

# VENTILATOR-ASSISTED LIVING

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IVUN's mission is supported by its Membership.

## “We can now go outdoors all day ... we enjoy every moment”

Submitted by Candy Wasserman, Senior Manager,  
Global Product Marketing Communications, ResMed Ltd

Celine is almost 13 years old. Like most girls her age, technology means a lot to her, but it's not the latest phones or iPads that are of interest. For Celine it's a state-of-the-art portable ventilator that is most important.

Celine has needed a ventilator since birth. She was born with tracheomalacia (the cartilage in the trachea has not developed properly and instead of being rigid, the walls of the trachea are floppy). Because of this, along with a range of heart and lung problems, doctors predicted she was unlikely to live beyond 12 months.

However, ventilation was established. Operations were performed. Infections were treated. And after nine months, Celine was discharged from hospital – fully ventilated – to the care of her mother, Ariane.

At that time caring for a fully ventilated child at home was a relatively new occurrence – even in innovative Germany where Celine and her mother live. But Ariane was determined to give her daughter every opportunity to enjoy life and develop to her full potential.

Challenges were many. In the beginning the dry air being blown into Celine's lungs

was irritating, causing her to cough and making her vulnerable to infections. The air needed to be humidified, but finding the balance between sufficient moisture and too much fluid took a long time.

Celine is now established on the HumiCare™ humidifier, which she uses overnight and if she is ill. “HumiCare is fantastic,” says Ariane. Not only has it reduced the coughing but also Celine has had far fewer respiratory infections since she started on an earlier version of this device three years ago.

Another major challenge in Celine's case has been accessing the multiple services, therapies and even enjoyable activities that Ariane knew her daughter needed if she were to have a healthy and happy life.

Fundamental to meeting this challenge was to have a ventilator that was readily portable.

“It needed to be small and lightweight,” said Ariane, “and the batteries needed to last as long as possible.”

Ariane was packing three batteries along with everything else for a day's outing, when she was asked if she would trial Celine on ResMed's latest ventilator, Astral™, which has a battery life of up to 24 hours.\*

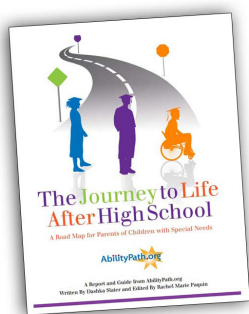
The changeover of ventilators was done at home, without any problems, and immediately both Ariane and Celine noticed an advantage.

*\*Internal battery plus two external batteries*



Celine on an outing with her Astral.

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## AbilityPath.org releases comprehensive guide

Will help families with special needs children prepare for challenging transition period

Millions of American families of children with special needs, ages 5 to 17, will be going back to school this month and taking one step closer to facing the critical transitional period from high school to adulthood. To assist those individuals and families with this stage in life, and to reduce the stress and impact on the household, AbilityPath.org released a comprehensive new report and guide, "The Journey to Life After High School: A Road Map for Parents of Children with Special Needs." This report examines the laws that impact youth with special needs, the importance of the individualized education plan and the different paths a young adult with special needs can take after graduating from high school. A national state-by-state directory of supporting agencies is included.

The report and resource guide was released on August 12, 2014, and is available for FREE download at [www.abilitypath.org/lifeafterhighschool](http://www.abilitypath.org/lifeafterhighschool).

## FDA expands approval of drug to treat Pompe disease

The U.S. Food and Drug Administration recently announced the approval of Lumizyme (alglucosidase alfa) for treatment of patients with infantile-onset Pompe disease, including patients who are less than 8 years of age. In addition, the Risk Evaluation and Mitigation Strategy (REMS) known as the Lumizyme ACE (Alglucosidase Alfa Control and Education) Program is being eliminated.

Pompe disease is a rare genetic disorder and occurs in an estimated 1 in every 40,000 to 300,000 births. Its primary symptom is heart and skeletal muscle weakness, progressing to respiratory weakness and death from respiratory failure.

