounted to \$6,000 and was covered by a combination of funds from the New York State Departments of Health and Education, grants, individual donors and Owen's parents.

Lilla's nasal feeding tube connects to a regulated dispensing pump that requires that her parents be present all the time to make sure that the tube isn't pulled out when she moves. Adaptive Design created a pushcart for the pump and storage for Lilla's toys. In addition to giving her greater freedom, the pushcart concealed Lilla's feeding pump. She loved not being able to see it. ▲



Lilla with her pushcart
Photo property of Adaptive Design Association



Ventilator Users and Meditation

Adolf Ratzka, PhD, Stockholm, Sweden, adolf.ratzka@independentliving.org

“Since contracting polio in 1961 at age 17, I have used a volume-controlled ventilator that delivers a fixed number of breaths per minute at a fixed tidal volume. My interfaces are a nasal mask at night and a thin plastic tube held between my teeth during the day.

“My disability due to polio prevented me from engaging in physical exercises, but it directed me instead towards more mentally-oriented practices.”

Today, many people seek to improve their physical and emotional well-being by physical exercise, training techniques such as yoga, or by the aid of an increasing number of mental disciplines such as meditation. In most of these mental practices, breathing plays a central role. As a ventilator user, I can advise other ventilator users that they need not feel excluded from practicing these techniques because of their limited breathing.

Mindfulness meditation

I had not been seriously interested in meditation, except for a short course in Transcendental Meditation in the 1970s, until about five years ago. At that time I began reading books about cognitive behavioral therapy and became attracted to the related concept of mindfulness. Mindfulness, derived from 2,000-year-old Buddhist traditions, has been stripped of the religious trimmings and successfully applied to helping people overcome stress-related health conditions.¹

In mindfulness meditation techniques, the practitioner’s attention is on the here and now. Some of the techniques consist of “just sitting” and observing one’s train of thought as one would watch leaves floating down a stream. When a new thought enters one’s stream of consciousness, the meditator is to accept and acknowledge it without passing judgment and to gently return to paying attention to, for example, sounds in the environment or to observing the sensations of one’s body. One of the most common practices is to focus on the breath as it enters and leaves the body.²

Due to my lack of a functional diaphragm and intercostal muscles, I have had a limited vital capacity for decades, and my breathing is not automatic. Without a ventilator, every breath requires a conscious effort for

activating my auxiliary breathing muscles. When using the ventilator, I am also often aware of my breathing. Physical exertion or emotional stress immediately reminds me of my breathing limitations; I lose my breath, get a flushed face, an increasing heart rate, a drizzling nose or forget what I wanted to say. For these reasons, observing my breathing has become second nature.

Given this habitual observance, it is natural for me to focus on breathing while practicing mindfulness meditation. Whenever a thought comes to mind, the aim is to return to watching my breathing and the sensations it produces in my body. I direct my attention to my mouth, its tendency to get dry as the air leaves the ventilator tube in my mouth; to my lungs as they fill with air; and to the accompanying rise and fall of my abdomen.

Air stacking

The literature on mindfulness emphasizes that paying attention to one’s breathing should not influence the breathing pattern. The intention is to merely observe and not to force one’s breathing. I often do not follow this advice and use a breathing technique known as air stacking. I hold a breath after it has been delivered and, instead of letting it leave my body, I put the next breath from my ventilator on top of the first one until I have three or

four breaths stacked up, amounting to approximately 3 liters of air. (My vital capacity is probably less than 1 liter these days.)

While air stacking requires an active role – I have to consciously close the soft palate to prevent air from escaping – I still can observe the resulting sensations in my body. Air stacking increases the satisfying sensation caused by the gradual inflation of my thorax. As the ventilator forces in yet another breath, I can feel the pressure deep into my bronchi and alveoli, and my rib cage stretching. Beyond a certain pressure, the gratifying sensation will turn into discomfort. I observe these sensations until my attention is broken by a thought. After becoming aware of the interruption, I refocus on my breathing.

