



VENTure

THINK TANK

VENTure Think Tank: Policy and Technology Innovation to address the unmet needs of individuals who are dependent on ventilators



The First Annual VENTure E-Vent

September 12, 2014
The Center of Excellence in Wireless and
Information Technology (CEWIT)
at Stony Brook University

Program

11:00 AM - 11:15 AM

Welcome
Pamela Block

11:15 AM - 11:30 AM:

**Introduction to the VENTure
Think Tank**
Brooke Ellison

11:30 AM - 12:15 PM

Keynote: Marcie Roth, FEMA
*Turn on Your Power - Getting the
Whole Community to Plan for
Emergency Power Outages*

12:15 PM - 12:30 PM

Art, Politics, and Life on a Vent
Nick Dupree

12:30 PM - 1:30 PM

Art Show and Lunch

1:30 PM - 2:30 PM

Allies Roundtable
*John Brittelli, Susan Miale, Miriam
Rafailovich, Stephen Smith, Mary
Squillace*

2:30 PM - 3:00 PM

Wrap Up – What's Next?

Keynote Speaker

Marcie Roth was appointed by President Obama in June 2009 to be the Senior Advisor on Disability Issues for FEMA. Once at FEMA, she developed the new Office of Disability Integration and Coordination, where she now serves as Director. In this role, she leads the Agency's commitment to meet the access and functional needs of children and adults with disabilities in emergency and disaster preparedness, response, recovery and mitigation. Before coming to FEMA, Ms. Roth was President and CEO of Global Disability Solutions Group, a leading national organization promoting diverse workforce initiatives with a focus on disability issues. She served as a senior member of the Obama for America Disability Policy Committee and served on President Obama's Justice and Civil Rights Transition Team. Over the past 20 years, Ms. Roth has held leadership positions with the National Coalition for Disability Rights, National Spinal Cord Injury Association, National Council on Independent Living and TASH, the national disability rights organization. She is known for her work in developing and managing effective coalitions to advance public policy initiatives and is frequently consulted as an expert on strategic approaches that fully integrate preparedness, response and recovery solutions. Ms. Roth led private sector response to the additional needs of survivors with disabilities during and after Hurricanes Katrina and Rita, and she was commended by the White House for her efforts on behalf of New Yorkers with disabilities in the aftermath of the 2001 terrorist attacks. In addition to her own personal experience with disability, Ms. Roth is the parent of two children with disabilities, both on their way to achieving independence.

Pamela Block, Ph.D. is Associate Dean for Research in the School of Health Technology and Management, Associate Professor in the Occupational Therapy Program, and Director of the Concentration in Disability Studies for the Ph.D. Program in Health and Rehabilitation Sciences at the State University of New York, Stony Brook. She is a Fellow of the Society for Applied Anthropology and was recently President of the Society for Disability Studies (2010-2011). Dr. Block received her PhD in cultural anthropology from Duke University in 1997. Her dissertation was entitled "Biology, Culture and Cognitive Disability: Twentieth Century Professional Discourse in Brazil and the United States." She researches disability experience on individual, organizational and community levels, focusing on socio-environmental barriers, empowerment/capacity-building, and health promotion. Her qualitative research combines historical analyses with community-based ethnographic and participatory approaches. Most recently, Dr. Block has been involved in supporting disability social entrepreneurship through organizations such as EmpowerSCI—a nonprofit providing independent living skills and secondary rehabilitation to individuals with recent spinal cord injury, and VENTure—a policy and technology think tank on issues of concern to people who use ventilators. She also studies autism in Brazil and the United States, and the emergence of Brazilian disability studies.

John Brittelli, BS, RRT-NPS, RPFT, earned both a Bachelor of Science degree in Respiratory Care and a Master of Science degree in Healthcare Policy and Management at Stony Brook University. John has been working in the profession since 1982 and started his career at University Hospital at Stony Brook. Professor Brittelli later joined private industry and held numerous administrative positions in home health care. He was the founder of two home medical equipment companies that served adults and children who were technologically dependent at home. John was later offered the opportunity to start-up a 40-bed ventilator unit at a chronic care facility, the largest in Suffolk County. John is currently responsible for teaching cardiopulmonary physiology, pulmonary diagnostics, and advanced respiratory care techniques. He also provides instruction for students in the Polysomnographic Technology Program and is the research coordinator for the department. John is the current Chair of the New York State Education Department, Office of the Professions, Respiratory Therapy Board. He is also part of an interdisciplinary team at Stony Brook that holds 3 patent pending applications for breakthrough medical technology products. He is also a member of the Office of the Professions Respiratory Therapy Board.

