

# Speak for Yourself Workshop

## September 22, 2017 | Washington, DC



**Lisa Stewart, MA**, is an Engagement Officer at the Patient-Centered Outcomes Research Institute (PCORI). She acts as a liaison between the Engagement and Science programs, helping to manage the organization's research portfolio and supporting the engagement of patient and other stakeholders throughout the course of research studies.

Prior to joining PCORI, she led patient and stakeholder teams as a co-investigator on patient-centered research projects. She began working in health systems as a patient/family navigator in pediatric care, providing peer support to families of children with complex medical conditions and serving as a consumer representative on system-level quality improvement initiatives. She co-led Children's National Health System's patient and family advisory council and the community advisory board for its NIH Clinical and

Translational Science Award. She was formerly a member of the DC-Baltimore Research Center for Child Health Disparities and a qualitative researcher for the District of Columbia's Community Health Needs Assessment. Before becoming active in health care, she worked for many years in the arts field as a grant-maker and performance curator.

Stewart earned a BA in business administration, marketing and finance from Florida A&M University and a MA in socio-cultural anthropology with a concentration in medical anthropology from the University of Virginia.



**Dr. Katherine (Katie) McDonald** is a Professor of Public Health in the *Falk College of Sport and Human Dynamics* and a Faculty Fellow at the *Burton Blatt Institute at Syracuse University*. Dr. McDonald received her B.S. with Distinction from Cornell University and her Ph.D. from the University of Illinois at Chicago. Dr. McDonald is a Fellow with the American Association on Intellectual and Developmental Disabilities.

Dr. McDonald's scholarship has two areas of emphasis: (1) She engages in research aimed to promote the respectful, safe inclusion of people with developmental disabilities in health-related research (for example, Project ETHICS <http://bbi.syr.edu/projects/ETHICS/index.html>); and (2) She uses participatory, capacity building models of action research to understand and address health and community participation disparities among people with disabilities (for example, the Academic Autistic Spectrum Partnership in Research and Education [www.aaspire.org](http://www.aaspire.org) and the Americans with Disabilities

Act Participatory Action Research Consortium [http://centerondisability.org/ada\\_par/index.php](http://centerondisability.org/ada_par/index.php)). In her work, Dr. McDonald collaborates with community groups to define problems to study, design research studies, interpret and disseminate findings, and use findings to foster positive change.

Dr. McDonald teaches about health and disability from a public health perspective, and previously lived in community with people with intellectual disability. She has also served on the Board of Directors for several disability-focused non-profit organizations and is currently the Chair of the Institutional Review



Board (IRB) at Syracuse University. More information, including links to Dr. McDonald's publications: <http://falk.syr.edu/people/mcdonald-katherine/>.



**Unni G. Narayanan, MBBS, MSc, FRCSC**, is a Pediatric Orthopaedic Surgeon and Senior Associate Scientist at the Hospital for Sick Children in Toronto. He is an Associate Professor in the Department of Surgery at the University of Toronto. He is a consultant at the Holland Bloorview Kids Rehabilitation Hospital where he also holds an Adjunct Senior Scientist position at the Bloorview Research Institute.

A graduate of Madras Medical College in India, he completed his orthopaedic residency at the University of Minnesota, a cerebral palsy (CP)/gait analysis fellowship at Gillette Children's Hospital in St. Paul, and a pediatric orthopaedic fellowship at The Hospital for Sick Children. He completed a MSc degree in Clinical Epidemiology at the University of Toronto, before he was appointed to his current position.

A major part of Dr. Narayanan's clinical practice is in the care of children with CP. His research program has focused on understanding patient priorities, their role in clinical decision making, the development and validation of meaningful outcome measures that reflect these priorities, and applying these in clinical trials to evaluate the effectiveness of interventions and health technologies for pediatric musculoskeletal disorders particularly CP. He currently leads two major projects: a randomized trial to evaluate the effectiveness of gait analysis for surgical decision making in children with ambulant CP; and an international multi-centre study of hip outcomes in cerebral palsy. His research is funded by the Canadian Institutes of Health Research (CIHR) and other agencies.