The benefits of air stacking are well documented.³ Briefly, it prevents the buildup of secretions in the lungs, helps to maintain one's vital capacity and is very helpful in coughing. I repeat air stacking probably 30 times during my daily 30-minute meditation session. Practicing air stacking during meditation has become such a strong habit that I now do it automatically many other times during the day, e.g., at work when I have to wait for my DSL connection, while driving the car, or during a boring meeting.

Brain entrainment meditation

A few years ago I came across a meditation technique that stimulates the brain with sound. The promotional literature promises instant beta or theta brain waves which meditators normally achieve only after years of arduous practice. The technique uses earphones and recorded sounds such as rainfall or surf with embedded,

hardly recognizable frequencies which supposedly cause your brain to produce the brain wave patterns associated with deep meditative states.⁴

I have not verified these claims with an EEG, but after sitting for 30 minutes with my MP3 player and earphones, I usually find myself more relaxed and rested.

Current meditation practice

Every day I try to find a half an hour in a quiet spot where I listen to the brainwave-inducing records in my MP3 player with eyes closed. At the same time, I do my mindfulness meditation and air stacking. Combining these three activities may sound unorthodox to most mindfulness meditation practitioners, but it has worked for me. Since I have started my combination practice, I very seldom have had colds or respiratory infections. According to my wife, I am less irritable and more relaxed now. I have also noticed that I have become better at handling stress and that my outlook on life has become more balanced.

I cannot prove that these benefits are real and sustainable, and due to my meditation practice. But even if they were only caused by a placebo effect, the pleasures I derive from my meditation practice are real, and I look forward to meditating almost each time. Somebody else might experience different results. My point is that using a ventilator need not necessarily present an insurmountable obstacle but finding the technique that fits your needs and physical condition might take some experimentation. ▲

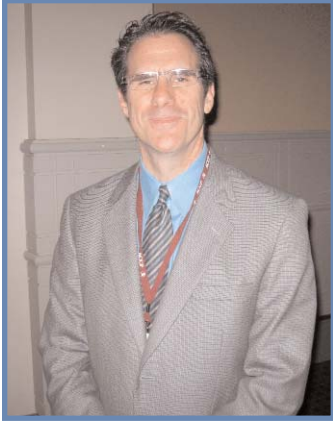
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There are many different companies on the Internet offering recorded sounds on CDs for stimulating your brain. I have tried only a couple of products and am not aware of any scientific comparative evaluation.

Bilevel or volume-cycled ventilation?

Judith R. Fischer, IVUN Information Specialist, info@ventusers.org



Josh Benditt, MD, FCCP



Noah Lechtzin, MD, MHS, FCCP
Photo by Hannah G. Lechtzin

At CHEST, the annual fall gathering of the American College of Chest Physicians, a lively discussion recently ensued between Josh Benditt, MD, and Noah Lechtzin, MD, about whether to use bilevel pressure ventilation or volume-cycled ventilation in people with neuromuscular conditions requiring long-term noninvasive ventilation. Both agreed that unfortunately the decision is driven more by reimbursement issues than what is best for the patient, at least in the US.

Dr. Lechtzin, arguing for the use of bilevel ventilation, stated the advantages as decreasing the work of breathing, improving the gas exchange in the lungs, and improving comfort and compliance. Bilevel units are smaller, lighter, less expensive and more available than volume/pressure control ventilators. The units have fewer alarms and can store usage data. One main advantage is leak compensation, although the exact tidal volume the patient is actually receiving is hard to determine.

Disadvantages of bilevel units include limited O₂ delivery and the inability for the individual to breath stack. There is also the “rent to own” reimbursement phenomenon in the US, in which the patient owns the unit after 13 months but with no assurance of respiratory care services or equipment monitoring.

The BiPAP® AVAPS™ (Average Volume-Assured Pressure Support) ventilator may be more useful for people with progressive disorders – this is a ventilator that can adapt to an individual’s increasing needs for ventilatory support. The AVAPS ensures a preset tidal volume and maintains inspiratory pressure to meet the goal tidal volume.