The disease causes gene mutations to prevent the body from making enough of the functional form of an enzyme called acid alpha-glucosidase (GAA). This enzyme is necessary for proper muscle functioning. GAA is used by the heart and muscle cells to convert a form of sugar called glycogen into energy. Without the enzyme action, glycogen builds up in the cells and, ultimately, weakens the heart and muscles.

Lumizyme is believed to work by replacing the deficient GAA, thereby reducing the accumulated glycogen in heart and skeletal muscle cells.

Myozyme and Lumizyme are marketed by Cambridge, Massachusetts-based Genzyme.

## New DMD drug conditionally approved

Ataluren, a drug being developed by PTC Therapeutics to treat Duchenne muscular dystrophy caused by specific genetic mutations, has received conditional approval in the European Union; Muscular Dystrophy Association gave a \$1.5 million grant to PTC in 2005 for ataluren's development.

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*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.*

### How to contact IVUN

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International Ventilator Users Network (IVUN)

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### Moving? Change of address?

Notify IVUN before you move by calling 314-534-0475 or email [info@ventusers.org](mailto:info@ventusers.org), and tell us your old and new addresses.

### Away temporarily?

Send us your second address and dates you will be there and we'll do our best to send you your newsletter.

## DMD Pathfinders Publishes Life and Breath: Worry Free Breathing During a Power Failure

DMD Pathfinders has produced a seven-page guide/fact sheet for people with Duchenne muscular dystrophy and others who use respiratory equipment (e.g., positive pressure machines/ventilators, cough assistance, nebulizers) to develop strategies and plans for emergency situations such as power failures. Compiled from the experiences of people who have faced such emergencies, it is a practical guide with checklists for developing an individualized plan of action. Click here to access: [Life and Breath pdf](#).



## Screening device launched in St. Louis market

ApneaStrip™, the first disposable, in-home sleep apnea screening device for adults, launched in select St. Louis Walgreens® pharmacies on August 8, 2014.

People with untreated sleep apnea stop breathing for brief periods of time during their sleep, resulting in poor quality and insufficient sleep. According to the American Sleep Apnea Association (ASAA), sleep-disordered breathing affects as many as 43 million adults in the United States, most commonly in the form of sleep apnea. The ASAA estimates that at least 85% of sleep apnea sufferers go undiagnosed.

Untreated sleep apnea has been linked to a number of serious health concerns, including hypertension, diabetes and stroke.

ApneaStrip™ was created to address the growing need to easily and objectively identify potential sufferers of sleep apnea. It provides a simple, inexpensive first step for people who suspect they may have sleep apnea. A prescription is needed for the device for initial screening purposes. The retail pharmacy cost is \$29.99. Additional information can be found at [www.apneastrip.com](http://www.apneastrip.com). ■

## "We can now go outdoors all day ..."

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"The Astral is not as loud as the previous ventilator which used to sometimes wake us up at night," Ariane said. Its small size and weight make it easily transportable but it's the extended battery life that has made the biggest difference.

"We can now go outdoors all day," Ariane says. Celine attends physical therapy, speech therapy and even swimming. She can walk with a walker and is able to make sounds, which will hopefully soon become words.

Celine has not just survived full-time ventilation, she has flourished. "We enjoy every moment," Ariane says.

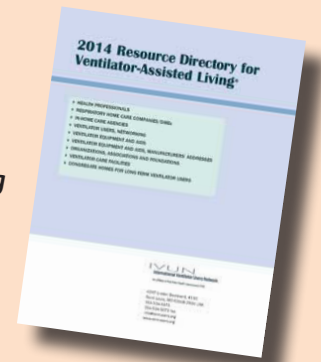
When considering the future, Ariane hopes her daughter "will have the freedom to do anything she wants."

