IVUN News

International Ventilator Users Network
Saint Louis, Missouri USA

Spring 2002 ■ Vol. 16, No. 1

Living with SMA in Hong Kong

Mei Ling Fok (Mlfok@netvigator.com)

At two months of age, Howard was diagnosed with spinal muscular atrophy (SMA) of the severest form. My husband, a medical doctor, and I were told that there was "zero" chance of him surviving past one year because SMA would quickly affect his breathing and ventilation might not be an option due to the poor prognosis. We disagreed. Howard underwent a tracheotomy, and I quit my job as a lawyer and began an odyssey into the unknown.

Ten years and seven months later, Howard is now 5 feet 2 inches tall, chubby, delightful, and the first child using 24-hour ventilation in a special needs school in Hong Kong. He is an extremely clever little boy, excellent with mathematics, and able to understand both English and Chinese. Although there are obvious problems and multiple physical constraints, he is a happy boy and a joy to be around.

I view these ten years and seven months as 3,860 days – one day at a time. Each day is made up of careful monitoring at home.

His bedroom is a mini intensive care unit equipped with ventilator, humidifier, oximeter, oxygen cylinders (big and small), resuscitator ... and his toys. The routine consists of sterilizing ventilation tubing, daily cleaning of stomas for tracheostomy and gastrostomy tubes, turning him every two hours to keep him comfortable, ensuring that the PLV®-100 ventilator is working properly, chest physiotherapy and making sure a common cold does not become pneumonia, constant suctioning because he has no swallowing reflexes, changing and bathing, and persuading him to use his standing frame.

However, those are only the basic medically-related essentials for Howard's care. Equally important is realizing that his life is worth saving and ensuring that his life is worth living. I must consider Howard's quality of life.

The first few years centered around just trying to keep him alive. His muscles were floppy and he was so fragile. I was even afraid to hold him for fear that the tracheostomy tube would dislodge, yet, I had to change his tube every month to stave off infection. I had to learn to resuscitate him in case he became cyanotic. I actually had to do that on several occasions and cardiac arrests (for me) were imminent.

My mind had to be retrained to be more nimble just to be able to cope with the added mental stresses. Many times, I thought of escaping from reality, but I did not have the luxury of any time and just pressed on. Luckily, things became a little easier.

Another blessing was that I was able to get very good househelp. In Hong Kong, it is possible, for about US$500 per month, to hire a domestic worker to help with the housework as well as take care of the children.

The government provides some financial help but there are criteria to meet, e.g., the father must be out of work. There is a formula for the amount of money received based on the size of the family, but it is usually not enough and causes more frustration on the part of the father. There are many situations in which the father is working, but due to the added costs of caring for a child with a severe disability, he cannot make ends meet.

The maximum disability allowance is HK$2600 (US$300) per month for the child. The family must pay for the tubing, maintenance of the machinery, parts, etc., out of their own pockets. The government will take full responsibility when the child is in the hospital, but after he/she

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is discharged, the families are on their own. Some aid is available through charitable organizations.

When Howard became more stable medically, there came the challenges of grappling with a wheelchair adapted to hold the ventilator and secure the tubings. And, after that, there was the problem with his schooling because the education system in Hong Kong was not quite prepared for a medically fragile child using 24-hour mechanical ventilation.

Has it been easy? The answer is clearly no. But it has been very rewarding to see Howard beat the odds and blossom. Although he is not able to move his mouth, lips, or tongue, Howard is able to make different distinctive tones and sounds. When he was very little, I taught him phonics using 26 different tones and sounds that he could make to replace the 26 letters of the alphabet. In this way he could communicate with us by spelling anything that he wanted, e.g., "B-O-O-K" or "T-V." It is not difficult to recognize the sounds, and my homehelper can also communicate with him using this method. Now that he is older, his speech therapist designed a speech software program that enables him to click with his right big toe (the only part of his body he is able to control) on the computer which will then "speak" for him.

He has certainly changed my life in many ways. My encounter with SMA and Howard's total dependency on the ventilator have made me revisit the meaning of life and its associated adversities. Whatever life throws at you, it is still possible to live life meaningfully and happily.

Because of my experience with Howard, I established a charitable organization to help other children and adults with SMA – www.fsma.org.hk. I also successfully lobbied the Hong Kong government to start a centre, the first in Southeast Asia, for the rehabilitation of ventilator-assisted children and to train the parents in the care of their children after discharge from hospital.