Dr. Benditt argued for the use of volume-cycled ventilation. (He admitted

that he has personally tried both volume-cycled and pressure-limited methods, and found pressure-limited to be more comfortable.)

Dr. Benditt finds the volume ventilator better for diurnal use, especially with the intermittent mouthpiece positive pressure ventilation system he uses because there are problems with flow triggering and autocycling when attempted with bilevel units. Breath stacking is not possible with a bilevel ventilator, which Dr. Benditt finds highly beneficial to his patients for increasing lung volume and improved cough and speech. Dr. Benditt argued that improving cough function is critical in patients with neuromuscular disease and that cough can be augmented by breathstacking or by other devices such as the mechanical in-exsufflator.

Daytime mask use is becoming more common in people with ALS and DMD. Both Drs. Benditt and Lechtzin recommend a quality of life study in people who use masks 24/7. ▲

Josh Benditt, MD, FCCP, Northwest Assisted-Breathing Center, University of Washington, Seattle, Washington, benditt@u.washington.edu

Noah Lechtzin, MD, MHS, FCCP, Johns Hopkins University, Baltimore, Maryland, nlechtz@jhmi.edu

Homebound Demonstration Report

In 2001, David Jayne, who has ALS and uses a ventilator, formed the National Coalition to Amend the Medicare Homebound Restriction to force Medicare to change restrictions on home healthcare beneficiaries. Jayne's benefits had been stripped when he ventured out to watch a football game. The benefits were restored with aid of Jayne's congressman.

Jayne's campaign led to Congressional approval for a demonstration project to determine what would happen if individuals with severe disability who received home health care benefits were permitted to leave their homes for occasions such as a baseball game, a funeral or a family reunion.

The demonstration project, 2004–2006, took place in Colorado, Massachusetts and Missouri. In an analysis of the project completed in October 2007, entitled "Evaluation of the Home Health Independence Demonstration: Barriers to a Successful Experiment Were Multifaceted, and Difficult Policy Issues Remain," Mathematica Policy Research, Inc. found that there were many barriers to enrollment, communication problems between Medicare and the home health agencies, and reimbursement issues. It is unclear what the next steps are in changing the restrictions, but several leaders in the home health care industry have urged starting over.

For the full 140-page report, go to www.cms.hhs.gov/Reports/downloads/homebound.pdf.

American with Disabilities Amendments Act of 2008

The Americans with Disabilities Act (ADA), signed into law by President George H.W. Bush on July 26, 1990, has been viewed as an emancipation proclamation for people with disabilities in the US. However, in the almost 18 years since its passage, decisions made by the Supreme Court have so narrowed the definition of disability under the ADA as to effectively shut out scores of people with a variety of disabilities from the civil rights protections in the workplace.

To correct the situation, the ADA Amendments Act was passed and signed into law on September 25, 2008 by President George W. Bush. The Act, which has new rules for the definition of disability, goes into effect January 1, 2009.

The Disability and Business Technical Assistance Centers (DBTAC) are part of a national network of 10 regional ADA Centers that provide up-to-date information, referrals, resources and training on the ADA to businesses, employers, government entities, and individuals with disabilities, as well as media and news reporters. www.adata.org

United Nations International Day of Persons with Disabilities

December 3, 2008 – The 2008 theme of the International Day of Persons with Disabilities is "Convention on the Rights of Persons with Disabilities: Dignity and justice for all of us." The convention, or international treaty, identifies the rights of persons with disabilities as well as the obligations of States party to the Convention to promote, protect and ensure those rights.

The Convention marks a "paradigm shift" in attitudes and approaches to persons with disabilities, from viewing persons with disabilities as "objects" of charity, medical treatment and social protection to viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent, as active members of society.

The Convention on the Rights of Persons with Disabilities and its Optional Protocol was opened for signature on March 30, 2007 and was entered into force on May 3, 2008, after the Convention received its 20th ratification. To date, the Convention has been ratified by 41 countries. Ratification is a concrete action taken by States which signals the intention to undertake legal rights and obligations contained in the Convention.