He has served on numerous committees and the Board of Directors of POSNA and the AACPD. He is the 2016-17 President of the AACPD. Dr. Narayanan has won numerous research and teaching awards and has traveled widely to speak about his work on CP, patient priorities and outcome measurement and a wide range of pediatric orthopaedic subjects.



**Jerry Robinson** is a Ph.D. candidate at *Syracuse University's School of Information Studies (iSchool)*. His dissertation research explores the different ways individuals with disabilities make their everyday life practices accessible via life hacking. Jerry's experiences as a person with Cerebral Palsy inspired his research interests. He firmly believes people with disabilities possess a unique ability to individually or collaboratively figure out ways to adapt themselves, the objects they use, and the environments they inhabit to make daily life tasks more amenable to their goals, capabilities, and needs. Jerry is actively looking for career opportunities that will allow him to empower more individuals with disabilities to not only demonstrate their abilities but also live self-determined lives. He expects to defend his dissertation during the spring 2018 semester.

Before starting graduate school, Jerry spent five years working in the financial services industry in New York City. Jerry earned a B.A. in Business Administration from Morehouse College in 2004. He is originally from Saint Louis, Missouri.



**Julia Bascom** serves as Executive Director at the Autistic Self Advocacy Network. Previously, she did state-level work in her home state of New Hampshire, where she served on the DD council and co-led an inter-agency team to revitalize self-advocacy within the state, in addition to her work with ASAN. Julia edited *Loud Hands: Autistic People, Speaking*, an anthology of writings by autistic people, and currently serves on the Disability Equality Index advisory board, the Centene National Disability Advisory Council, and the boards of Advance CLASS, Inc., Felicity House, and The Alliance For Citizen Directed Supports.



**Sara Traigle van Geertruyden** is the *Executive Director of the Partnership to Improve Patient Care (PIPC)*, which is also chaired by former Congressman Tony Coelho, primary author of the Americans with Disabilities Act. Sara joined PIPC in January 2011, and also serves as a Partner at the firm Thorn Run Partners. Her work is focused on policies to advance a patient-centered health system, from patient engagement in research to driving outcomes that matter to patients in healthcare payment and delivery.

Sara is a healthcare and welfare policy expert with 14 years of experience. Sara began her career on Capitol Hill, working for former Senator John Breaux (D-LA) from 1996-2003, first as a projects assistant handling Congressional appropriations and advising constituents on the federal grant process, and ultimately spending over 3 years as a legislative assistant overseeing Senate Finance Committee issues for health and welfare.

In 2003, she joined the law firm Patton Boggs where she practiced in the public policy group handling regulatory and legislative issues related to health care, welfare, and appropriations for clients. Sara has represented clients including hospital systems, pharmaceutical companies, health care provider associations and coalitions. Her scope of work in health policy combines expertise in working with all of the major health care agencies, including the Medicaid Payment Advisory Commission (MedPAC), the Centers for Medicare and Medicaid Services, the Administration on Aging, and the Food and Drug Administration. Sara has also been closely monitoring and engaging the newly created Medicaid and CHIP Payment and Access Commission (MACPAC), the Federal Coordinated Health Care Office, and the Center for Medicare and Medicaid Innovation.

Sara has a strong reputation on both sides of the political spectrum, having staffed Senator Breaux in his efforts to pass legislation that he championed with former Senator Bill Frist (R-TN) to modernize the Medicare program, and in his efforts to raise bipartisan ideas for health reform and T.A.N.F. reauthorization. Sara also has expertise in counseling clients through the Congressional appropriations process.

Ms. Van Geertruyden received her bachelors degree from Wake Forest University and earned her juris doctor at the Catholic University Columbus School of Law.