Ventilator-Assisted Living
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www.ventusers.org

National Program in Chile Improves Quality of Life for Vent-Assisted Children

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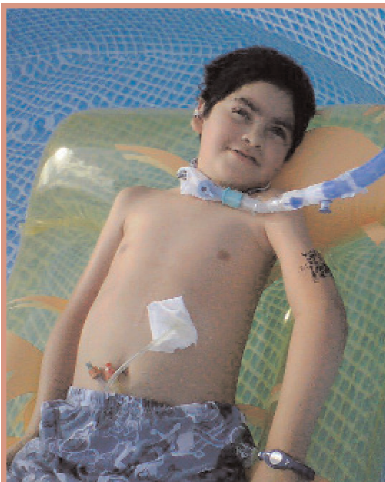
Lucía Gutiérrez will never forget November 13, 2010. Her seven-year-old son, Diego, and his grandmother were struck by a vehicle that was speeding. The grandmother died and Diego remained tetraplegic. At that moment, Lucía and Diego's lives changed dramatically.

Initially, the medical team said Diego was brain dead, although Lucía believed that Diego would recover over time, and she waited patiently while he was hospitalized six months in the intensive care unit of the Hospital Sótero del Río in Santiago, Chile. Here, she would become familiar with a critical unit's care and with a world completely strange and different from her reality until that moment.



Diego Gutiérrez enjoys a swim. He is in the process of being weaned from his feeding tube and currently eats most foods by mouth.

After several weeks, Diego opened his eyes and began to awaken. It was then that Lucía realized that there was hope and painfully understood that her child would no longer lead the life he had before the accident. He would require technological and physical assistance.

They had passed a great test, her son had survived. However, now they faced a difficult situation: Diego needed permanent special care. He could not go home, and the family was separated most of the time. His parents had to take turns staying with Diego and taking care of their other children.

Lucía heard about the National Invasive Mechanical Ventilation Program, a national initiative that provides home mechanical ventilation, and professional and technical assistance to children with similar conditions in their homes.

In the early 2000s, a small number of children were reported to be on prolonged mechanical ventilation, principally due to neuromuscular causes. Their experiences became the basis for a solid public policy to support these children, who were until then systematically relegated to second place in public and private health care.

Thanks to these successful experiences and based on similar programs in developed countries, in 2006 the National Noninvasive Ventilation Program in Primary Health Care was initiated. Its objective was to systematically deal with the need for home ventilatory support in children and adolescents with nocturnal hypoventilation resulting from various pathologies of the respiratory pump, airway or lung parenchyma. It integrates different levels of care in the health

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IVUN
International Ventilator Users Network
An affiliate of Post-Polio Health International (PHI)

Networking

From Around the Network

Judith R. Fischer, MSLS, IVUN Information Specialist, 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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Product News

Global Ventilation Systems and Accessories Market 2011-2015 from TechNavio is an in-depth analysis of the industry that covers the American, European and Asian-Pacific ventilator equipment markets. Its analysts forecast growth at about 7.9 percent, as a result of increased use of ventilators for multiple purposes, in addition to a gradual shift in the ventilator replacement market. The report is licensed, beginning at $1,500 for a single user.

www.technavio.com/content/global-ventilation-systems-and-accessories-market-2011-2015

More on Flu Vaccine

Recently the American Academy of Pediatrics, the Centers for Disease Control and Prevention, Families Fighting Flu and Family Voices held a live chat to discuss the need for influenza vaccine for children with underlying neurologic disorders. This chat resulted from an article, "Neurologic Disorders Among Pediatric Deaths Associated With the 2009 Pandemic Influenza" in *Pediatrics*.

http://pediatrics.aappublications.org/content/130/3/390.abstract

Many of these children have additional risk factors for complications, such as pulmonary disorders that impair muscle or lung function that can lead to more problems with coughing, swallowing and/or clearing secretions from the airways. The article concludes, "Because of the potential for severe outcomes, children with underlying neurologic disorders should receive influenza vaccine, and be treated early and aggressively if they develop influenza-like illness."