Nick Dupree is an artist, activist and writer in New York City. He has been on different forms of mechanical ventilation since 1992, and is best known for his campaign in Alabama, "Nick's Crusade," which ended in a new Medicaid program to extend home care past age 21 for vent-dependent Alabamians. He studied at Spring Hill College, a Jesuit college in his hometown, Mobile, AL on the Gulf coast. He works to articulate and advocate for the interests of people on ventilators, and in addition to writing for VENTure Think Tank, he blogs about topics as varied as the constitution, Medicaid, and 19th century America, at www.nickscrusade.org. The collected Bloggings of Ventboy Alcatraz can be found at: <http://www.nickscrusade.org/coler-chronicles-collected-bloggingsof-institutionalization/>. If you are interested in purchasing a physical print, please contact him at nick@nickscrusade.org.

Brook Ellison, Ph.D. 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 Health and Rehabilitation Sciences and Master's Program in Health Care 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 mom, 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. In 2004, Dr. Ellison received her Masters degree in Public Policy from the Harvard Kennedy School of Government, after which she ran for New York State Senate. In 2007, Dr. Ellison was appointed by the New York State Governor's office to serve on the Empire State Stem Cell Board, New York's funding source for stem cell research. Dr. Ellison received her PhD in 2012 from Stony Brook University, and holds honorary degrees from Misericordia College and Rutgers University. As a faculty member at Stony Brook University, Dr. Ellison teaches in the Behavioral and Community Health concentration of the PhD program in Health and Rehabilitation Sciences, teaching courses on health policy, ethics, and leadership. She is also Associate Director of the Center For Community Engagement and Leadership Development. In 2014, Dr. Ellison was chosen by the World Economic Forum to be a Young Global Leader, given the charge to help devise solutions to global challenges. She was also selected by the American Neuro-Rehabilitation Society to receive the annual educator award.

Jean Ellison has been the primary caregiver of a ventilator user for nearly 25 years. A high school educator with a specialization in special education, Mrs. Ellison left her career in 1990, to provide care for her daughter. Since that time, Mrs. Ellison has become a veritable, hands on expert in such areas as access to nursing coverage, the family dynamic in challenging circumstances, and advocating for necessary medical services. As such, she has become a valuable member and leader within the VENTure Think Tank.

Susan Miale, PT, DPT, PCS, graduated from the University of Scranton with her Master of Physical Therapy degree in 2000. She began her career at The Rusk Institute of Rehabilitation Medicine at New York University Medical Center where she gained experience in acute care, outpatient orthopedics, neurologic rehabilitation, and both inpatient and outpatient pediatrics. Her devotion to treating children earned her two awards for advanced clinical skills and assisting with overall departmental efficiency and management. In 2006, Dr. Miale was hired by Memorial Sloan-Kettering Cancer Center where she maintained the position of Physical Therapy Pediatric Specialist. She initiated several new pediatric programs, including the creation of a new screening tool for acute care pediatric oncology. She was also responsible for all new employee orientation in the areas of pediatrics and chest physical therapy. Dr. Miale received her Doctor of Physical Therapy degree from Rocky Mountain University of Health Professions in 2008 and is a Pediatric Certified Specialist through the American Physical Therapy Association (APTA). She has given lectures and in-services across the country on physical therapy intervention for children with cancer and currently serves as the Chair of the Pediatric Oncology Special Interest Group in the Oncology Section of the APTA. Dr. Miale is also a member of the APTA EDGE (Evidence Database to Guide Effectiveness) Taskforce to review outcome measures that can be used with survivors of breast cancer. She currently teaches Principles of Inpatient Care, and Growth and Development Across the Lifespan in the Entry-Level DPT curriculum and also coordinates the second Case Studies course. Other research interests include the rehabilitation of children with cancer during the active phase of their treatment and early mobility programs in the ICU critical care setting.