The Centre for Ventilator Assisted Children is housed in the Duchess of Kent Children's Hospital. The rehabilitation team consists of a respirologist, neurologist, anaesthetist, occupational therapist, physical therapist, nurses, clinical psychologist, and social workers. (In Hong Kong, there are no respiratory therapists.)

The Centre was approved by the government in mid-1999. It took some time to gear up the centre; the nurses and therapists were sent to the ventilation rehabilitation centres in New Jersey and Toronto for training. Now, there are between 4-6 children, but the Centre hopes to care for 11 children. All must have full rehabilitation potential.

Discharge is complicated by more social problems than medical ones. In Hong Kong, the flats can be very small and renovations are required before a child with wheelchair and ventilator can even enter the flat. Meanwhile, these children can attend the hospital school run by the Red Cross. Plans and discussions are underway to ensure continued education after discharge. ■

2002 CAMPS FOR VENTILATOR-ASSISTED CHILDREN

June 2-7. **TRAIL'S EDGE CAMP,** Mayville, Michigan. Contact Mary Dekeon, RRT, C.S. Mott Children's Hospital, 734-763-2420, mdekeon@med.umich.edu.

June 9-14. **FRESH AIR CAMP,** Hiram House Camp, Moreland Hills, Ohio. Contact Kathy Whitford, CNP, Cleveland Clinic Foundation, 216-721-7159, whitfok@ccf.org, www.freshaircamp.org.

June 23-27. **PENNSYLVANIA VENT CAMP,** Camp Victory, Millville, Pennsylvania. Contact Debra Randler, 877-455-3311, drandler@psu.edu, www.collmed.psu.edu/pedsvent.

June 23-28. **CHAMP CAMP AND CHAMP CAMP ADOLESCENT RETREAT,** Recreation Unlimited, Ashley, Ohio. Contact Nancy McCurdy, 317-415-5530, nmccurdy@champcamp.org, www.champcamp.org.

June 30-July 5. **CAMP INSPIRATION,** Rocky Mountain Village, Empire, Colorado. Contact Monte Leidholm, RRT, The Children's Hospital, 303-837-2502, leidholm.monte@tchden.org.

August 30-September 2. **SKIP CAMP,** Seashore Methodist Assembly, Biloxi, Mississippi. Contact Judy Abney, SKIP of Louisiana, 118 Ned Avenue, Slidell, Louisiana 70460, 985-649-0882. ■

Ventilator Users and Health-Related Quality of Life

Helen Simson, MA, Project Coordinator (hsimson@oise.utoronto.ca)

Funded by a small grant from The GINI Research Fund, this Canadian research project was designed to investigate the perceptions of ventilator users about their personal health-related quality of life and about the influence of mechanical ventilation (MV) on quality of life.

Preliminary findings indicate that the participants generally regard their health and quality of life positively. Most rate their health as good; some rate it as excellent. They report that MV boosts their energy, improves ability to sleep, and supports increased independence.

Several key issues are emerging:

◆ Participants who have a tracheostomy find that restrictions on funding for attendants who can perform suctioning restricts their ability to get out and about. They feel that they would have increased independence if they had attendants who could accompany them on trips out of the house. Many participants who require suctioning rely on family and friends to assist them, which increases their dependency and, in some cases, isolation.

◆ Medical practitioners are not always well informed about non-acute MV, and this can affect the quality of care that consumers receive, especially during hospitalizations for conditions that are not related to MV. Some participants reported that they delayed or decided against having surgeries (especially those requiring general anaesthetic) because they perceived a risk in going into hospital and being treated by practitioners who do not understand MV.

◆ Sleep, energy, and independence all improved after the introduction of MV. Participants regard MV as a positive part of their daily lives and appreciate the benefits it provides, rather than perceive it as disruptive or intrusive on their routine.

◆ Support from family and friends is a significant aspect of satisfaction with their lives. Family and friends provide psychosocial support and supplement the care and services provided by paid personal support workers.

◆ Participants tend to be, and believe they have to be, highly proactive in informing themselves about how to stay healthy, how to manage their MV, and how to direct attendant care.

