

## Young Vent User Is a Happy Camper

**E**lise Glore is the only child out of 400 in her school in southeastern Louisiana with a trach. So she's really looking forward to returning to Camp Pelican again this year, where trachs are not that unusual.

Camp Pelican is a week-long overnight resident camp for children ages 5 to 15 with pulmonary disorders and serves more than 100 children each year with cystic fibrosis, with severe and chronic asthma, and those who have had tracheotomies and are ventilator-assisted. The camp is a joint venture between the Louisiana Lions Camp and the Louisiana Pulmonary Disease Camp, a nonprofit organization founded in 1976 by a group of health care professionals to provide children with chronic and debilitating lung diseases with recreational and educational opportunities.

Eight-year-old Elise was born with congenital central hypoventilation syndrome (CCHS), a multisystem disorder of the central nervous system where the automatic control of breathing is absent or impaired. Elise breathes on her own during the day, and a nurse accompanies her to her second grade class to assist with suctioning. At night, she uses a Trilogy 100 ventilator, having just transferred from an LTV®950 ventilator.

"Elise absolutely loves camp," says her mother Samantha Glore. "She talks about it all the time and can't wait to get back. It was hard for us to let her go, but Camp Pelican is very thorough in its evaluations and leaves no stone unturned. It gives her a chance to feel 'normal,' and to be away from us constantly asking her if she's OK."

A wide variety of activities including swimming, sports, arts and crafts and special events entertain and educate campers. Staffed by a volunteer force of professionals including physicians,



*Elise enjoying swimming pool.*

nurses, respiratory therapists and educators, they also provide extensive medical and pulmonary care.

"Camp Pelican is a special place for campers and staff. Many of us return year after year because we know how much it means to our campers and also what it means to each of us," says assistant director Cathy Allain.

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*Elise Glore*

## From Around the Network

Judith R. Fischer, MSLS, IVUN Information Specialist, [info@ventusers.org](mailto:info@ventusers.org)

*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 ...  
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## New Products

**Swift™ FX Bella** nasal pillows from ResMed offers female vent users more options for their hairstyles with Bella loops that fit around the ears. (The Bella loops are also available for Swift™ FX for Her.) The Bella's fit range is customized for women. The rotating elbow and flexible tubing, as well as the soft cushion of the pillows, provide a stable and comfortable fit and seal.

[www.resmed.com/us/products/swift\\_fx\\_bella](http://www.resmed.com/us/products/swift_fx_bella)

**SleepWeaver® Feather Weight™ Tube** from Circadiance, the manufacturers of the cloth SleepWeaver™ nasal mask, is lightweight and flexible. It reduces the pull of the hose that could break the seal of the mask. It can be used with a 22-millimeter connection.

[www.circadiance.com](http://www.circadiance.com)

## Journal Articles

Decision-making about assisted ventilation is the topic of "Formal ventilation patient education for ALS predicts real-life choices" from a group of Canadian physicians and respiratory therapists led by Doug McKim, MD, FCCP, Ottawa Hospital Rehabilitation Centre.

In one single hands-on education session, people with ALS and their families and caregivers were presented information to guide them in making an informed choice about using assisted ventilation, either noninvasively or invasively. They were able to handle different types of ventilators, masks and trach tubes, and learn about methods of clearing secretions and assisted coughing.

Questionnaires were administered before, during, immediately after and one month after the session to assess the individual's knowledge of assisted ventilation and self-reported emotional well-being. The choices of assisted ventilation accurately predicted the actual decision made by 76 percent of the individuals. The education session reduced the uncertainty and anxiety of the individuals with ALS, as well as their caregivers, about making the assisted ventilation decision.

*Amyotrophic Lateral Sclerosis*, 2012; 13:59-65.

[www.informahealthcare.com](http://www.informahealthcare.com)

**"Monitoring of noninvasive ventilation by built-in software of home bilevel ventilators: A bench study"** reports on the testing of seven popularly used bilevel ventilators by a group of French and Swiss pulmonologists and respiratory therapists under Jean-Louis Pepin, MD, PhD; Philippe Jolliet, MD; and Jean-Paul Janssens, MD.

The study concluded that "Physicians monitoring patients who use home ventilation must be aware of differences in the estimation of leaks and V<sub>T</sub> [tidal volume] by ventilator software. Also, leaks are reported in different ways according to the device used." Physicians need to be aware that the reporting of leaks is not standardized, and there is considerable variability that can produce misleading results. *CHEST*, 2012; 141(2):469-476. [www.chestnet.org](http://www.chestnet.org) ▲

## Vent Alarms and Product Safety

Recent news reports of deaths in the USA related to ventilator alarms have led ventilator users to caution their caregivers about listening for and responding quickly to ventilator alarms. An analysis of the FDA's adverse events' reports showed that problems with ventilator alarms were more frequently related to human error rather than a malfunction of the ventilator.