Stephen G. Smith, MPA, RRT, received a Bachelor of Science Degree in Respiratory Therapy from Long Island University in 1978 and a Masters in Public Administration with an emphasis in Health Care Administration from Long Island University in 1983. Professor Smith started his career as a respiratory therapist at Queens Hospital Center in Jamaica, NY. In 1980 he accepted a position as a Respiratory Care Clinician at Stony Brook University Hospital and in 1981 was promoted to Assistant Director of Respiratory Care. In 1984 Stephen accepted a position as Director of Respiratory Care at Long Island Jewish Medical Center. In 1985 he became a partner and Vice President of Operations and Clinical Services at Anthony Home Health Care, Inc. In 1995 Stephen left the corporate world to return to clinical practice as the Assistant Director of Respiratory Care at Southside Hospital in Bay Shore, NY. He remained there until October of 2000 when he returned to Stony Brook University Hospital as Associate Director of Respiratory Care. Stephen accepted a full-time faculty position at Stony Brook in 2005 and is currently responsible for teaching the department's cardiology courses. Professor Smith is our liaison to the Long Island State Veteran's Home which is located on the Stony Brook campus and has served as Vice-President and President of the school's Faculty Assembly. Professor Smith was appointed as a member of the New York State Education Department Respiratory Therapy Board in 2002, where he was elected as Chair, and now serves as an Extended Member of the licensure board. He has spoken at many conferences, reviewed textbooks, is involved in research and has been published in medical journals. His areas of interest include all aspects of cardiac care, medical and professional ethics, and chronic care.

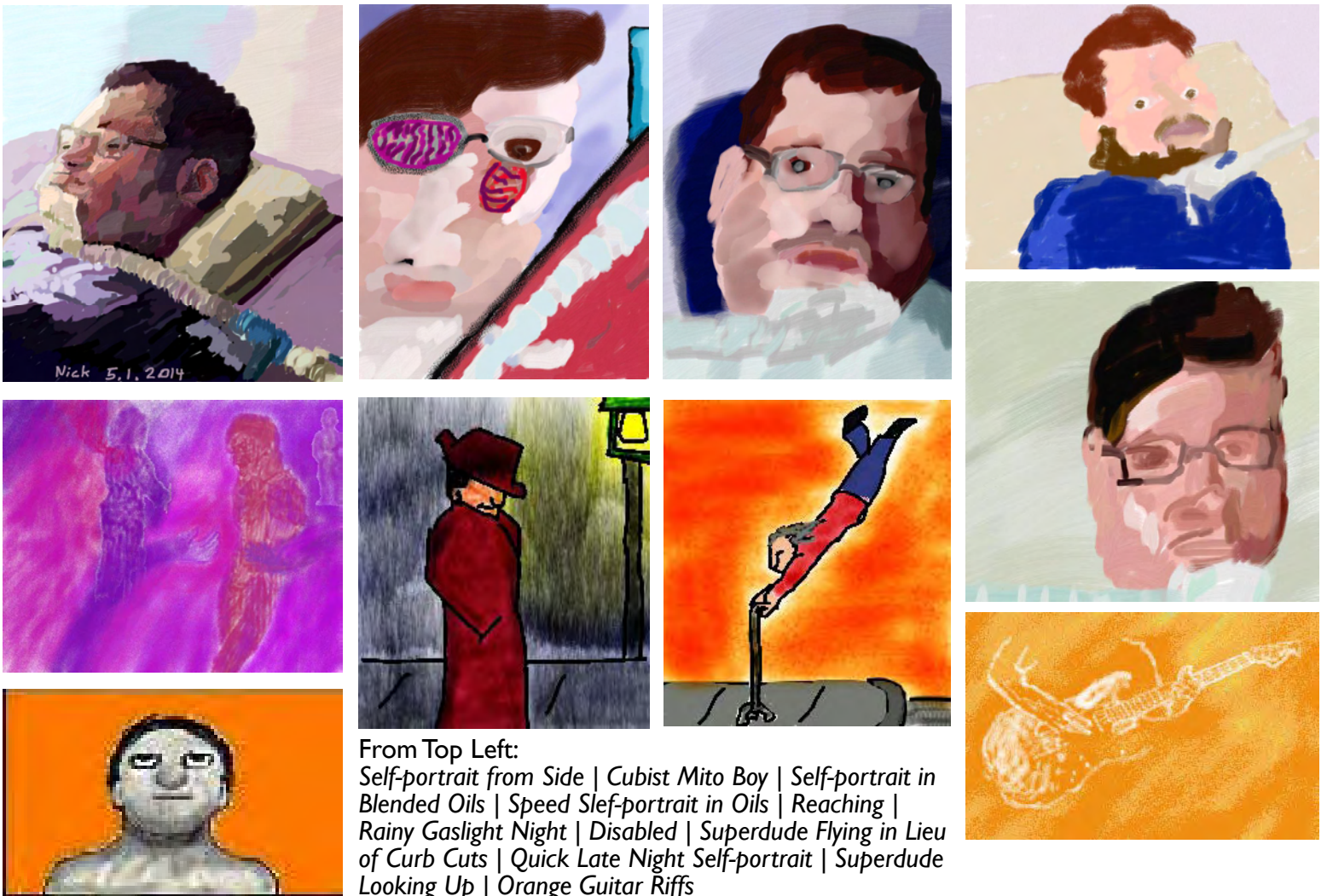
Mary Squillace, DOT, OTRL, received her Doctorate of Occupational Therapy from Temple University in 2009 and her Bachelor's/Master's combined degrees from Touro College in 1996. Her clinical practices range from Traumatic Brain Injury, Spinal Cord Injury, Hand Therapy, Physical Disabilities with adults, Neonatal Intensive Care, Pediatrics with a specialty in early intervention in ages 0 to 3 years of age, Sensory Integration with a certification in Sensory Integration Praxis Test administration. Prior to her full time position as an Assistant Clinical Professor, Professor Squillace was an adjunct professor at several universities including Stony Brook University's COTA/OT weekend program for 3 years. Professor Squillace is responsible for teaching a number of courses including Adult Physical Dysfunction, Acute Care, Research Design, Pediatrics, and Disabilities and Occupational Therapy. Additionally, she lectures to students in other programs giving specialty lectures on Sensory Integration and NICU interventions. Professor Squillace is involved with Stony Brook Hospital's National Clinic for Pediatric Multiple Sclerosis where she is involved in research with a team of neurologists, and a nurse practitioner assessing and investigating primary factors related to the disease of pediatric MS. Other responsibilities include mentoring students performing research projects in their areas of interest.