The study is qualitative, relying on the perceptions of the ventilator users to provide insight into the experience of living with MV. To gather these perceptions, we used a structured interview format to probe into participants' experiences and opinions about their daily lives, their introduction to MV, and their life since initiating MV.

The team has completed 18 in-depth interviews out of our target of 25, with the majority of the interviews conducted in Toronto. The diseases and conditions of the ventilator users include spinal muscular atrophy, neuropathy, amyotrophic lateral sclerosis, Duchenne muscular dystrophy, post-polio, myopathy, and spinal cord injury. The ages range from 23 to 72 years.

We interviewed only non-ambulatory ventilator users needing a high level of support with activities of daily living in order to determine whether ventilator use which requires the additional physical assistance of others might impact further on quality of life.

We also asked what advice the participants would give to others who are contemplating MV and the feedback they would like to provide to medical practitioners about the impact of MV on one's health and independence. Most participants would encour-

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International Ventilator Users Network

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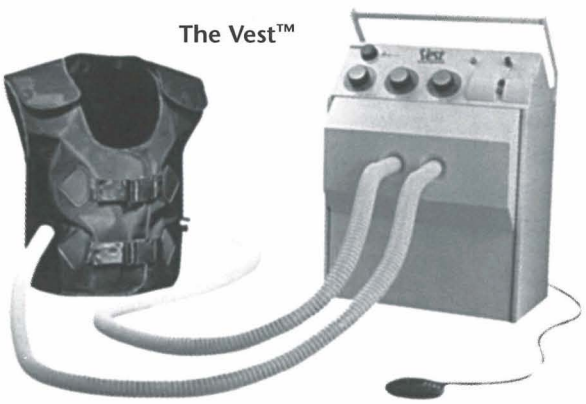
Airway Clearance Therapy for Neuromuscular Patients with Respiratory Compromise

Louis Boitano, MS, RRT, and Joshua Benditt, MD, Departments of Pulmonary and Critical Care Medicine and Respiratory Care, University of Washington Medical Center, Northwest Assistive Breathing Center, Seattle, Washington (boitano@u.washington.edu)

Recently, IVUN asked for our advice on answering this query, "I have Duchenne muscular dystrophy, and I have heard about two machines that will help me cough: The Vest™ and the CoughAssist™ device. Which would be best for me?"

This question has arisen as the result of the new direction Advanced Respiratory Company (Saint Paul, Minnesota; 800-426-4224; www.thevest.com) has taken in marketing their airway clearance device, The Vest™, as an effective means of assisting cough and preventing respiratory infection in neuromuscular patients with respiratory compromise.



The Vest™

The Vest™ consists of an inflatable vest worn by the individual that is connected by air hoses to an air pulse generator. During therapy, the vest inflates and deflates rapidly, applying gentle pressure to the chest wall to loosen and thin mucus and move it to the central airways to be cleared by coughing or suctioning.

A number of short-term clinical studies have shown The Vest™ to be as effective as other forms of airway clearance therapy for patients with intrinsic lung disease, such as cystic fibrosis, that result in retained secretions. Although The Vest™ can effectively mobilize retained mucous secretions, there are no clinical studies that show this device to be effective in augmenting peak cough flow in neuromuscular patients at risk for complications of pulmonary infection due to a weakened cough strength.

Most neuromuscular patients with respiratory compromise are limited by weakened inspiratory and/or expiratory muscle strength, but not by intrinsic lung disease. The mucociliary systems are functional and able to move pulmonary secretions to the larger airways. The problem is that cough is ineffective, and secretions cannot be expelled from the larger airways.

The CoughAssist™ (J.H. Emerson Company, Cambridge, Massachusetts; 800-252-1414; www.coughassist.com) was specifically designed to augment weakened cough function by mechanically replicating the cough maneuver. This device, in either manual or automatic mode, provides an inspiratory pressure support breath followed by a rapid change to expiratory flow that can generate enough peak air flow to clear proximal mucous secretions that may not otherwise be cleared by the neuromuscular patient with an ineffective cough strength.

The CoughAssist™

The onset of chronic pulmonary infections in these individuals is often the result of deteriorating ventilatory function that results in chronic atelectasis (collapse of the lung). A weakened cough can further complicate pulmonary infection if the individual cannot adequately clear the increased mucous secretions associated with infection. The individual may be at risk for acute respiratory failure, because his/her already limited ventilatory strength is taxed by chronic ineffective cough and increasing pulmonary congestion. The support of the CoughAssist™ may prevent the development of pulmonary congestion, and possibly avoid hospitalization and potential acute respiratory failure.