The three strains in the vaccines for the 2012-2013 season are: H1N1 virus (same as used in the 2011-2012 vaccine), H3N2 vaccine and B vaccine. The vaccine manufacturers are licensed by the FDA to produce and distribute the vaccines in the USA. The following vaccines are available:

Fluria® (CSL)	for ages 5 years and older
Fluarix® (GlaxoSmithKline)	ages 3 years and older
FluLaval® (ID Biomedical)	ages 18 years and older
FluMist® (MedImmune)	ages 2-49
Fluvirin® (Novartis)	ages 4 years and older
Fluzone® (Sanofi Pasteur)	ages 6 months and older
Fluzone® High-Dose (Sanofi Pasteur)	ages 65 and older
Fluzone® Intradermal (Sanofi Pasteur)	ages 18-64

Support H.R. 6490

H.R. 6490, recently introduced by Rep. Tom Price (R-Georgia), himself an orthopedic surgeon, is an alternative to the competitive bidding process for home medical equipment (including bilevel ventilators). Also known as the Medicare DMEPOS (Durable Medical

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Transitioning to the Trilogy100:

IVUN Educational Conference Call

Joan L. Headley, Executive Director, Post-Polio Health International,
St. Louis, Missouri, director@post-polio.org

The PLV-100, 102 volume ventilator was developed by LIFECARE International in the mid-1980s. The company was purchased in 1996 by Respironics, Inc., which is now part of Philips, the "sense and simplicity" company. With the development of new equipment, the company announced in November 2009 the "manufacturing discontinuation of the PLV-100, PLV-102b and the PLV-102 portable ventilators as of 12/31/2009." The notice states that they will make all reasonable efforts to provide service until 12/31/2014.

With this in mind, IVUN scheduled a series of educational conference calls to provide information from manufacturers and health care professionals. The first call in September was with Cheryl Needham, Philips Respironics, who spoke about switching to the Trilogy, a multi-mode ventilator manufactured by Philips.

Needham compared the Trilogy to the PLV noting these new key features not available on the PLVs:

- Both passive (single connection and the user passively exhales) and active (multiple connection and the user has to "actively" move the valve to get air) circuit configurations.
- Bias flow of 10LPM during expiration. This means that air is constantly in the tubing and taking a breath could be easier. If you don't take a deep breath to trigger the machine, you can tap into this air. The bias flow feature will feel really different to many ventilator users.
- Internal PEEP (positive end expiratory pressure), so there are no accessory parts; PEEP can be turned on or off.
- Leak compensation (makes sure the volume set is the amount received) and triggering available with passive circuit (not active).
- Auto-Trak sensitivity automatically adjusts triggering and cycling to fit the user's breathing pattern (only available with the passive circuit).
- AVAPS (average volume assured pressure support) is available. When using volume it may take more or less pressure at times to maintain the needed volume. When using pressure, the volume may change to maintain the wanted pressure. AVAPS makes these adjustments automatically.
- It has a sigh (periodic hyperinflation) just like the PLV-102.

Trilogy, which can be used invasively or noninvasively, is lighter (11 pounds) and can act as a volume, pressure or bi-level device It has several modes, is blower driven, has an oxygen valve connector, has a three-hour internal battery and a three-hour detachable one, and is FAA cleared for flying. It can also be attached to an external battery if required.

Individuals when transitioning should take the following into consideration.

- Leak compensation (passive circuit only) and bias flow will make the delivery of air "feel different" than the PLV's.
- Current settings may need to be modified, especially if switching to a passive circuit.
- Follow any transition protocol established by physician and DME. May not be able to set exact settings

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Philips Respironics' Trilogy100

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on both devices; be prepared to spend time making adjustments. So, obtain necessary approval from physician to adjust settings as needed.

- Be patient. Everyone will respond differently.

Needham's advice was to start with the setup that most closely resembles your current situation.

Since the PLVs had an active circuit, users should start with the active circuit configuration.

It is suggested that users should start with flow triggering and not Auto-Trak.

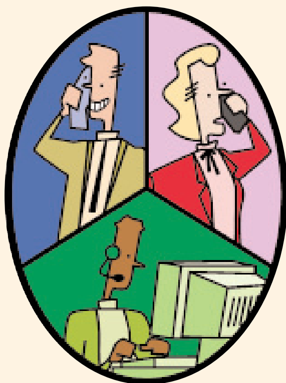
One of the most helpful settings when trying to make the transition from the PLV, is the wave form pattern.

The ramp gives a breath and then slowly ramps it down on exhalation. The square wave brings in the breath and stays there for a while and then allows the air to decrease. The PLV has what is called a decelerating wave form and it is closest to the ramp form on the Trilogy. If the breath of the Trilogy "feels different," try using the ramp form.