The vent alarms may be improperly set or set to sound too low for a caregiver in another room to hear, and caregivers may have silenced the alarms.

In hospitals, "alarm fatigue" can cause nurses to become desensitized to audible alarms, many of which turn out to be false alarms, and thus tune them out.

Last year, the FDA issued an alert to hospitals and nursing facilities, warning that ventilator alarms are going unheard or unattended. The commission that accredits hospitals is revisiting a requirement that alarm safety be a patient safety goal in order for a hospital to be accredited.

Vent user Sandy Stuban suggested to the agency providing two of her caregivers that emphasis on

alarm safety be incorporated into their continuing education program for all staff that cares for home ventilator users.

To be proactive on ventilator safety, vent users and health professionals can use the FDA's website:

**MedWatch** – to voluntarily report a serious adverse event, product quality problem, product use error, or "therapeutic nequivalence/failure" suspected of being associated with the use of an FDA-regulated medical device. [www.fda.gov/Safety/MedWatch/HowToReport/default.htm](http://www.fda.gov/Safety/MedWatch/HowToReport/default.htm)

**MAUDE (Manufacturer and User Facility Device Experience)** – to check a database of adverse events caused by medical devices. It includes voluntary reports since June 1993, user facility reports

since 1991, distributor reports since 1993, and manufacturer reports since August 1996. [www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfmaude/search.cfm](http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfmaude/search.cfm)

**Medical Device Recalls** – to learn about specific vent recalls, go to [www.fda.gov/MedicalDevices/Safety/default.htm](http://www.fda.gov/MedicalDevices/Safety/default.htm).

### Be Proactive

Vent users can also be proactive by taking care of their vents and following the instructions in the vent user manual. This includes cleaning the outside of the vent and the tubing, changing the inlet filters, making sure the batteries are operating and fully charged, the humidifier water is clean and other appropriate preventive maintenance for their particular vent. ▲

### HOME MECHANICAL VENTILATOR USERS:

#### Tell Us What You Think About Flying!

IVUN is conducting a survey, available in [English](#), [Dutch](#), [French](#) and [Spanish](#), that explores the experiences of flying as a ventilator user.

We ask you to complete it even if you think you will never fly. There are questions for ventilator users as well as for parents, who are invited to share their experiences when traveling with their child.

Please go online at [www.ventusers.org/adv/issues.html](http://www.ventusers.org/adv/issues.html) and complete the survey by **March 5, 2012**.

IVUN is surveying the manufacturers of portable/home use ventilators and numerous airlines, too. What will we do with this information?

IVUN will post a report and a summary of its findings from all three groups on [www.ventusers.org](http://www.ventusers.org) and on a poster presented at the joint meeting of the 13th International Conference on Home Mechanical Ventilation and the 4th European Respiratory Care Association Congress March 15-17 in Barcelona, Spain.

*Help us include as many users of home mechanical ventilation as possible. Ask your colleagues and friends to provide their experiences and opinions at [www.ventusers.org/adv/issues.html](http://www.ventusers.org/adv/issues.html).*

# Traumatic to Be Conscious during Ventilator Treatment

**M**ore and more people being cared for on ventilators are conscious during the treatment, but what is it like to be fully conscious without being able to communicate with the world around you? A thesis from the Sahlgrenska Academy has lifted the lid on a world of panic, breathlessness and unheard pain.

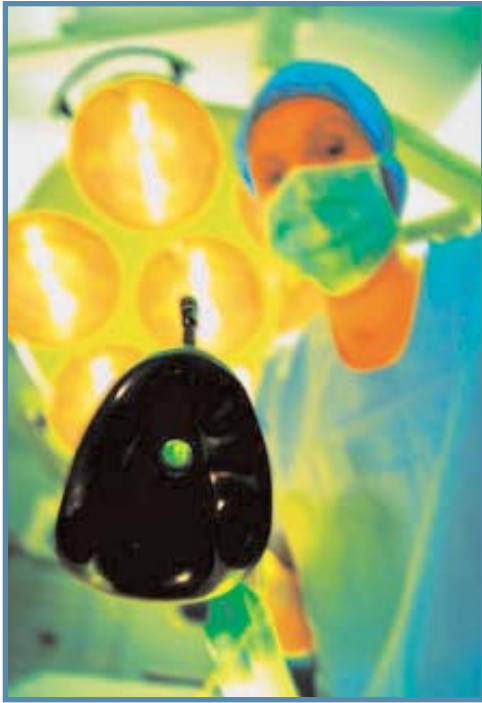


Photo Credit: University of Gothenburg

It has been far more common since the beginning of the 21st century for patients to be conscious during mechanical ventilation when cared for in an intensive care unit (ICU). This new approach has resulted in medical advantages as well as shorter time on mechanical ventilation and in the ICU.