It's a dream that would have been impossible when Celine was first ventilated over 12 years ago, but now given the new technology, it is a dream that looks well within reach. ■

## IVUN Resources Updated

### Resource Directory for Ventilator-Assisted Living

has been updated once again. IVUN's 47-page *Directory* is organized by country and state and can be downloaded for free from IVUN's website at <http://www.ventusers.org/net/vdirhm.html>. Should you or your facility be listed? If so, contact us at [info@ventusers.org](mailto:info@ventusers.org).



*IVUN's Home Ventilator Guide* is also up-to-date. The grid-like design includes the details of the many devices available for use in the home, e.g., bilevel positive airway pressure devices, volume-cycled ventilators, pressure support ventilators and combination or multi-mode ventilators. The 27-page *Guide* can be downloaded for free at [www.ventusers.org/edu/HomeVentGuide.pdf](http://www.ventusers.org/edu/HomeVentGuide.pdf)

# VENTure Think Tank

## Seeks Policy and Tech Solutions to Vent User Challenges

Brooke Ellison, PhD, and Pamela Block, PhD, Stony Brook University, Stony Brook, New York

Ventilator users lead rich but complex lives. For far too long, experiences, challenges and unique needs of members of this diverse population have either gone underappreciated or unaddressed by a larger society, and this has been felt in matters of health policy, public policy, emergency response strategies, and even academic literature. Precisely how little attention the ventilator user population receives became nothing short of a public health concern in the United States for Southeasterners in 2003 after Hurricane Katrina and Northeasterners in 2012 after Super Storm Sandy when widespread and prolonged power outages put ventilator users' lives in jeopardy.

It was in response to these circumstances that we founded VENTure Think Tank, to provide policy and technological solutions to the challenges experienced by ventilator users, their families and their caregivers.

Founded at Stony Brook (New York) University's School of Health Technology And Management by Brooke Ellison, PhD, and Pamela Block, PhD, VENTure is a collaborative and multidisciplinary think tank designed to meet the unmet needs of individuals who are dependent on ventilators to breathe. VENTure is comprised of a group of vent users, family members, experts and advocates who specialize in a diversity of fields, including respiratory care, physical therapy, occupational therapy, health policy, medical ethics, nursing and disability studies. Important Stony Brook university partners include the Stony Brook University School of Engineering and the Stony Brook University Center for Excellence in Wireless and Information Technology.

As "ventilator dependence" is not a diagnosis, in and of itself, the vent-user population is comprised of people of all ages and experiencing many different circumstances that precipitate ventilator assistance. What unifies members of this population is their very intimate and constant reliance on a biomedical technology that both complicates their existence yet makes existence possible.

Similarly, because members of the ventilator-assisted population come from many different medical diagnoses, there are essentially no data on who, specifically, these individuals are, where they are located, what their individual needs and experiences are or how these needs can be met.

In its short existence, VENTure has proposed a number of projects and initiatives in a diversity of disciplines to begin to understand, identify and then address the socio-cultural challenges that negatively impact quality of life for the vent-user population.

Areas of interest include technology that is accessible for ventilator users, policy changes to promote community living as opposed to living in medical institutions, quality of life measures, demographic research and emergency response protocols for natural disasters. We believe that research and program development in these areas will set the stage to significantly impact quality of life for ventilator users, their families and their caregivers.

VENTure has focused its attention recently on the development of a solar-powered battery system. Working with Stony Brook University engineers and a local sustainable technology company, VENTure members are testing the feasibility of using solar powered battery backup systems to power ventilator users' homes in the event of a power failure.

The battery backup system, called the STAR system, was developed by engineers to provide clean, safe and sustainable power to communities around the world that lack it.

Through the work of VENTure, it became apparent that this technological system could be applicable to ventilator users. While it is in testing stages currently, the expectation is that, STAR systems could be housed in local fire departments to be brought to the ventilator users in times of need.

