

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

continued on page 6

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), he blogs about various topics at www.nicksrusade.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.

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. ■