But lying fully conscious on a mechanical ventilator is a traumatic experience, reveals a thesis from Veronika Karlsson, a doctoral student at the University of Gothenburg's Sahlgrenska Academy, where she interviewed patients and relatives during and after ventilator treatment. She is also

an intensive care nurse at Skaraborg Hospital in Skövde.

“The studies show that many people who are conscious while ventilator treatment experience feelings of panic,” says Karlsson. “Many describe being breathless, and pain from the tube and probes makes it hard for them to relax and sleep.

“After breathing, the most difficult thing was not being able to talk. All of the patients who were interviewed communicated by nodding or shaking their head, but also developed individual communication patterns using facial expressions, looks and body language to express their suffering.”

## Attentive Caregivers Important

The 14 patients who were interviewed were in ventilator treatment between two and 88 days. Regardless of the duration they all stated that they felt helpless and powerless in relation to the ventilator treatment, and completely dependent on the caregivers' ability and willingness to help them.

## New Set of Demands

However, the ventilator treatment was perceived as less unpleasant if caregivers were attentive in their communication and actively “there for” patients, in other words concentrated all of their attention on the mechanical ventilator user when they needed help.

“Having patients conscious during ventilator treatment brings a new set of demands in terms of the care given and the environment that the patients are in,” says Karlsson. “For example, it's very important that nurses are attentive and present, use a friendly tone of voice, have the ability to read patients' facial expressions and body language and adopt a warm approach. When it comes down to it, they need to be able to get across to patients that they are in it together.”

## Most Preferred to Be Conscious

The negative experiences were still perceived as such a week after the patients had left intensive care. However, when subsequently asked

whether they would have chosen to be conscious or sedated, eight out of 12 patients said that, in spite of everything, they would have preferred to have been conscious.

“My interpretation is that those who chose consciousness had nurses who were standing by,” says Karlsson.

### **Ambivalence among Relatives**

The patients’ relatives also showed a degree of ambivalence towards sedation where they could see that the patients were suffering. Furthermore, many did not have the opportunity to talk to the caregiver in private without the patient being able to hear.

“The results show that it is difficult and painful to be cared for while conscious during ventilator treatment, but that by actively ‘being there’ for patients, nurses can alleviate the situation and help patients to get through it,” says Karlsson. ▲

**Source: The Sahlgrenska Academy, University of Gothenburg, Sweden.**  
**Link to thesis:**  
<http://hdl.handle.net/2077/27823>

## **Help Us Find Solutions**

**IVUN is looking for researchers worldwide, although the proposals must be in English, to submit requests for its \$25,000 grant to be awarded in December 2012 for research done in 2013.**

IVUN funds projects that will improve the lives of users of home mechanical ventilation regardless of their diagnosis. IVUN will provide funds for pilot studies intended to generate data to be used in obtaining larger grants and requests that supplement important research in progress.

We encourage you, our Members, to help spread the word about this opportunity to your circles of colleagues and friends. Or, you may send us names of researchers and we will send the “Call” directly to them.

Go to [www.ventusers.org/res/](http://www.ventusers.org/res/). The online [“Call for Proposals”](#) includes detailed criteria and submission requirements. The reports from previous recipients are online at [“Prior Awards.”](#)

### **Deadlines:**

Postmark deadline for Phase 1: Friday, May 4, 2012

Invitation to submit for Phase 2: Friday, July 13, 2012

Postmark deadline for Phase 2: Friday, October 5, 2012

Final decision: Friday, December 14, 2012

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“As staff members, I think we benefit as much or more as the campers because we learn so much from them each day.”

The oldest of four daughters, Elise is very polite and well-mannered and handles her trach well, says her mother. “She’s a Girl Scout, she dances and does gymnastics. She doesn’t think she has any limitations and wants to do it all.

“She gives us a lot of laughs and joy.” ▲



Elise Glore

## 2012 Camps for Ventilator-Assisted Kids

**MARCH 10-16. Ventilator-Assisted Children’s Center (VACC) Camp,** Miami, Florida. Contact Bela Florentin, VACC, Miami Children’s Hospital, 305-662-8222, [bela.florentin@mch.com](mailto:bela.florentin@mch.com), [www.vaccamp.com](http://www.vaccamp.com).