VENTure is also concerned about helping individuals secure access to needed medical services. We see this as a basic human rights issue. With exceptions, ventilator users with a tracheostomy, typically require medical care in the form of nursing. This service is imperative in order for these people to live in the community as opposed to an institutionalized medical setting. Too many ventilator-assisted individuals have been essentially forced to live in medical institutions like nursing homes solely because they do not have access to the nursing required to remain in the community, and finding facilities that accept trached individuals is difficult. VENTure is centrally committed to ensuring that ventilator users are given

every opportunity to live where they choose, and, for individuals using invasive ventilation continually, ensuring access to nursing coverage is a primary means to do this.

To this end, we have begun studying the levels of nursing coverage afforded to ventilator users, and under what circumstances, by insurance companies in New York State. With the knowledge that New York has been historically committed to establishing a comprehensive healthcare system, we expect that most of nursing coverage in New York will provide an upper limit, with other states falling somewhere below. From these data, we plan to develop a series of policy recommendations about how nursing coverage can be better accessed by those who use ventilators.

We at VENTure feel the effects of these issues, not simply from an academic standpoint but also from a deeply personal standpoint. Most members of VENTure work with, are related to, or are themselves, ventilator users who have seen firsthand how societal challenges manifest themselves in the lives of this population. For instance, VENTure member and ventilator user Nick Dupree

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**Brooke Ellison, PhD**, is the Director of Education and Ethics at the Stony Brook University Stem Cell Research Facility Center. In addition, she is an Assistant Professor in the University's PhD program in Rehabilitation and Movement Sciences and Masters Program in Healthcare Policy and Management. In 1990 at age 11, she was hit by a car on her way home from school and was left paralyzed from the neck down and dependent on a ventilator. Ten years later, she graduated magna cum laude from Harvard University. In 2002, Brooke and her mother, Jean Ellison, published a book entitled *The Brooke Ellison Story*, which documents their family's experiences. Their book subsequently was made into a movie, directed by Christopher Reeve.



**Pamela Block, PhD**, is Associate Dean for Research in the School of Health Technology and Management, Associate Professor in the Occupational Therapy Program, Director of the Concentration in Disability Studies for the PhD Program in Health and Rehabilitation Sciences, a former President of the Society for Disability Studies (2009–2010), and a Fellow of the Society for Applied Anthropology. She is also affiliated with the Stony Brook University Department of Cultural Analysis and Theory, the Center for Latin American and Caribbean Studies and the Center for Medical Humanities, Compassionate Care and Bioethics.

Self-portrait by Nick Dupree, a New York City artist, activist, writer and ventilator user. Best known for his campaign in Alabama, "Nick's Crusade," which resulted in a new Medicaid program to extend home care past age 21 for vent-dependent Alabamians, he works to articulate and advocate for the interests of people who use ventilators. In addition to writing for VENTure Think Tank ([www.stonybrook.edu/commcms/venture](http://www.stonybrook.edu/commcms/venture)), he blogs about various topics at [nicks crusade.org](http://nicks crusade.org).



lived in the South during Hurricane Katrina and in New York during Super Storm Sandy, and, in the more recent storm, was forced to resort to makeshift, rudimentary but essential, and creative means to secure the electric power he needed to survive.

Similarly, through her position as a World Economic Forum Young Global Leader, Dr. Brooke Ellison is hoping to devise strategies to help make technology more accessible to ventilator users and people with disabilities. The issues addressed by VENTure, and proposed solutions to them, emerged directly from the experiences of ventilator users in a community-based manner. We believe strongly in the disability rights idea of "nothing about us without us."

Through the initiatives that VENTure has undertaken, it has established partnerships with a number of stakeholders and community organizations involved in the lives of ventilator users. These local, regional and national stakeholders beyond Stony Brook University include Federal Emergency Management Agency (FEMA), the Red Cross, our local public utility, the United Way of Long Island, New York State Department of Health, Center for Medicare and Medicaid Services (CMS) and private businesses that support vent users through health, mobility and information technologies or through providing nursing support, and several vendors that work to address the needs of those who are vent users.

