



Kevin enjoying camp festivities.

Our Camp Inspiration at Double H Ranch Experience

Pete Hansen, Freehold, New Jersey, hanseni597@msn.com

Our son, Kevin, has attended the Double H Ranch, Lake Luzerne, New York, each June for the last four years and has thoroughly enjoyed the Camp Inspiration experience. Kevin is 11 years old and has both a tracheostomy and feeding tube; he needs ventilator-assisted breathing at times. My wife Kim found out about the Double H Ranch camp via a trach website, and we decided to give it a try. It is now one of Kevin's favorite annual events that he looks forward to attending.

Camp Inspiration at Double H Ranch June 9-13, 2010

Application deadline: April 15.
Submit to Tara Bogucki,
Admissions Director, Double H
Ranch, 97 Hidden Valley Rd.,
Lake Luzerne NY 12846,
518-696-5676, ext. 222,
theranch@doublehbranch.org.

Upon arrival at the camp, campers are greeted with cheers and clapping by the enthusiastic counselors. A team effort is behind everything that goes on. The positive energy by the counselors is amazing. In the morning, they come in early to our son's room, music is playing, and there are lots of hugs and playing around to make the kids feel really special.

Each day is full of many activity offerings. Some past activities include arts and crafts, fishing, Pinewood Derby races, talent show, discovery, nature trail, animal petting at the farm, dance, baseball, zip-line rope rides, and much more.

Swimming in the indoor pool is a favorite activity. (Yes, kids with a trach can swim!)

Each year a few new activities are introduced based on input from the parents.

Behind the scenes, but always closely shadowing the counselors, are the



Kevin swimming with his mom.

many doctors, nurses and respiratory therapists who have generously volunteered their time. The administration staff does an outstanding job at also providing parents with nice dinners and other leisure activities. The last day of camp is always the hardest because all involved become very much attached to the kids who now must go home until next year.

For Kevin, June can never come too soon! ▲

MORE on www.ventusers.org

A complete list of the
2010 Camps for
Ventilator-Assisted Kids

[www.ventusers.org/net/
calendar.html#camp](http://www.ventusers.org/net/calendar.html#camp)

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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IVUN Newsletter Changes

Ventilator-Assisted Living, the newsletter of International Ventilator Users Network (IVUN), will be published bi-monthly in 2010. IVUN Members will receive Volume 24 of *Ventilator-Assisted Living* in February, April, June, August, October and December.

The eight-page newsletter will be distributed electronically to IVUN Members, Supporters and Friends. IVUN Members will also receive an electronic *IVUN Membership Memo* in January, March, May, July, September and November.

IVUN Members without email access may request print copies by contacting IVUN. (See back page.)

Your email address is important. Please report any changes to info@ventusers.org so we can stay in touch.

Our email addresses are important. Set your spam filters to allow messages from info@ventusers.org (IVUN) and info@post-polio.org (PHI).

Invitation: Ventilator users, health professionals and manufacturers are invited to submit information for *Ventilator-Assisted Living* and *IVUN Membership Memo*. Contact Joan L. Headley at director@post-polio.org.

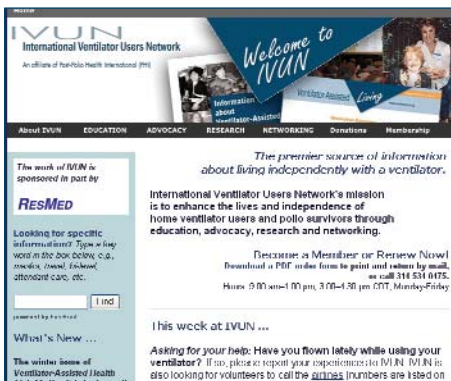
REMINDERS FROM IVUN

International Ventilator Users Network's deadline for Phase 1 of proposals for the 2011 \$25,000 research award is Friday, March 5, 2010.

Details are available at www.post-polio.org/res/rfcall.html. If you have questions, call Joan L. Headley at 314-534-0475 or email director@post-polio.org.



