A Different Kind of Booster

Robert Sharkey, MD, Fort Myers, Florida, Shark6400@aol.com

ur 13-year-old son Ryan has been vent-dependent since the age of four months. He has always been very sensitive to humidity, having great difficulty using a stand-alone heat-

moisture exchanger (HME). This made venturing out of our home very difficult. When my wife, Jackie, and I took Ryan anywhere for any length of time, he suffered with thick secretions and a blocked tracheostomy for days afterwards, requiring lots of suctioning and several trach changes. We were severely limited in what we could do outside our home, because the risks to Ryan's health were not



Ryan with his parents and a friend.

needs child, I am always on the lookout for medical products to benefit my son. Several years ago, I came across an advertisement for the HME-Booster® in a respiratory journal. Intrigued, I contacted the distributor and purchased one (about \$200 which was eventually reimbursed by our insurance) to try with my son. It works in conjunction with an HME, adding extra humidity and heat to the vent circuit.

As a physician and parent of a special

worth it.

I was immediately impressed with how well it worked for Ryan, but decided to make some modifications to make it more portable. The Booster I purchased is DC-powered with an AC transformer. I removed the AC transformer and direct-wired the booster to the battery on my son's chair, eliminating the need for AC power.

Initially, we used the Booster for outings around town, and Ryan did very well, but the real test came during our annual vacation to Walt Disney World®. Before the Booster, we needed

to add saline to Ryan's HME throughout the day, and even though Ryan loved the experience, he would suffer for a week after our trip with respiratory issues.

With the Booster, we can spend the entire day at the parks with no problems whatsoever. This product has completely eliminated the problems Ryan had when traveling, giving us all the freedom to enjoy life.

Now, we are out and about all the time. Ryan has a custom bike, similar to a rickshaw; the front half is a wheelchair and the back is a regular bike. Thanks to the Booster, we enjoy weekend bike rides as a family. We have even used the Booster to take Ryan out on a boat and to numerous concerts by his favorite musicians.

The difference this product has made in the quality of all of our lives is astounding. The Booster has given our family more opportunities to explore the world; it enables Ryan to live his life to the fullest.

EDITOR'S NOTE: The HME-Booster® is manufactured by Medisize (www.medisize.com) in The Netherlands and is distributed by Hamilton Medical Products in the USA. (Customer Service, 800-426-6331, ext. 222, www.hamiltonmedical.com.) A version of the Booster that is "modified" similar to Dr. Sharkey's modifications may be available later in the year. Contact Eric Kroon, Product Manager, Eric.Kroon@ hamiltonmedical.net.



An affiliate of Post-Polio Health International (PHI)

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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Special thanks ...

Judith R. Fischer, MSLS

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

Talking Stem Cells

from Susan Howley, Executive Vice President, Research, Christopher and Dana Reeve Foundation, information@ChristopherReeve.org

The Reeve Foundation watches, along with the rest of the world, as the first clinical trial using human embryonic stem cells (hESCs) moves forward after the FDA's January 23rd go-ahead for a Phase I study. The Geron* trial will be a groundbreaking first.

Patient safety, not efficacy, is the endpoint in a Phase I study. A small number of acutely injured spinal cord patients (ASIA A complete) will receive Geron's hESCs. Acutely injured animals receiving the transplanted cells showed some recovery of function. Presumably this is because the cells prompted some remyelination and/or production of nerve growth factors.

Since the isolation of hESCs by Dr. James Thompson in 1998, they have been the object of intense research by scientists throughout the world and have been imbued with magical properties by many who seek cures. Human embryonic stem cells could be used in regenerative therapies for diseases and disorders. Scientists are using them to better understand how humans develop and what happens in the course of injury and disease. And they can be used to test and screen new drugs.

In spite of excitement about this trial, we should remember that the leap from laboratory to clinic is filled with challenges. There are rats "walking" in labs all over the world, the result of one therapy or another, none of which has yet been translated to the clinic. Many interventions that worked well in animals have failed in clinical trials. And in this instance, some experts have expressed concern about Geron's move to the clinic with these cells at this time.

So, while we hope for success in and new insights from this Phase I safety study, we acknowledge that it's a first step in what is essentially an un-mapped journey down the regenerative medicine road.

For more information about stem cells go to our online Stem Cell Research Center (www.christopherreeve.org)

*In January 2009, the Geron Corporation of Menlo Park , California , won approval from federal regulators to start the world's first trial of an experimental therapy derived from human embryonic stem cells. Geron will inject the cells into the spinal cords of about 10 newly injured patients whose nerve damage to the mid-back is severe enough to permanently paralyze the lower body.