Through these collaborations, VENTure has been able to establish a broad perspective on how members of the ventilator-assisted population engage with the world and their environment. However, in order for any efforts or initiatives to be useful we need to know who comprises this population, and where do these individuals reside? Unfortunately, though not surprising

given the relative lack of attention to or interest in this population, there is no registry or collected information about the size of the ventilator-assisted community or its demographics in terms of age or location. This lack of information has a significant effect on the ability of local governments, emergency responders and healthcare providers to respond effectively to the needs of these individuals.

To this end, we would welcome contact, input or involvement from readers like you. Are you a vent user? A family member? A friend or ally? We would like you to join us!

On September 12, 2014, from 11 a.m. to 3 p.m. (EDT), the VENTure Think Tank will be holding its first community-based E-vent, designed specifically to address initiatives that we have been working on and issues of importance to ventilator users and their families. Our tentative speaker list includes representatives from the U.S. Department of Homeland Security/FEMA, engineering and alternative energy specialists and ventilator users. Our E-vent will cover a range of topics with particular attention given to emergency response. We will also have an art show featuring the work of vent user Nick Dupree. We welcome your attendance, either in person or online! If you cannot attend in person, you may attend virtually via this link: [https://www.youtube.com/channel/UCsb38pMA\\_nfiYOQvZNNvypg](https://www.youtube.com/channel/UCsb38pMA_nfiYOQvZNNvypg).

For more information, please see the VENTure E-vent announcement, or to become involved in our work, visit our website: <http://www.stonybrook.edu/commcms/venture/> and Facebook page: <https://www.facebook.com/venturethinktank>. You may contact us directly at [venture.sbu@gmail.com](mailto:venture.sbu@gmail.com). ■

## IVUN Wants Your Opinion

Feedback from readers of *Ventilator-Assisted Living* tells us that they like to hear from ventilator users on various topics. In the last issue we published answers to, “Do you consider your vent life support?” IVUN uses this format to educate, network and to advocate by letting you expose the problems you face.

**New question:** Are you satisfied with the professional clinical support (e.g., service from a respiratory therapist) you receive in your home? If so, why? If not, why not?

You may remain anonymous, but we would like the following information about you.

- Ventilation: invasive or noninvasive?
- Ventilator: Brand name and specific model. If you use a multi-mode ventilator such as a Trilogy, a Newport, an LTV, tell us what mode you use.
- Diagnosis: e.g., restrictive diseases such as chest wall diseases (scoliosis) or neuromuscular disease such as ALS, MS, post-polio syndrome; sleep apnea (obstructive or central), COPD, etc.
- Would you recommend your home health care company? If so, please list the name, address and phone number. ■

Please respond to [info@ventusers.org](mailto:info@ventusers.org) by September 15, 2014.

## CALENDAR

### 2014

- October 20-21, 2014 **17th Annual Focus Fall on Respiratory Care and Sleep Medicine Conference.**  
Desmond Hotel & Conference Center, Albany, New York. <http://foocus.com/stay-tuned/>
- October 25-30, 2014 **Chest 2014.** Austin Convention Center, Austin, Texas. [www.chestmeeting.chestnet.org](http://www.chestmeeting.chestnet.org)

### 2015

- March 26-28, 2015 **JIVD 14th International Conference on Home Mechanical Ventilation & ERCA 5th European Respiratory Care Association Congress.**  
Cité Centre de Congrès, Lyon, France. [www.jivd-france.com](http://www.jivd-france.com)
- April 23-25, 2015 **Canadian Respiratory Conference**  
Westin Ottawa, Ottawa, Ontario, Canada

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You can join online at <http://shop.post-polio.org> or send or fax (314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. Questions? 314-534-0475 .

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