The first step in becoming a party to the Convention is signing the treaty. Currently, 136 countries have signed it. www.un.org/disabilities/index.asp. ▲

From Around the Network

Judith R. Fischer, IVUN Information Specialist, info@ventusers.org



SmartPulse

New Products

SmartPulse, from SeQual Technologies Inc., is a fingertip oximeter that provides fast, accurate readings of blood oxygen saturation on a full multicolor LED display. The oximeter comes with a four-year warranty. www.sequal.com

Swift™ LT for Her. Especially designed for women, ResMed's Swift has very small nasal pillows to fit petite noses. The mask frame width is also smaller to match women's faces. www.resmed.com



Swift™ LT for Her by ResMed

Veterans with ALS Gain US Benefits.

The federal government will provide disability pay, lifetime health care and death benefits for all veterans with ALS (amyotrophic lateral sclerosis, also known as Lou Gehrig's disease). The Department of Veterans Affairs said the disease was linked to military service. All veterans with the illness will be eligible, regardless of when or where they served. The decision is based on studies suggesting that veterans are more likely to develop the disease, though none could explain why. Theories on why veterans may be having an increased risk of ALS include psychological or physical stress, vaccinations, exposure to electromagnetic fields or to toxic agents used in the Gulf wars. www.va.gov

National Resource Directory for Veterans

The US Department of Defense has launched the *National Resource Directory* (www.nationalresourcedirectory.org), a collaborative effort between the departments of Defense, Labor and Veterans Affairs. The directory is a web-based network of care that includes resources for wounded, ill and injured service members, veterans, their families, families of the fallen, and those who support them.



Take Charge, Not Chances, the IVUN project funded by the Dana and Christopher Reeve Foundation, has been translated into Spanish courtesy of Dr. Martha Castilleja, Medical Editor and Translator, Miami, Florida, (BIOMEDICApres@fastmail.fm).

The four documents – Home Ventilator User's Emergency Preparation Checklist, Caregiver's Emergency Preparation Checklist, Patient's Vital Information for Medical Staff, Treating Neuro-muscular Patients Who Use Home Ventilation: Critical Issues – are on IVUN's website at www.ventusers.org/vume/.

Cardiac Involvement in CCHS

Mary Vanderlaan, Director and Founder of the CCHS Family Network advises, "In 2008 we alerted all CCHS families to the association of various mutation levels with the risk of sudden death due to long cardiac pauses and urged all patients to routinely use Holter monitoring to watch for these intermittent pauses. If pauses of three seconds or more are observed in the CCHS patient, cardiac pacing is recommended by CCHS experts." www.cchsnetwork.org

Ventilator-Assisted Children's Center (VACC) Camp

April 4-10, 2009, Miami, Florida. Contact Bela Florentin, VACC, Miami Children's Hospital, 305-662-8222, bela.florentin@mch.com, www.vaccamp.com ▲



Mirage® Vista™ nasal mask



Swift™ LT nasal pillows

My Favorite Masks

Audrey King, Toronto, Ontario, Canada

I have used the Mirage® Vista™ nasal mask successfully with the PLV®-100 volume ventilator and the LTV®950 (in both volume and pressure modes). The Vista's soft floating air-filled surface does a good job of preventing air leaks as well as totally eliminating any redness caused by pressure.

During the past two years, I have also used the Mirage® Vista™ successfully with the BiPAP® Synchrony (I:E pressures 18/4). As a daytime alternative, I also use the Swift™ nasal pillows with the Synchrony. The Swift nasal interface is small, and although I cannot apply it by myself, I can adjust it. It causes no skin pressure, seals adequately, and enables me to comfortably watch television. In fact, both the Swift™ and the Synchrony are so comfortable that I always fall asleep within minutes, missing the program I intend to watch. ▲

BiPAP® Synchrony

(available outside USA)

PLV®-100

Respironics Philips

www.respironics.com

Mirage® Vista™ nasal mask

Swift™ LT nasal pillows

ResMed Corp.

www.resmed.com

LTV®950

Pulmonetic Systems, Inc./

VIASYS Healthcare Inc./

Cardinal Health

www.viasyshealthcare.com/ltv/

Forrest Bird Honored

During the recent meeting of the American College of Chest Physicians, inventor and scientist Dr. Forrest M. Bird was honored with the establishment of the "Forrest M. Bird, MD, PhD, ScD, Endowment in Mechanical Ventilation." The endowment will support innovation and education in the field of mechanical ventilation for clinicians and their patients.