Check out www.ventusers.org, IVUN's comprehensive website.



The site is divided into four sections – education, advocacy, research and networking – clearly reflecting IVUN's mission.

IVUN adds current information at "This week at ..." Send your news to info@ventusers.org.

QUESTION: What are the advantages of using a volume ventilator rather than a bilevel unit? When is it appropriate or necessary for an individual to transition from a bilevel to a volume ventilator?

ANSWER: My response comes from experience because there is not a lot published on this particular topic.

At our clinic, transition to volume rather than pressure ventilation occurs in two situations.

The first instance is when a patient requires day-time ventilator support and has opted to use a mouthpiece interface. In this case, volume ventilators are preferred because they avoid the auto-cycling that often occurs when using pressure ventilators.

Auto-cycling is when the ventilator is initiating frequent breaths on its own (often in response to a mask leak) and not responding to the patient's signal for a breath. It makes interaction with the ventilator difficult for the patient and ventilation ineffective. Proper set-up usually avoids this.

The second situation in which we transition patients to volume ventilation is during nocturnal (night-time) mask ventilation when pressure ventilation is not tolerated or when adequate volume cannot be delivered with maximum pressures. In this case, volume ventilation with an oral or nasal mask interface can be used with the caveat that an exhalation valve must be added to the ventilator circuitry and a mask without vents must be used (vented masks are used with the pressure ventilators).

Joshua Benditt, MD, FCCP, Medical Director, Respiratory Care Services, University of Washington Medical Center. Director, Northwest Assisted-Breathing Center of Excellence in Noninvasive Ventilation, Seattle, Washington, benditt@u.washington.edu

ANSWER: I agree with Dr. Benditt. There is not a lot published. In fact, only two percent of our patients now use volume ventilators.

A volume ventilator allows the patient to take multiple breaths ("breathstacking") to assist with cough, so we use it if breathstacking would help our neuromuscular patients.

I have resorted to its use in morbidly obese individuals because some of the volume ventilator models are the most powerful available, but in this situation one misses positive pressure in expiration.

Many in our neuromuscular group use cough assist machines, and because a combination of pressure support and cough assist works well, we rarely change from pressure preset to volume modes.

We have a group of neuromuscular patients who have done well using volume ventilation for many years and are stable and happy with it. Here we would not wish to "rock the boat."

Anita K. Simonds, MD, FRCP, Royal Brompton & Harefield NHS Trust Sleep & Ventilation Unit, London, England, a.simonds@rbht.nhs.uk ▲

Do you have a question about ventilator-assisted living?

Are you a health professional with a question for ventilator users?

Send it to info@ventusers.org, and IVUN will find experts to answer it.



“Today the NeuRx Diaphragm Pacing System (DPS)[™] exists as an alternative to lifelong ventilator dependency,” according to Steve Annunziato, Senior Vice-President, Marketing and Sales for Synapse Biomedical. “In 2009, 75 people living with spinal cord injury (SCI) were treated with NeuRx DPS[™] for respiratory insufficiency. Today 31 centers in the U.S. and 6 centers outside the U.S. have established a treatment program for SCI.” (For a list of the centers, visit www.synapsebiomedical.com/news and click on “US Centers” or “European Centers.”)

The NeuRx DPS[™] is implanted through a minimally invasive outpatient procedure and provides electrical stimulation to the diaphragm muscle and nerves. When the muscle is stimulated, the diaphragm contracts and fills the upper and lower parts of the lungs with air. When this contraction eases, the air is expelled from the lungs – essentially the same as regular breathing. The NeuRx DPS[™] pulse generator is slightly larger than a TV remote and provides approximately 500 hours of continuous operation between battery changes.

After the procedure, the pulse generator is programmed to allow an effective yet comfortable breath. If a person has been using a ventilator for an extended period, the diaphragm is initially weak, and a person may only breathe with the pulse generator for a short period of time. A person will need time to re-strengthen their diaphragm to increase the amount of ventilator-free time. Many people have successfully progressed to full-time use of the diaphragm pacing system, and although they may no longer need the ventilator, they do need to maintain a tracheostomy.

