

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

Rodrigo Torres, Respiratory Therapist, National Program of Mechanical Ventilation, Santiago, Chile, hackrod@yahoo.com

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.



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

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.

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

continued, page 6

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

continued from page 1

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

continued from page 2

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. ▲