Riding Out Hurricane Ike

Margaret (Peg) A. Nosek, PhD, Houston, Texas, mnosek@bcm.edu

don't know what I was thinking. Throwing caution to the wind, I made the decision that my family, including my two helpers, three small children and me; my power wheelchair; and my ventilator could withstand a direct hit by a Category Two hurricane with a gasoline-powered generator, plenty of canned food, water and batteries, and a good supply of chocolate. We rode out the storm, completely prepared and dutifully following instructions to shelter in place. It was terrifying, but, luckily, we had no damage to the house, only a lot of fallen tree limbs. Here are six lessons I learned:

- 1. The decision about whether or not to evacuate should be made out of consideration for the people who are my life support, not just me. I was completely confident we would be all right, and my house would hold up. My attendants, however, were terrified. They didn't sleep the whole night, just huddled in the next bedroom with the children. They came to my bedroom around four o'clock in the morning to move my bed away from the window. The wind was howling, and there was a constant rumble like a freight train, with trees swirling as if they were lassos and limbs snapping all over. By the morning, we all agreed, "Never again!"
- 2. Generators smell really bad. Several of our neighbors came over the next morning to check on me and to help set up the generator. Everything worked, and we plugged in the refrigerator and battery chargers for my ventilator and wheelchair. It was still raining, and the wind was still blowing hard, making all the fumes from the generator surround the whole house. The combination of fumes. heat and humidity really started to bother me by the afternoon, and I was having a lot of trouble breathing. This was the main reason, plus other reasons listed below, that I made the quick decision that we had to leave.

- 3. Even shelters can't help. I had registered with 2-1-1 Texas (a service of the Health and Human Service Commission's Texas Information and Referral Network where people with disabilities can register for special assistance in evacuating before a natural disaster), but found it impossible to get through to them after the storm.
- I called the Red Cross to ask about emergency shelters and found out that there was no guarantee I would have access to electricity even there. With all of my extraordinary care needs. I decided that it would be best to use my own resources and to look for somewhere to stay outside of the city, hoping that FEMA would eventually help me cover the costs.
- 4. Sprint cell phones don't work in a crisis. Apparently they don't build their towers as robust as Verizon. Due to my helper's Verizon cell phone, I was able to connect with my nephew in Atlanta. He searched the Internet and booked what was probably the last available hotel room in Austin.
- 5. When electricity goes out, you don't just lose your lights. In my naïveté about how the world works, I never realized that without electricity, gasoline pumps won't work and water

continued, page 4

Peg presented the following testimony before the Texas Legislature's Select Committee on **Hurricane Ike Storm** Devastation to the Texas Gulf Coast. November 10, 2008.

Peg is Executive Director, Center for Research on Women with Disabilities, and Professor, Department of Physical Medicine and Rehabilitation, Baylor College of Medicine, www.bcm.edu/crowd/.

continued from page 3

purification plants shut down. Generators only run about 10 hours before you have to put in more gas. No gasoline stations were open or functioning. The fact that our water was contaminated was the final straw propelling us down the road to Austin. We finally reached the hotel in Austin by midnight. It was really eerie driving the first hour through a totally dark city. Only the car dealerships were lit up. Once I was able to get a cell phone signal, I kept in constant touch with my nephew and my neighbors. My neighbors called me when the electricity came back on my side of the street, and we came home the next day.

6. Hurricanes stir up a lot more toxins than they clear out. Driving around town the week after returning deeply saddened me, mostly for the utter devastation in low income and older neighborhoods. Being out and about, however, had another negative effect, because it exposed me to larger than normal doses of pollen and mold. The combined effect of these physical and mental stresses made my lungs more vulnerable, and I began to feel the symptoms of what promised to be a life-threatening respiratory infection. Luckily, I have good health insurance and good doctors, so I was promptly able to get a strong antibiotic that helped turn a potential hospital stay into just a couple weeks of misery.