Synapse Biomedical continues to seek FDA approval for additional indications for the NeuRx DPS[™] technology beyond SCI. In October 2009, Synapse filed for approval with the FDA to treat ALS, also known as Lou Gehrig's disease. ▲

*Humanitarian Use Device:
Authorized by Federal Law for use in the treatment of respiratory insufficiency for high-level spinal cord injured patients. The effectiveness of this device for this use has not been demonstrated. Caution: Federal law (USA) restricts this device to sale by or on the order of a physician. A brief statement of intended use, contraindications, warnings, precautions and adverse events can be found at: www.synapsebiomedical.com/fdaapproval/IntendedUse.shtml.*

MORE on www.ventusers.org

For additional information on diaphragmatic pacing systems in past issues of *Ventilator-Assisted Living*, go to www.ventusers.org/edu/valnews/topic1.html, and scroll down to “Diaphragmatic pacing.”

Visit www.synapsebiomedical.com/news for personal accounts.

Trilogy100: Consumer Review

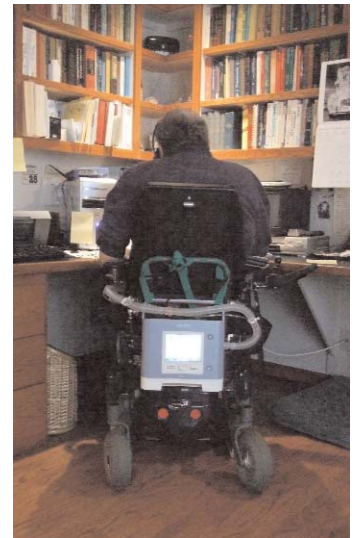
Charlie Elman, Los Altos, California, chartzmarkt@gmail.com, writes,

“I received my Trilogy100 in August 2009. It is different from my PLV®-102b because it is smaller, more portable, and has much better batteries. I use the Trilogy100 about 15 hours a day. It’s mounted on the back of my wheelchair and looks like a backpack. I use the PLV at bedside for about nine hours a day.

“I originally used a PLV®-100 (after a tracheotomy in May 1996 due to respiratory failure), later switching to a PLV®-102b. I investigated all of the portable vents because I was frantically looking for a portable vent to mount on my wheelchair. I was one of the first to get the Trilogy100 in my area, thanks to the advocacy of my respiratory therapist. I’m on Medicare, with United Health Care as my secondary insurance carrier. I did not have any problem getting it covered.

“The Trilogy100’s operation is a little bit different from a user’s standpoint. Instead of delivering a constant amount of air, it monitors the volume and adjusts it so that the user gets the correct tidal volume when averaged over time. Another plus is the alarm – it’s not nearly as annoying as the PLVs. It does tweedle (my term!) with different problems, but the alarm resets itself after a short while. The only downside is that it clicks on every breath. This is very annoying to me.

“As an electrical engineer, I have measured the power consumption of the PLV and think the Trilogy is very similar. I have a voltage converter mounted on my wheelchair which changes the voltage from the wheelchair (24V) to the voltage required by the Trilogy (12V). This converter handles up to 2 amps. I believe the Trilogy uses about one amp. Considering everything, I’m really glad I have the Trilogy100.” ▲



The Trilogy100 mounted on Elman’s wheelchair.

Air Travel: Vent Sticker Update

Ventilator users continue to report challenges over the “sticker” issue in flying with their ventilators. (See *Ventilator-Assisted Living*, Summer, 2009, p. 2, www.ventusers.org/edu/valnews/VAL_23-2sum09pAll.pdf) Vent users may be required by the airlines to produce evidence of the RTCA/DO-160F certification and to comply with other airline requirements for traveling with medical devices.

Frontier Airlines recently denied a flight to a vent user with an LP6+. The LP6+ was discontinued several years ago, and Covidien Ltd. (the company that purchased manufacturer Puritan Bennett) does not plan to pursue stickers for it. However, Covidien is trying to expedite the process of obtaining stickers for the Puritan Bennett 540 ventilator. www.puritanbennett.com

Trilogy100 ventilator from Philips Respironics has been certified for use aboard commercial airlines taking off or landing within the United States. Go to www.philips.com/trilogy100.

