

In Memoriam/Obituary

MARGARET ANN NOSEK

Dr. MARGARET ANN NOSEK (Peg) (January 25, 1952 - November 21, 2020), a world-renowned social activist, advocate for people (especially for women) with disabilities, and a staunch defender of human rights, passed away in Houston, Texas on November 21, 2020.

As a person with a severe congenital physical disability due to spinal muscular atrophy, Dr. Nosek was a pioneer and activist in the disability rights and independent living movements. She worked closely with Justin W. Dart, Jr., in the 1980's to lay the foundation for and vigorously support passage of the Americans with Disability Act (ADA) of 1990. For her work on the ADA, Dr. Nosek was the recipient of The Americans with Disabilities Act Award and honored as a "Disability Patriot" by the President's Committee on Employment of People with Disabilities (1991). She served as President of Health Care for all Texas for three years.

Born in Schenectady, NY to Stanley M. and Regina A. Nosek, she moved with her family that included her brother Thomas M. Nosek, to Fairfield, Ohio where she attended grammar school. From there the family moved to Berea, Ohio where she graduated co-valedictorian of the Midpark High School Class of 1970. She received the Bachelor of Fine Arts degree from Baldwin Wallace College, Berea, Ohio in 1974 with a concentration in oboe and the Masters of Arts Degree from Case Western Reserve University in Cleveland, Ohio, in Music History in 1976. During her master's studies, she was a Lecturer in the Department of Music at Baldwin Wallace College, publishing a series of articles on "The Recorder in the Sixteenth and Early Seventeenth Centuries" and a collection of songs she composed to celebrate Vedanta. She organized an early music consort which was very popular in the Cleveland area in which she played the recorder. She left Cleveland in 1977 to pursue a Ph.D in Music Theory at the University of Texas in Austin, Texas (1977-1979) where she was an Assistant Instructor in the Department of Music (1978-1979). While there, she became involved in the independent living movement and met Justin Dart, Jr. who became her mentor. She stopped her studies to work with Mr. Dart and they toured the country visiting Independent Living Centers and wrote a seminal paper together titled "A Philosophical Foundation for the Independent Living Movement". Following the publication of this work, she was a coordinator for the 504 Training and Technical Assistance Project at Barrier Free Environments, Inc. in Raleigh, NC.

To further the cause of women with disabilities, she returned to the University of Texas where she earned a Master of Arts Degree in Rehabilitation Counseling (1980-1982) and then a Ph.D. in Rehabilitation Research (1982-1984). While at the University of Texas, she served as a Special Assistant to Mr. Dart on the Governor's Long-Range Planning Group for Texans with Disabilities (1982-1983). After graduating with the Ph.D., she went to The Baylor College of Medicine in Houston, Texas as an Assistant Professor, working her way up the academic ladder to tenured Full Professor (1998) in the Department of Physical Medicine and Rehabilitation

where she worked for 36 years until the time of her death. In 1993, Dr. Nosek founded and served as executive director of the Center for Research on Women with Disabilities (CROWD, <https://www.bcm.edu/research/labs-and-centers/research-centers/center-for-research-on-women-with-disabilities>). She was also Adjunct Professor in the College of Nursing at Texas Woman's University in Houston, Texas, Adjunct Associate Professor in the Department of Family Practice and Community Medicine at the University of Texas, Houston, Research Professor in the Department of Technology at the University of Texas, Houston, and Adjunct Associate Professor in the College of Occupational Therapy at Texas Women's University in Houston. During her early years at Baylor, Dr. Nosek served as Director of Research for the Independent Living Research Utilization Program at the Texas Institute for Rehabilitation Research (TIRR). She also held the position of Senior Scientist and Research Coordinator at the TIRR Memorial Hermann Outpatient Medical Clinic from 2014-2018.