Although antibiotics and airway clearance therapy such as The Vest™ may be warranted for acute pulmonary infection, this management only treats the pulmonary insult and not the underlying cause of the problem. A preventive maintenance regimen of airway clearance therapy alone cannot prevent the reoccurrence of pulmonary infections in neuromuscular patients with chronic progressive underventilation and weakened cough strength.

The onset of pulmonary infections may signal a need to start

ventilatory support in order to maintain adequate lung inflation. An assessment of the patient's pulmonary vital capacity and peak cough flow can help to identify whether ventilation and/or cough strength is the limiting factor that may be contributing to the development of chronic pulmonary infections.

Implementing noninvasive ventilation that supports adequate ventilation and cough assist therapy that supports adequate ventilation and cough function can provide adequate pulmonary maintenance and significantly decrease the potential for pulmonary infection. A respiratory management plan and progressive support of both ventilation and cough strength can help to maintain a high level of quality of life for the neuromuscular patient with developing respiratory compromise. ■

Editor's Note: The CoughAssist™, distributed through Respironics, Inc., received a Medicare HCPCS code (E0482) for reimbursement in January 2002. The cost for the automatic model ranges approximately $4,500 to $6,000 and higher, depending on whether it is sold to a hospital or a home care company.

The Vest™ has no Medicare code. It is available through a lifetime lease over 15 months, amounting to $15,900. When the lease is paid, the equipment belongs to the company but the individual has the use of it for life. (A one-time payment discount of 10% is also offered.) Individuals can try The Vest™ at no cost or obligation before paperwork is submitted to the insurance company. Advanced Respiratory promises complete reimbursement services, and a lifetime warranty.

NCAHB Update

David Jayne, National Coalition to Amend the Medicare Homebound Restriction (NCAHB) for Americans with Significant Illness

HR1490, the Homebound Clarification Act, was to be offered as an amendment to Medicare reform last fall, but the tragic events of September 11 postponed Medicare reform. Recently, Senator Susan Collins (R-Maine) agreed to introduce a companion bill to HR1490 in the Senate. I plan to travel to Washington in May to continue to lobby for HR1490, which currently has 58 cosponsors.

A new organization formed in January 2002: Americans for Independence through Medicare and Medicaid (AIMM). This group has an ambitious agenda and plans to work with NCAHB on changing the homebound restrictions under Medicare. While congressional action ultimately may be necessary to completely amend the homebound rule, there is much the White House in particular can do to direct Medicare to ease up on the restriction.

Between now and May, AIMM and NCAHB will try to convince the White House to create a Medicare waiver. The waiver for Medicare beneficiaries who will need skilled home health care for the rest of their lives would enable them to leave home for any purpose so long as it is not contraindicated by their health or their physician's order. I also hope to meet with President Bush personally.

However, immediate action is needed to prevent an additional cut in the Medicare home health benefit, scheduled for October 1, 2002. This cut has no adjustment for more vulnerable patients and will fall heaviest on them. I urge you to write a letter or email the White House (president@whitehouse.gov) to prevent this cut. The White House is preparing a list of the Medicare relief it believes should be provided this year. Please contact your representatives and senators and ask them to do the same. ■

Editor's Note: David Jayne uses a ventilator fulltime due to ALS. The NCAHB petition appeared in *IVUN News,* Spring 2001. For the latest on NCAHB, visit www.amendhomeboundpolicy.

Ventilator Users and Health-Related Quality of Life

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age others who are facing decisions about MV to inform themselves about their options and assess their current health status, taking into consideration the improvements to energy and sleep that MV can provide.

Their advice to medical practitioners is similar: in order to support decision-making, practitioners need to be well informed about non-acute MV themselves. ■

The research team includes Mark Tonack, MA, Senior Research Officer, Toronto Rehabilitation Institute, Lyndhurst Centre; Dina Brooks, PhD, Research Associate, West Park Healthcare Centre, and Assistant Professor, Department of Physical Therapy, University of Toronto; Roger Goldstein, MD, Professor of Medicine, University of Toronto; Audrey King, MA, ventilator user and consumer advocate; and interviewer Maria Gould. A final report will be submitted to The GINI Research Fund in June 2002.