ResMed has successfully completed testing for many of its respiratory assist devices. The list has been posted on www.ventusers.org in the “Advocacy” section. ▲

Volunteers are needed to call the airlines

at the numbers posted on www.ventusers.org/net/AirCarriersPolicies.html to obtain their list of approved vents. United, Delta and American have been contacted.

All information gathered will be posted on www.ventusers.org.

If you want to help, email info@ventusers.org.

From Around the Network

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

New Products



Swift™ FX

Mirage™ SoftGel nasal mask from ResMed Corp. features a unique DoubleGel™ cushion. The clear gel layer gently conforms to individual facial contours, making it easy and quick to fit. The vents on the mask quietly direct air away from the individual.

www.resmed.com



Mirage™ SoftGel

Swift™ FX nasal pillows system from ResMed Corp. features a minimal design and flexible tubing that allow users to sleep on their side or back and move around without disturbing the fit. www.resmed.com

EasyFit™ nasal and full face masks are new from DeVilbiss Healthcare. www.devilbisshealthcare.com

Vivo™ 50 is a new multi-mode ventilator from BREAS with an internal battery that lasts up to four hours. Available only in Europe, but awaiting FDA 510K clearance. BREAS is a division of GE Healthcare. www.breas.com



Falco 202

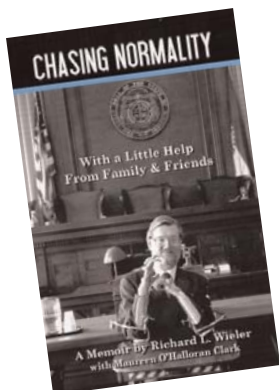
Falco 51 is a new bilevel ventilator with a backup rate from Siare Engineering International Group, S.r.l.

Falco 202 (pictured) is Siare's new lightweight multi-mode ventilator. Both are available only in Europe. www.siare.it

Practice Parameter Update: The care of the patient with amyotrophic lateral sclerosis (an evidence-based review) is a revision of the 1999 *Report of the Quality Standards Subcommittee of the American Academy of Neurology*. It includes information on the treatment of respiratory problems in people with ALS and a respiratory management algorithm.

www.aan.com/practice/guideline/index.cfm?

[fuseaction=home.welcome&keywords=ALS&Submit=Search+Guidelines](http://www.aan.com/practice/guideline/index.cfm?fuseaction=home.welcome&keywords=ALS&Submit=Search+Guidelines)



Chasing Normality, a memoir by Richard L. Wieler, is subtitled *With a Little Help from Family and Friends*. Wieler recounts his life, interrupted by polio in 1955, from a Nebraska farm kid to an attorney in the Missouri Attorney General's office, often arguing cases before the Missouri Supreme Court. A self-described quadriplegic, Wieler has used many forms of ventilation over the years beginning with an iron lung. Today he has a tracheostomy and a feeding tube. He recently learned to use a sip and puff wheelchair and a voice-activated computer (richardwieler@yahoo.com). His book can be purchased through www.chasingnormality.com. ▲

CALENDAR

FEBRUARY 26 -27.

"Towards a Brighter Future." University of Sydney, Australia.

Hosted by the Duchenne Foundation for Boys with Duchenne Muscular Dystrophy and the Institute for Neuroscience and Muscle Research.
Contact Deborah Robins, deborah.robins@duchennefoundation.org.au;
www.towardsabrighterfuture.org.au

MARCH 27-APRIL 2.

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.vaccamp.com.

APRIL 29-MAY 1.

"A Breath of Fresh Air," Canadian Respiratory Conference.

World Trade Convention Centre, Halifax, Nova Scotia, Canada.
www.lung.ca/cts

MAY 13-15.

FOCUS on Respiratory Care and Sleep Medicine, 10th Annual Conference. Disney's Coronado Springs Resort, Orlando, Florida.

www.foocus.com

IVUN invites you to promote your meeting in future issues of *Ventilator-Assisted Living* and on www.ventusers.org.