Miriam Rafailovich, Ph.D. obtained her BS from Brooklyn College in Physics and her PhD, in the Nuclear Structure Laboratory with Gene Sprouse, at Stony Brook University. She then did a post doctorate at Brookhaven National Laboratory's Tandem Laboratory and spend four years as a senior scientist in the Weizmann Institute Pelletron Accelerator group, where she developed several techniques for application of nuclear accelerators to the study of polymer structure. She subsequently served as Professor of Physics at Queens College, before she joined the Stony Brook Department of Materials Science, where she currently holds the position of distinguished professor and co-director of the program in chemical and molecular engineering. Her research interests are focused on polymer surfaces and interfaces, and she directs an NSF center on "Polymers at Engineered Interfaces" which has two major thrusts; (a) High performance polymers, which include flame retardant materials, nanocomposites, and materials for energy applications (b) Biomaterials; which include electrospun and other three dimensional scaffolds for bioactive filtration systems, Hydrogels for mechanotransduction of cell function, nanostructured materials for stem cell differentiation, functionalized nanoparticles for drug therapies and toxicity studies. She has more than 370 publications in peer reviewed journals, and graduated more than 30 PhD students.

VENTure is a newly-founded think tank, established in November 2012, designed to meet the unmet needs of individuals who are dependent on ventilators. This organization was founded as a result of many of the profound, even life-threatening, challenges that ventilator-users in the Northeast experienced as a result of the devastation caused by Hurricane Sandy. While the goals of VENTure far exceed this isolated issue, the circumstances that were generated as a result of the shortcomings following Hurricane Sandy brought to light just how socially pervasive these challenges are, and how ill-equipped society often can be in meeting the needs of some of its most vulnerable citizens.

VENTure is a nonpartisan, nonprofit think tank generating ideas and solutions to address challenges faced uniquely by people dependent on ventilators. We are a multidisciplinary group of experts and advocates, from such domains as respiratory therapy, physical therapy, occupational therapy, health policy, nursing, disability studies, private business and many ventilator-dependent people themselves, with experience well suited for devising strategies to help improve daily life for people dependent on ventilators. VENTure is an ongoing effort that advises proactively to meet the concerns of the ventilator-dependent community, and responds reactively to address the changing political and social environments.

Artwork by Nick Dupree



From Top Left:
 Self-portrait from Side | Cubist Mito Boy | Self-portrait in Blended Oils | Speed Slef-portrait in Oils | Reaching | Rainy Gaslight Night | Disabled | Superdude Flying in Lieu of Curb Cuts | Quick Late Night Self-portrait | Superdude Looking Up | Orange Guitar Riffs