More on Sleep Studies

Diana Guth, BA, RRT (diana@hrcsleep.com)

As the owner of a home respiratory care company in the Los Angeles area, I would like to offer additional comments in response to "Sleep Studies: At Home or In the Lab?" in the last *IVUN News*. The majority of my patients have obstructive sleep apnea (OSA), and I am also aware of the respiratory needs of the post-polio population and others with neuromuscular diseases, many of whom use noninvasive positive pressure ventilation (NIPPV).

Unfortunately, the vast majority of the sleep labs are ill-equipped to diagnose hypoventilation (underventilation), which is usually the primary respiratory problem of this group. Most of the polysomnographic (sleep study) technicians are not respiratory therapists; they are only trained to monitor for OSA.

Therefore, many people with neuromuscular disease are not assessed properly in that regard. In order to detect hypoventilation, an end-tidal CO_2 monitor should be used, and very few labs own one. The labs that do have them use them only if ordered to do so by the physician.

When some people with neuromuscular conditions reach the point of disturbed sleep secondary to hypoventilation, they do not consult a pulmonologist because they do not realize they are having a breathing problem. Many of the directors of the sleep labs are neurologists, not pulmonologists who are more aware of the respiratory problems of people with neuromuscular conditions.

The diagnosis and treatment of a sleep disorder usually involves two polysomnographic (sleep) tests. The purpose of the first one is to diagnose the sleep disorder. If the results of this study indicate that the individual has OSA or nocturnal hypoventilation syndrome, then a second polysomnographic study is performed to titrate (adjusting the pressure until symptoms are alleviated) the settings on the CPAP or BiPAP unit. Sometimes the two studies can be done in one night (called a split night study).

CPAP treats OSA by keeping the airway open with one Continuous Positive Airway Pressure. BiPAP (Bi-level Positive Airway Pressure) provides assisted breathing with two pressure settings: a higher Inspiratory Positive Airway Pressure (IPAP) and a lower Expiratory Positive Airway Pressure (EPAP).

Generally, the individual is started with CPAP because the standard goal is to eliminate obstructive events. BiPAP is tried infrequently, even though that is what people with neuromuscular conditions may actually need.

I have seen CPAP titrated to eliminate apneas, but the O_2 saturation remained abnormally low which should have been a tip-off for hypoventilation. An individual with post-polio whom I know recently went through this unfortunate odyssey. Through sheer persistence, he ultimately obtained the appropriate polysomnography with BiPAP titration; the end-tidal CO_2 monitoring identified the problem.

Under current Medicare guidelines, (www.cigamedicare.com/pdf/dmerc/supman/chapter09/sm011_chapter09_all.pdf) reimbursement for the use of NIPPV via BiPAP (referred to as RADS or respiratory assist devices) using pulmonary function tests **without** a sleep study must meet the following criteria:

– The individual must have documentation in his or her medical record of a progressive neuromuscular condition (post-polio, ALS, muscular dystrophy, etc.);

and one of the following:

- arterial blood gas PCO_2 >45 mm Hg;
- sleep oximetry demonstrates oxygen saturation <88% for at least five continuous minutes, done while breathing the patient's usual FIO_2;
- forced vital capacity of <50% of predicted or a maximum inspiratory pressure of <60 cm H_2O;

and chronic obstructive pulmonary disease does not contribute significantly to the patient's pulmonary limitation.

If an individual needs NIPPV via a volume ventilator, the medical coverage criterion under Medicare is simpler: a diagnosis of neuromuscular disease, thoracic restrictive disease, or chronic respiratory failure. ■

Ventilator Users, Assisted Living, and Nursing Homes

Aging with a ventilator is becoming a major concern of older ventilator users. The previous issue of *IVUN News* presented the dilemma and received these replies.

Linda Davison (ldavison@tm.net) writes, "I am 58 years old and have facioscapulohumeral muscular dystrophy. I have used a BiPAP system at night for five years. I have hired help for getting up in the morning and for cleaning, laundry, etc., but I have wondered about assisted living. Most of the places (in Michigan) where I have inquired require that one be ambulatory. I have often wondered about what will come of me as I age and cannot manage the help that I require."