Dr. Bird, recognized for developing the first mass-produced mechanical ventilators for acute and chronic cardiopulmonary care, invented one of the first modern respirators in the 1950s. The Bird Universal Medical Respirator was sold under the trade name Bird Mark 7 Respirator. After that first invention, Dr. Bird continued his work to improve mechanical ventilation and designed the "Babybird," an infant ventilator that reduced infant mortality due to respiratory complications. His TBird ventilator series is still on the market. ▲

CBS's show "60 Minutes" featured Dr. Bird in a segment in 2007. Go to www.cbsnews.com/stories/2007/10/05/60minutes/main3334433.shtml



Dr. Forrest Bird at CHEST 2008 receiving congratulations from Diana Guth, RRT, Home Respiratory Care, Los Angeles.

2009 Conference Calendar

To be included in the print and online directory, send details to info@ventusers.org.

JANUARY 22-24

“Creating a world without ALS, The ALS Association Annual Conference
Marriott Newport Beach Hotel, Newport Beach, California. www.alsa.org

MARCH 27-28

12th International Conference on Home Mechanical Ventilation
Fira Barcelona Conference Centre, Barcelona, Spain.
Deadline for abstracts is December 31, 2008. www.jivd-france.com

APRIL 23-25



“Living with Polio in the 21st Century,”
Post-Polio Health International’s 10th International Conference.
Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia.
www.ventusers.org

MAY 14-16

FOCUS on Respiratory Care and Sleep Medicine, 9th Annual Conference
Disney Coronado Springs Resort, Orlando, Florida
www.foocus.com

MAY 15-20

American Thoracic Society International Conference
San Diego, California
www.thoracic.org

JUNE 18-21

FSMA Family and Professionals Annual Conference
Cincinnati, Ohio
www.fsma.org

JUNE 25-28

Parent Project Muscular Dystrophy Annual Conference
Atlanta, Georgia
www.parentprojectmd.org

SEPTEMBER 12-16

European Respiratory Society Annual Congress
Vienna, Austria
www.ersnet.org

OCTOBER 31–NOVEMBER 5

CHEST, American College of Chest Physicians Annual Conference
San Diego, California
www.chestnet.org

Grant Awarded

The Research Fund of Post-Polio Health International (PHI) has awarded its fifth grant to a team of researchers from the University of Insubria Medical Center, Varese, Italy, led by Antonio Toniolo, MD, PhD, Professor of Medical Microbiology and Virology. The \$25,000 award, funded by PHI's Post-Poliomyelitis Research Grant, is for work to be completed in 2009-11.

The study, entitled "*Persisting Noninfectious Fragments of Poliovirus in PPS Patients: Virus Detection and Susceptibility to Antiviral Drugs,*" will complete the sequencing of the genome of persistent fragments of poliovirus strains and compare them to wild-type polioviruses. The last year of the study will test the susceptibility of the persistent fragments of poliovirus *in vitro* to antiviral drugs. (More details are available on www.post-polio.org by clicking on "Research.")

Funds are available for research "to study the cause(s) and treatment of neuromuscular respiratory insufficiency and the effects of long-term home mechanical ventilation."

The next request for proposals will be issued in the fall of 2009. The applicants will be reviewed in 2010 with the funds given in 2011. ▲

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Philips Respironics (800-345-6443, www.respironics.com)

Philips Respironics is expanding the company's solutions for patients who suffer from chronic respiratory diseases. With a broad range of oxygen, ventilation and monitoring products, the company offers an array of solutions for the home environment.



POST-POLIO HEALTH INTERNATIONAL
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