Although I was quite well prepared for the storm itself, I really had no concept of what the aftermath would be like. After attending several citywide emergency management meetings and pondering strategies that might have made coping with this disaster a little more reasonable for people like me, I came up with the following recommendations:

- Advance information about an oncoming potentially disastrous weather event should include realistic assessments of risks for people with disabilities, significant respiratory limitations, or other conditions that cause lifesustaining dependence on electrical equipment.
- Zip code-related advice about sheltering in place versus evacuation should include exception statements about people with extraordinary health care needs.
- A system is needed to enable individuals with extraordinary health care needs and life-sustaining dependence on electrical equipment to register with electricity providers for priority consideration in efforts to restore service.
- A similar system should be in place to enable people to visit or otherwise contact their closest fire station to discuss their emergency needs and register for rescue or follow-up visits after a disaster.
- The network of Neighborhood Centers should be established as emergency electricity resources during disasters. This resource could be used for charging equipment batteries, accessing air-conditioning, and using refrigerators for storing medications. Emergency preparedness literature should include information about their availability and what people must do to be eligible to use these emergency resources.
- The 2-1-1 registry system must be extensively revised and expanded. In addition to assisting with evacuation, a mechanism should be in place that will contact registered individuals in the aftermath to ask about their extra-



Energy Backup

Carol Purington, Colrain, Massachusetts, carpur@localnet.com

use a ventilator 24/7 and live in a rural section of Western Massachusetts that recently experienced major power outages due to an ice storm. My home was without electricity for 63 hours. How did I manage?

I contracted polio in 1955. When I was approaching readiness to leave the rehabilitation center near Boston, my parents were told that they couldn't take me home until they had a generator. They owned a dairy farm and bought a generator that could be powered by a tractor. It could keep my iron lung or chestpiece motor operating. It could also run the barn's milking machines, which proved to be much nicer than hand-milking 20 to 30 cows.

After a couple of decades, we got a bigger tractor that could operate a bigger generator, meaning there was power not only for the necessities – my ventilator and the cows – but also most household appliances. More decades passed, and family circumstances changed. Someone who could drive the rather complicated tractor to the generator wasn't always immediately available. Now we have a Honda portable generator that can be put into operation in just a few minutes by almost anyone.

The large generator and the portable generator were what we used during the recent ice storm. For another level of backup, my name is on the list of people to be contacted during power outages by the town's emergency coordinator. This is a tiny community,

and he is a relative of a relative, so I'm not likely to be forgotten.

At present, I use a PLV®-100 several hours a day with mouthpiece ventilation. This unit has a built-in battery good for up to 90 minutes and is also permanently connected to a car battery that should last 12-24 hours. The rest of the day I use the NEV®-100 to run either my chestpiece or the Porta-Lung™ in which I sleep. Unfortunately, the NEV®-100 can't be run by battery.

Power outages are more common in the country where we live than in the cities or the suburbs. The nearest hospital is 30 minutes away during good weather, but a severe storm could leave roads blocked by snow, ice or fallen trees for days. My family and I like to be prepared.



Carol in 1958-59.

ordinary disaster-related needs and to refer them to existing resources. This should include assistance with debris removal and prompt access to repair services.

I am also a survivor of the Hurricane Rita evacuation experience, so I can say with some authority that the city of Houston handled Hurricane Ike evacuation much more efficiently. However, more information should be provided about the extraordinary risks during disaster aftermath, as well as post-disaster resources to assist people with disabilities in returning to their normal independent lifestyles.

Hospital Experiences and Observations

Gary McPherson, CM, AOE, LLD, Edmonton, Alberta, Canada, gary@garymcpherson.com

In the last 20 years, I can recall visiting the emergency ward of University Hospital in Edmonton only two or three times, but in 2008 I equalled this total within six months. I was hospitalized for bleeding in my right lung in April and in May, and then in October for chest pains. There was some question about whether the bleeding involved a blood clot, and Coumadin was introduced. It further complicated the situation.

There are only three places within University Hospital (a teaching hospital) that consider taking a ventilator user, and these include intensive care, the emergency ward and the pulmonary ward. In the April hospitalization, I spent two days on the emergency ward until a bed opened up on the pulmonary ward, where I spent another two days before being discharged.

On the emergency ward I found that it was quite easy to get a nurse when requested but that emergency is not set up to house a person like me with a pre-existing and chronic condition for any longer than a few hours. If it hadn't been for my beautiful wife, Valerie, and my regular personal care attendant taking care of my daily routine (including eating, toileting,

dressing) during waking hours, it would be very easy for someone like me to be totally forgotten on the emergency ward.

On the pulmonary ward, I fared somewhat better in terms of daily needs, but I still found that my daily personal care would have been lacking if not for my wife and attendant.