**MAY 30-JUNE 3. Light the Way Camp,** Children’s Harbor Lodge, Alexander City, Alabama. Contact Kara Bishop, 205-370-9605, [karabishop@ventkidsofalabama.com](mailto:karabishop@ventkidsofalabama.com), [www.ventkidsofalabama.com](http://www.ventkidsofalabama.com).

**JUNE 3-9. Camp Pelican,** Lion’s Camp, Leesville, Louisiana. Contact Cathy Allain, 504-495-6346, [cathyallain@cox.net](mailto:cathyallain@cox.net), [www.camppelican.org](http://www.camppelican.org).

**JUNE 3-8. Trail’s Edge Camp,** Camp Fowler, Mayville, Michigan. Contact Mary Buschell, RRT, Camp Director, 231-645-0453, [mkbuschell@yahoo.com](mailto:mkbuschell@yahoo.com), [www.med.umich.edu/mott/trailsedge/index.html](http://www.med.umich.edu/mott/trailsedge/index.html).

**JUNE 6-10. Camp Inspiration,** Double H Hole in the Woods Ranch, Lake Luzerne, New York. Contact Tara Bogucki, Admissions Coordinator, 518-696-5676, ext. 222, [tbogucki@doublehranch.org](mailto:tbogucki@doublehranch.org), [www.doublehranch.org](http://www.doublehranch.org). *Admissions deadline: April 15* (later admissions accepted if there are vacancies).

**JUNE 10-15. Fresh Air Camp,** Camp Cheerful, Strongsville, Ohio. Contact Kathy Whitford, MSN, PNP, Cleveland Clinic Foundation, 216-448-6257, [whitfok@ccf.org](mailto:whitfok@ccf.org), [www.freshaircamp.org](http://www.freshaircamp.org).

**JUNE 24-28. CHAMP Camp,** Bradford Woods, Martinsville, Indiana. Contact Jennifer Kobylarz, 317-679-1860, [jenniferk@champcamp.org](mailto:jenniferk@champcamp.org), [www.champcamp.org](http://www.champcamp.org).

**JUNE 24-28. PA Vent Camp,** Camp Victory, Millville, Pennsylvania. Contact Robin Kingston, MSN, CRNP, 717-531-5337, [rkingston@hmc.psu.edu](mailto:rkingston@hmc.psu.edu).

## CONFERENCE CALENDAR THROUGH JUNE 2012

**MARCH 15-17. International Conference on Home Mechanical Ventilation**, Barcelona, Spain. Journées Internationales de Ventilation à Domicile (JIVD) and European Respiratory Care Association (ERCA). [www.jivd-france.com](http://www.jivd-france.com)

**APRIL 10-12. Medtrade Spring: Connecting the HME Industry.** Sands Expo and Convention Center, Las Vegas, Nevada. [www.medtrade.com/medtrade-spring/](http://www.medtrade.com/medtrade-spring/)

**APRIL 13-15. Parent Project Muscular Dystrophy West Coast Connect Meeting.** San Diego Marriott Mission Valley, San Diego, California. [www.parentprojectmd.org](http://www.parentprojectmd.org)

**APRIL 19-21. International Conference on Mechanical Ventilation.** Hotel NH Málaga, Málaga, Spain. [www.mechanicalventilationconference.com](http://www.mechanicalventilationconference.com)

**APRIL 26-28. "A Breath of Fresh Air," Canadian Respiratory Conference.** Westin Bayshore Hotel, Vancouver, British Columbia, Canada. [www.lung.ca/cts](http://www.lung.ca/cts)

**MAY 10-12. Spring FOCUS on Respiratory Care, Sleep Medicine, and Critical Care Nursing Conference.** Gaylord Opryland Hotel, Nashville, Tennessee. [www.foocus.com](http://www.foocus.com)

**MAY 18-23. American Thoracic Society International Conference.** San Francisco, California. [www.thoracic.org](http://www.thoracic.org)

**JUNE 21-24. FSMA Family and Professionals Annual Conference.** Bloomington, Minnesota. [www.fsma.org](http://www.fsma.org)

**JUNE 28-JULY 1. Parent Project Muscular Dystrophy 2012 Connect Conference.** Harbor Beach Marriott, Ft. Lauderdale, Florida. [www.parentprojectmd.org](http://www.parentprojectmd.org)

## Join IVUN!

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The eight-page newsletter will be sent electronically in February, April, June, August, October and December. (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.*

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**Yes, I want to support IVUN's mission of education, research, advocacy and networking and its comprehensive website, [www.ventusers.org](http://www.ventusers.org).**

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