Additional friendly features of the Trilogy include an audio pause button to silence alarms for one minute, a button to black out the screen at night, a keypad lock so settings aren't inadvertently changed and a dual prescription feature that allows for saving two setting preferences so one can switch from day to night settings easily. The device also has a removable air path in case of a communicable disease – it can be switched out. There are some settable alarms that can be disabled.

Needham finished with an example of transition steps to switch from the PLV-100, first using an active circuit and then a passive one. Details of each step are outlined in a PowerPoint presentation, which is available as a pdf at www.ventusers.org/edu/PhilipsIVUNwebinar.pdf.

In our next issue, we will summarize the October conference call with Cyndy Miller, RRT, Respiratory & Monitoring Solutions, Covidien, Costa Mesa Facility. ▲



Do you have suggestions for other topics? If so, please send them to info@ventusers.org.

Upcoming Educational Conference Calls

IVUN's series of hour-long educational sessions via telephone are continuing. The call is free, but reservations are required, and available space will be first-come, first-served. To reserve your place to participate in the call, send an email to info@ventusers.org or call 314-534-0475.

Wednesday, November 28, 2012 at 1:00 CT
More Options for Switching from Older Vents with an experienced respiratory therapist from the Respiratory Technologies – Ventilation division of CareFusion.

Third week in January 2013
Tell Me about a Trach Before I Need One with Linda K. Dean, RRT, Educational Consultant and Clinical Specialist, Passy-Muir, Inc.

Third week in February 2013
How Do I Know When I Need a Trach? With professional to be announced. ▲

Ask The Experts

QUESTION: *What and when is the best use of pulse oximetry for someone like me with a neuromuscular disorder? I am concerned because I have a new device, and the number fluctuates up and down. This happened in the hospital too, and I was told the device was working properly.*

ANSWER: **Jennifer Armstrong, RN, MSN/MHA, Clinical Nurse Supervisor, Division of Neuromuscular Medicine, Northwestern Medical Faculty Foundation, Chicago, Illinois, JArmstrong@nmff.org**

When discussing pulse oximetry in neuromuscular disease, one must differentiate between a spontaneous finger pulse oximetry while awake and alert and an overnight pulse oximetry. To check pulse oximetry while awake and alert is to determine the oxygen saturation at that moment in time. In neuromuscular disease, this type of pulse oximetry is usually normal unless there is lung disease or infection, such as pneumonia.

Overnight pulse oximetry is used to determine sleep-related hypoventilation that results when a neuromuscular disorder affects the breathing muscles. An overnight pulse oximeter is used to record the oxygen saturation while sleeping over a period of six to eight hours. Figure 1 is an example of a normal overnight pulse oximetry. Figure 2 is an example of an abnormal pulse oximetry reading showing very pronounced sleep-related hypoventilation. The person in Figure 2 demonstrates the need for corrective action with a BiPAP or non-invasive ventilator during sleep.

To answer the question "what" and "when" is the best use of pulse oximetry: Pulse oximetry will fluctuate during the day according to how clear the lungs are and will react if there is a diseased lung or cardiologic interruption. Otherwise, for most people with neuromuscular disease, a pulse oximeter reading on the finger during the day will be normal (greater than 90 percent oxygen saturation). If the pulse oximetry during the day hours is only around 90 to 91 percent, then an arterial blood gas test is indicated to define further respiratory function.

Abnormal readings should be discussed with the care team. A good airway clearance regimen will help keep the lungs clear and free from infection. If you suspect you have sleep issues, an overnight oximetry test can be ordered by your doctor. ▲

Figure 1.

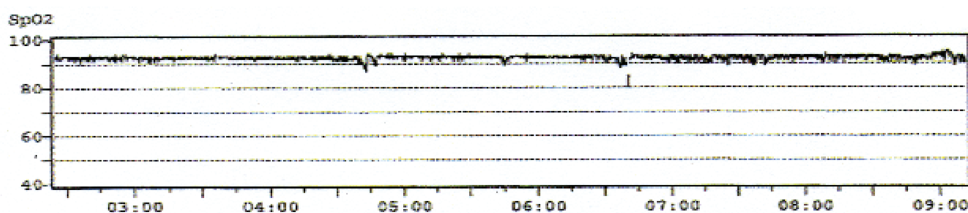
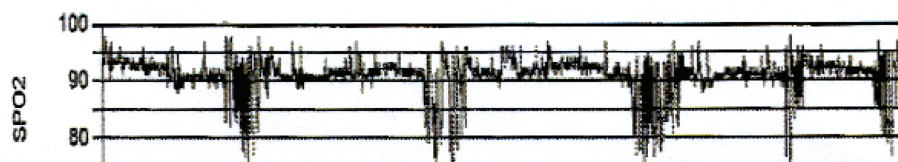


Figure 2.