When I revisited the emergency ward in May for a second lung-bleeding episode, I never did transfer anywhere else in the hospital, due to a lack of beds being available for someone who was a ventilator user. Therefore, I spent four days and four nights on the emergency ward, and I am sure that I collected enough material and recollections to write a book that would be both tragic and humorous at the same time.

Bleeding from the lung was thought to be caused by damage to the lung from fighting infections over the years. To prevent further episodes of bleeding, two invasive procedures were suggested. One involved insertion of coils or beads into the problematic blood vessels to deaden them, and thus prevent future bleeding. The other involved removal of the lower lobe of the right lung. I opted for the coils in an angioplasty-type procedure that was successful.

In April and May, I was able to use my LP10 ventilator in the hospital. In July, I received a new ventilator, the Legendair® (www.puritanbennett.com), through the Home Respiratory Care Program in Alberta.

October has been my most difficult medical month since contracting polio on October 2, 1955. I finally realized a few years ago that problems in October were deeply embedded in my subconscious mind because I often wound up with a severe chest infection in that month.



Gary McPherson

This time it was different. I first experienced chest pains after going to bed on the evening of October 14, 2008. I began to wonder if I was not experiencing some sort of a psychosomatic symptom, but in a different form when compared to a chest infection. However, after continuing to experience some chest pain off and on during the next day, October 15, I again went to bed, but the constant and severe chest pain required some priority attention.

By way of personal history, on October 15, 1955, I was transferred by ambulance from the Royal Alexandra Hospital (under the excellent care of Dr. Russell F. Taylor who later became one of the top cardiologists at University Hospital) to the University Hospital. Fast-forward to the afternoon of October 16, 2008; as I am being transferred from the emergency ward to the CCU, I looked up to read a sign that said, "Welcome to the Russell F. Taylor Memorial Intensive Cardiac Care Unit."

Coronary blockages were found in the left anterior descending (LAD) artery and in another artery branching off from the LAD. The cardiologist thought I was a good candidate for bypass surgery, but considering my high-risk status as a ventilator user and after many tests, he and his colleagues decided on angioplasty with stents to clear the blockages. A mild sedative was administered, and I used my new Legendair ventilator. This procedure was successful.

I received excellent medical care in the CCU, but again I had to rely on my wife and attendant for my daily requirements, particularly as I re-

gained my strength and was able to get up in my wheelchair on a daily basis.

I now take a cocktail of heart medications that are supposed to lessen the workload on my heart, and I have resumed normal activities.

In conclusion, I have come to the realization that anyone with a preexisting chronic condition is at peril within our high-tech medical care system of today. Yes, the medical care can be and often is excellent, but that same care could turn out to be lethal when administered to someone like me.

When a person with a chronic condition enters the hospital, either for emergencies or elective procedures, and needs daily personal care, he or she had better be prepared for all possibilities. In my experience, even if the nurses have the time, they often don't have the expertise or the necessary training. And if they have the necessary expertise and training, they are very unlikely to have the time to deliver quality nursing care due to the shortage of nurses.

I highly recommend that ventilator users utilize Take Charge, Not Chances (downloadable from www.ventusers.org/vume). It is also available in Spanish.

Audrey King, my friend and fellow polio survivor, summed it all up. "Isn't it ironic that ventilator users have a terrible time moving out into the community and, once there, have an equally difficult time trying to get back in when hospitalization is required?" ▲

Networking

My Favorite Mask

Gary Presley, Springfield, Missouri, ke0i@yahoo.com



Gary Presley had both bulbar and lumbar polio in 1959. His essays have appeared in a variety of publications, and his memoir, Seven Wheelchairs: A Life beyond Polio, was published in October 2008 by the University of Iowa Press.

Twenty-two years of noninvasive nasal ventilation in response to post-polio respiratory insufficiency began with the bridge of my nose rubbed near to the bone.

"How can you stand that?" asked another polio survivor.

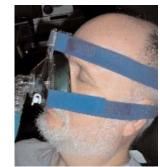
I laughed. For the first time in six years, I was resting so well, feeling so good, reducing edema, and gaining energy that I would have put up with a cut on my nose for the rest of my life.

That first mask was LIFECARE's (later Philips Respironics) standard issue. It was triangular with a hard plastic outer shell and a plastic gasket inner seal. I don't know why it was tough on my nose. Perhaps I kept it too tight to prevent the noise and flutter of seal leaks that I hate. Perhaps it was the shape of my face. I didn't complain, but I eventually compensated for the weak spot by making a "saddle blanket" from a single Kleenex® tissue to lay over the bridge of my nose. The piece of tissue – I later came to prefer Puffs® because of their lotion content – also helped seal air leaks.