Send the details to info@ventusers.org.

Join IVUN and receive Ventilator-Assisted Living, IVUN's bi-monthly newsletter

(February, April, June, August, October, December).
The eight-page newsletter will be sent electronically. (IVUN Members without email access may request print copies by contacting IVUN). Members will also receive an electronic *IVUN Membership Memo* in alternate months. To become a Member, complete this form. *Memberships are 100 percent tax-deductible.*

\$30 Subscriber – Bi-monthly *Ventilator-Assisted Living* and *IVUN Membership Memo* (both delivered electronically).

Yes, I want post-polio news, too.

\$55 Subscriber Plus – *Ventilator-Assisted Living* (bi-monthly; electronic) AND *Post-Polio Health* (quarterly; print)

\$100 Contributor ALL the benefits of Subscriber Plus AND *Resource Directory for Ventilator-Assisted Living* and *Post-Polio Directory*; discounts on special publications and meetings sponsored by IVUN

\$150 Sustainer ALL the benefits of Contributor AND one additional complimentary gift membership to:

- Person of your choice (include name and address) or
- Person who has expressed financial need to IVUN.

Yes, I want to support IVUN's mission of education, research, advocacy and networking and its comprehensive www.ventusers.org.

Membership at the following levels includes ALL benefits PLUS special recognition in IVUN publications:

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- \$500 Silver** **\$1,000 Gold** **\$5,000 Platinum**
- \$10,000 Gini Laurie Advocate**

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4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA,
314-534-0475, 314-534-5070 fax

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RESMED 800-424-0737, www.resmed.com

ResMed Corporation is a leading developer and manufacturer of products for the treatment and management of acute and chronic respiratory conditions for both adults and children. ResMed is committed to developing innovative and effective ventilation solutions, including masks and accessories, to offer assistance to health personnel and improve the quality of life of patients around the world.

Meet Our Supporters ...

 **COVIDIEN** www.covidien.com/pb540

At only 9.9 lbs., Covidien's new Puritan Bennett 540™ portable ventilator is a weight off your mind. The real-time battery life indicator shows how much time you have until you need to recharge (up to 11 hours* - depending on settings and other factors).

* Fully charged battery at room temperature, set to Vt=200 ml (± 5ml), PIP=10 cmH2O (±2 cm H2O), Rtot=15 bpm. Level adjustments, environmental conditions and physiological characteristics of the patient affect battery life.

DALE

≡ Patient Care Incorporated™ 800-343-3980, www.dalemed.com

Dale Medical Products, Inc.'s Dale® Tracheostomy Tube Holders have always provided the quality you demand for maximum security, patient comfort and ease of use. With Dale® the frustrations associated with twill ties and other holders are eliminated while minimizing secondary complications. The Dale® Family of Tracheostomy Tube Holders includes the Dale® 240 Blue™, which fits most; the Dale® 241 PediStars™ which fits up to an 18" neck; and the Dale® 242 PediDucks™ which fits up to a 9" neck. *FREE evaluation SAMPLE available upon request.*

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 the introduction of the new BiPAP AVAPS noninvasive homecare ventilator. Released the week of February 15th, the ventilator automatically delivers optimal therapy even as patient needs change. For more information, check out <http://bipapavaps.respironics.com>



BiPAP AVAPS

Meet Our Volume 24, Number 1 Supporter ... See page 4.



Synapse Biomedical Inc. a neurostimulation company, markets the NeuRx Diaphragm Pacing System (DPS)™. The NeuRx DPS™ is designed for laparoscopic implantation to address respiratory insufficiency or chronic ventilator dependency for high spinal cord injury. The system has CE mark approval for treating ALS (Lou Gehrig's disease) in select countries outside the US. Customer Service: 440-774-2488 x137, www.synapsebiomedical.com/products/patientInfo.shtml

How to contact IVUN ... International Ventilator Users Network (IVUN), An affiliate of Post-Polio Health International (PHI)
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