Condition of Test: Overnight Room Air



Are you a ventilator user or health professional with a question about home mechanical ventilation?

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

National Program in Chile Improves Quality of Life for Vent-Assisted Children

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care network and considers the home and family as the central axis.

The program aimed to improve life expectancy and health-related quality of life, along with lowering costs associated with prolonged mechanical ventilation in patients whose only possible scenario was being hospitalized in critical patient units. This program was made possible by pioneering professionals with the unconditional support of the state and currently, there are 360 patients living at home.

With experience in noninvasive mechanical ventilation, in 2008, the government started a program of home care for patients needing invasive mechanical ventilation, as in Diego's case.

For proper care and patient follow-up, the program has specialized professionals. Physical therapists, nurses and physicians regularly visit patients at home.

The program gave Diego a modern mechanical ventilator, all the necessary supplies and a personal assistant for 12 hours. The other 12 hours are responsibility of the parents who took the commitment and responsibility of caring for Diego, as they were trained in a transient specialized unit in chronic care before returning home.

This program, unprecedented in Latin America, has managed to maintain the unity of hundreds of families seeking a better life, despite dramatic circumstances. Quality of life has been given to children and their families at a lower cost for the state. Many of our children have been able to return to school, some are already attending college, and they have maintained their family and social networks, which was unthinkable prior to the existence of the program.

Today Diego is nine years old and is living at home. He uses a Philips Respironics Trilogy100, a Passy-Muir speaking valve and a Fisher & Paykel MR850 humidifier. A nongovernmental organization sends a teacher to his home to continue his formal education. He goes to the supermarket, to plazas, visits relatives, and he goes to the beach during summer. None of these activities would have been possible without the program.

Please visit our website www.avni.cl for more information. ▲

GUÍA PARA EL USO DE RESPIRADOR EN EL HOGAR

IVUN's *Home Ventilator Guide* has been updated and translated into Spanish. Go to www.ventusers.org/edu/HomeVentGuide.pdf.

En colaboración con los autores del documento original, la Red Internacional de Usuarios de Respiradores Mecánicos (International Ventilator Users Network, IVUN), un afiliado de Salud de Post Polio Internacional (Post-Polio Health International, PHI), el Centro de Recursos para la Parálisis de la Fundación Christopher y Dana Reeve ha creado una traducción al español para aumentar el alcance a usuarios a nivel nacional e internacional.

From Around the Network

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Equipment, Prosthetics, Orthotics, and Supplies) Market Pricing Program Act of 2012, H.R. 6490 calls for a market pricing system through an auction instead of competitive bidding.

The competitive bidding process was designed to cut costs and save money but the process is flawed and could force many small and patient-oriented home health care companies out of the marketplace. The market pricing alternative is endorsed by the American Association of Home Care. If passed, the bill would take effect in July 2013. For a comparison of the two processes, go to www.aahomecare.org. There is also a link to easily enable contacting your congresspersons. ▲

Congratulations to Audrey King, PhD, who was awarded the Queen Elizabeth II Diamond Jubilee Medal by Ontario Lieutenant Governor David C. Onley at a special ceremony in September. The medal honors the Queen for her service to Canada, and also serves to honor significant contributions and achievements by Canadians. King, a psychologist and a ventilator user, played a key role in establishing Ontario's attendant services, supportive housing, outreach services and the Direct Funding program.

Congratulations to Norma M.T. Braun, MD, FCCP, who presented the Margaret Pfrommer Memorial Lecture in Long-term Mechanical Ventilation at the recent annual meeting of the American College of Chest Physicians. Her lecture was entitled "Advocacy for Patients Supported by Home Mechanical Ventilation: Impact on Readmissions and Quality of Life." It illustrated how effectively physicians can partner with their patients for optimal health care.

Join IVUN!

...online at shop.post-polio.org and receive *Ventilator-Assisted Living*.

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.

Annual Memberships are 100 percent tax-deductible.

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