Now I use a Profile Lite™ nasal gel mask with the PLV®-100 (both from Philips Respironics). It's comfortable, and it seals relatively well. I love it. I would even use it if it cut my nose, but I'm thankful that two decades of progress in noninvasive ventilation have overcome that minor problem.

Because I sometimes labor with nasal congestion, I tried nasal cannulas about three years ago, thinking direct insertion of positive pressure would help keep my nose clear. I found myself back in the same boat, although this time it wasn't the bridge of my nose being worn thin – it was the interior of my nostrils.

I went back to the comfortable Profile Lite $^{\text{\tiny TM}}$ and added a chin strap to my night-time wardrobe. It's not perfect, but I rest easily nine nights out of ten, and I ventilate well enough to keep my blood gas levels in the right place.



Gary sleeping with his Profile Lite™ mask

My advice to new noninvasive ventilator users is to not to worry if things don't seem perfect initially. It is an adaptation process. There is no one-size-fits-all solution, but there is an interface out there that will sustain your respiratory function without damaging your face. To find it, I suggest a three-prong approach: consult a pulmonologist knowledgeable in neuromuscular conditions, talk with a competent respiratory therapist, and finally don't take "It can't be done" for an answer.

Pain-free TV Watching

Jerry Daniel, Vancouver, Washington, jerry.daniel@comcast.net

In Rancho Los Amigos Medical Center, the polio rehabilitation hospital in Southern California, we kids coined an expression long before "Use it or lose it." It was "If you can't use it, fuse it." The promise was that we could get rid of braces, casts and splints by fus-ing joints. They fused ankles, wrists, fingers, lots of thumbs, and even a shoulder or elbow, or two.

Most often it worked. There were decisions to be made when fusing a hip. Do you have it fused standing or sitting?



The most serious fusions were of the spine. Because I had developed severe scoliosis after getting out of the iron lung, my rib cage was collapsing, and my breathing was becoming more difficult. I had my spine straightened with casts, and then fused from C3 to the sacrum in 1956 when I was 8 years old.

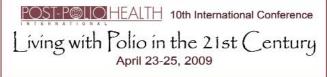


Closeup of Jerry's TV rack

I am glad I had it done and am convinced it saved my life. However, it took away the natural slump in my neck and shoulders and sitting up in bed watching TV caused a strain on my eyes and was painful to my fused neck. Instead of taking strong pain medications for my neck, I took action.

Today's 19" flat panel TV only weighs 15-20 pounds. So I constructed a rack out of 2x4s that extend from under the bed to the TV holder near the ceiling (about five feet from my eyes) that cradles the screen with eight tabs. No screws or plates attach to the TV. The right-angle joints are glued and screwed with 45-degree angle braces.

I lie with my head and legs just slightly flexed in a position comfortable to my fused neck and spine. My caregiver, who is my wife, likes the setup, because it does not interfere with suctioning. She knows it is not stylish living room furniture, but it looks good.



Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia.

Visit www.ventusers.org for details.

Want to reach 300+ polio survivors, ventilator users, and health professionals during the third week in April, with the potential to reach another 500+ after the meeting? Advertise in the program booklets (one for each of the three days). The deadline for artwork and payment are due by March 12, 2009.

The booklets will be offered (watch www.ventusers.org) for a nominal fee to those who cannot attend. ▲

Networking

From Around the Network

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



Philips Respironics' ComfortFusion[™] nasal mask

New Products

ComfortFusion™ (*left*) nasal mask features a FitPack™ that comes with either a small or medium cushion. Philips Respironics, www.respironics.com

Zest™ nasal mask features the Easy-Clip Silicone Seal for one-step removal. Fisher & Paykel Healthcare, Inc., www.fphcare.com

Acquisitions

GE Healthcare acquired Vital Signs, Inc. (that had acquired BREAS) and VersaMed in 2008. www.gehealthcare/respiratory

Networking

PatientsLikeMe.com is a website dedicated to making a difference in the lives of people diagnosed with life-changing conditions, such as ALS, Parkinson's disease, multiple sclerosis and fibromyalgia, to give individuals the power to control their disease and to share what they learn with others. It is organized by Patients, Treatments, Symptoms and Research. Go to www.patientslikeme.com, click on "Treatments," then click on "Non-invasive Ventilator" to read some interesting contributions about ventilator use.