Gene Gantt, RRT (ggantt@twlakes.net) reports, "In response to a growing need and in spite of limited reimbursement, The Health Center at Standifer Place in Chattanogga, Tennessee, opened an eight-bed Respiratory Management Unit in July 2001. It became the first skilled nursing center in Tennessee to accept long-term ventilator users and to provide 24-hour respiratory therapy.

"The goal is to work with ventilator users to wean them from the ventilator or teach their families how to care for them at home. Of course, in cases of chronic respiratory insufficiency, some cannot be weaned.

"The Unit is staffed with an aggressive team of respiratory therapists. Effective management is a must because there is little to no additional reimbursement by Medicare for this patient population.

"All patients in the unit receive physical, occupational, and speech therapies. Patients who use tracheostomy positive pressure are started with a speaking valve. The ventilators used are the TBird® Legacy (VIASYS Healthcare) and LTV900™ (Pulmonetic Systems, Inc.). All patients are continuously monitored with pulse oximetry.

"Another service that is offered is a temporary stop-over. One

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Potpourri

Traveling with a ventilator post-September 11. The Department of Transportation issued a fact sheet "Steps Taken to Ensure New Security Requirements to Preserve and Respect the Civil Rights of People with Disabilities (www.dot.gov/airconsumer/Civil%20Rights%20Fact%20Sheet.htm). Although ventilators are not referred to specifically, significant points for ventilator users include:

– caregivers or attendants assisting passengers with disabilities allowed beyond the screener checkpoints should present themselves to the airline's check-in desk to receive a pass allowing them to go through the screener checkpoint without a ticket;

– limit of one carry-on bag and one personal bag for each traveler does NOT apply to medical supplies and/or assistive devices;

– personal wheelchairs and battery-powered scooters may still be used to reach departure gates after they are inspected;

– individuals who use a wheelchair may be patted down at the screener checkpoints; private screenings remain an option.

Anyone who feels that he/she has been subjected to discriminatory actions or treatment by air carriers may file a complaint by contacting the Aviation Consumer Protection Division of the Department of Transportation: airconsumer@ost.dot.gov or Aviation Consumer Protection Division, US Department of Transportation, Room 4107, C-72, Washington, DC 20590.

The Virtual Museum of the Iron Lung has a new Web site: www.geocities.com/ironlungmuseum.

Muscular Dystrophy Epidemiology at the CDC. In December 2001, the US Congress passed appropriations ($2 million) legislation for the first funding at the Centers for Disease Control and Prevention on the prevalence and incidence of Duchenne and Becker muscular dystrophies.

The MD Care Act (HR 717) has three essential components: establishes an interagency at the National Institutes of Health (NIH) to expand, intensify, and coordinate research activities related to muscular dystrophy; authorizes three centers of excellence for muscular dystrophy research at NIH; and authorizes the Centers for Disease Control and Prevention to initiate epidemiology, data collection, and surveillance activities specific to muscular dystrophy. ■

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Calendar 2002

APRIL 25-27 **Focus on Respiratory Care and Pulmonary Medicine.** Saint Louis, Missouri. Contact Bob Miglino, Focus, 800-661-5690, www.focus.com.

APRIL 26 **Continuing Education Conference for Respiratory Care: Mechanical Ventilation and Airway Clearance.** Saint Paul Heart and Lung Center, Saint Paul, Minnesota. Contact Barbara Rogers, Respiratory Resources, 212-666-2210, brogers@breethezy.com.

MAY 15-17 **ALS Annual Leadership Development and Clinical Conference.** Crystal Gateway Marriott, Arlington, Virginia. Contact ALSA, 800-782-4747, www.alsa.org.

JUNE 21-23 **FSMA Family and Professional Conference.** Hyatt Woodfield, Schaumburg, Illinois. Contact Families of SMA, 800-886-1762, www.fsma.org.

JUNE 27-30 **The Parent Project Muscular Dystrophy Conference.** Pittsburgh Hilton, Pittsburgh, Pennsylvania. Contact Pat Furlong, 513-424-0696, www.parentdmd.org.

VENTILATOR USERS, ASSISTED LIVING
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polio survivor who uses ventilation at night recently retired from her job in West Virginia and moved to Tennessee to be near family. While she is selling her home and building a new one, she stays in the unit.

It is anticipated that there are other people who are relatively independent who will use the service this way. Similarly, family caregivers of ventilator uses in need of respite care now have a place where the ventilator users can stay." ■