Respiratory Therapy Services

In an attempt to improve patient access to and Medicare reimbursement for respiratory therapists, the Medicare Respiratory Therapy Initiative Act of 2009 was introduced recently in the US Congress. The Act will amend Title XVIII of the Social Security Act so that Medicare can reimburse for "the services of a qualified respiratory therapist performed under the general supervision of a physician" outside the hospital setting, including doctor's office, outpatient clinic and an individual's home. The American Association for Respiratory Care (AARC) is chief advocate for the initiative, www.aarc.org.

Reimbursement for ventilators in USA

Competitive bidding, the program devised by the Centers for Medicare and Medicaid (CMS) to hold down costs of certain durable medical equipment (DME) items, including bilevel ventilators and CPAP units, was delayed by an act of Congress. Known as The Medicare Improvement for Patients and Providers Act (MIPPA) of 2008, the act delayed implementation of Round 1 in order for CMS to improve the collection of financial documentation from suppliers and other aspects of the process. The Round 1 rebid competition begins in 2009. The MIPPA also required all durable medical equipment suppliers to met quality standards for Medicare accreditation by September 30, 2009. www.cms.hhs.gov/medicareprovidersupenroll

There have been some reports from ventilator users who are being told by home healthcare/DME suppliers that the suppliers are not maintaining a large stockpile of ventilators due to the outlay for the ventilators and the low reimbursement costs. Some suppliers are limiting their service areas to ventilator users. Other ventilator users are reporting that Medicare is denying the second ventilator. Please contact info@ventusers.org if you are experiencing problems in reimbursement or servicing. A

2009 Camps for Ventilator-Assisted Kids

APRIL 4-10. Ventilator-Assisted Children's Center (VACC) Camp, Miami, Florida. Contact Bela Florentin, VACC, Miami Children's Hospital, 305-662-8222. bela.florentin@mch.com, www.vacccamp.com.

MAY 31-June 6. Camp Pelican, Lion's Camp, Leesville, Louisiana. Contact Cathy Allain, 985-764-0343. cathyallain@cox.net, www.camppelican.org.

JUNE 4-7. Light the Way Camp, Children's Harbor, Alex City, Alabama. Contact Kara Bishop, 205-370-9605. karabishop@ventkidsofalabama.com, www.ventkidsofalabama.com.

JUNE 7-12. Trail's Edge Camp, 20th Anniversary, Camp Fowler, Mayville, Michigan. Contact Mary Buschell, RRT, Camp Director, 231-228-3371. mdekeon@med.umich.edu, www.umich.edu/~tecamp/

JUNE 9-13. Camp Inspiration, Double H Hole in the Woods Ranch, Lake Luzerne, New York. Contact Tara Bogucki, Admissions Coordinator, 518-696-5676, ext. 263. theranch@doublehranch.org, www.doublehranch.org. Admissions deadline: April 15.

JUNE 14-19. Fresh Air Camp, Camp Cheerful, Strongsville, Ohio. Contact Kathy Whitford, MSN, RNP, Cleveland Clinic Foundation, 216-721-7159. whitfok@ccf.org, www.freshaircamp.org.

JUNE 22-26. CHAMP Camp, Recreation Unlimited, Ashley, Ohio. Contact Camp Administration, 317-679-1860. admin@champcamp.org, www.champcamp.org.

JUNE 27—JULY 3. PA Vent Camp, Camp Victory, Millville, Pennsylvania. Contact Robin Kingston, MSN, CRNP, 717-531-5337. rkingston@hmc.psu.edu.

Is your camp not listed? Send your information to info@ventusers.org. The camps are also on www.ventusers.org. ▲

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Name
Affiliation
Address
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Country Zip/Postal Code
email
Phone (include area/country code)
Fax (include area/country code)
I am enclosing a check for \$ made payable to "Post-Polio Health International." (USD only)
Please charge \$ to this credit card: ☐ VISA ☐ MasterCard ☐ Discover
Card No
Exp. Date Card Verification # (3 digits on back of card)
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Signature
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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.

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A Different Kind of Booster ... p. 1 ■ Riding Out Hurricane Ike & Energy Backup ... pp. 3-5 ■ Hospital Experiences and Observations ... pp. 6-7 ■ My Favorite Mask ... p. 8 ■ and more.

Moving? Change of address? Please notify IVUN before you move by calling 314-534-0475 or email nfo@ventusers.org. It is helpful if you tell us your old and new addresses. **Will you be temporarily away?** If you send us your "second" address and the date you will be at which address, we will do our best to send the newsletter.



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