Dr. Nosek served as principal investigator on research grants from the National Institutes of Health, Centers for Disease Control and Prevention, the National Institute on Disability and Rehabilitation Research, the National Library of Medicine, and from private funding sources. Her grant funding totaled more than \$16 million. She was an internationally recognized authority on the health of women with disabilities. Dr. Nosek published over 96 articles in refereed academic journals and over 25 book chapters. She was on the editorial boards of many prestigious medical journals including the Disability Health Journal, Rehabilitation Psychology, Journal of Rehabilitation Sciences, Journal of Disability Policy Studies, and Rehabilitation Counseling Bulletin. She was a reviewer for The Lancet, The Lancet-Public Health, Violence and Victims, Contemporary Clinical Trials, Journal of Clinical Epidemiology, Journal of Criminal Justice, American Journal of Preventive Medicine, International Journal of Obesity, Journal of Health Care for the Poor and Underserved, Preventive Medicine, Violence Against Women, Social Science and Medicine, Women's Health Issues, Journal of Women's Health, and the Archives of Physical Medicine and Rehabilitation. She served as a guest editor for Sexuality and Disability and the Archives of Physical Medicine and Rehabilitation. Dr. Nosek was on grant review panels for the National Institutes of Health, the Health Services and Population Health Research Committee of Scotland, the Executive Agency for Higher Education Research, Development and Innovative Funding – National Research Council of Romania, Centers for Disease Control and Prevention, National Institute on Disability and Rehabilitation Research, and the Texas Department of Human Services.

Dr. Nosek was a popular speaker for numerous local, state, and international disability organizations. She contributed to their popular publications, providing advice to people living a ventilator-assisted life that required attendant care. In the domain of independent living, she investigated community integration of women with spinal cord injury, the assessment of independent living outcomes, concepts of independence and self-esteem among persons with disabilities from cultural minority groups, personal assistant services, independent living program operations and management, and disability-related public policy. Her research and writings focused on the psychosocial and physical health of women with disabilities, Internet-based interventions, secondary conditions, health promotion, reproductive health care, disability-based health and healthcare disparities, sexuality, self-esteem, spirituality, and violence against women with disabilities. Her last research project was examining the efficacy and effectiveness of health promotion interventions tailored to the concerns of women with physical disabilities.

These interventions were designed for delivery using interactive websites and online virtual immersive environments, specifically Second Life (SL). She worked to promote the use of SL, serving on the Board of Directors of Virtual Abilities, Inc., a non-profit organization devoted to enabling people with a wide range of disabilities to thrive in online virtual worlds both through educational and social opportunities that may not be available to them in the “real” world.

Dr. Nosek was an expert in using of all forms of technology in order to enable her to interact with her professional and private communities. She used voice recognition when she found it difficult to type on her computer. When her ability to travel was curtailed, she continued to give professional presentations and take part in meetings with collaborators over the Internet, going so far as to use a robot (the one popularized on “Big Bang Theory”) that she could control from a distance to attend, present, and answer questions at an American Public Health Association national meeting.

In the local community and across the country, Dr. Nosek was a strong advocate for the rights of disabled women, helping them achieve equal access to inclusive, competent, and medically appropriate health services and information. Besides her professionally-related activities, Dr. Nosek was a founding member of the Vedanta Society of Houston, serving as their first president and helping them establish a strong presence in the community. She was also active with the Live Oaks Friends Meeting of Houston. On a lighter note, she was an advocate for the “total dark chocolate” diet!

Dr. Nosek’s honors are legion. From her alma maters, she received the Academic Hall of Fame Award from Midpark High School (2000), the Alumni Merit Award from Baldwin Wallace College (1974), the Outstanding Young Texas Ex Award from the University of Texas, Austin (1993), and was chosen as one of five most outstanding graduates of the University of Texas Department of Special Education (1990). She received the John Stanley Coulter Memorial Lectureship from the American Congress of Physical Medicine (1999), “The Vent Life” Print Journalism Award from the National Easter Seal Society (1997), the James F. Garrett Award for a Distinguished Career in Rehabilitation Research from the American Rehabilitation Counseling Association (2016), Lifetime Achievement Award from the American Public Health Association (2007), the W.F. Faulkes Award from the National Rehabilitation Association (1997), the James Garrett Early Career Achievement Award from the American Psychological Association (1994), and the Women on the Move Award from Texas Executive Women (1993). Dr. Nosek was a Fellowship recipient from the World Rehabilitation Fund-International Exchange of Experts and Information in Rehabilitation (1989) and was selected as a Switzer Scholar for the Ninth Switzer Memorial Seminar by the National Rehabilitation Association (1984). Dr. Nosek was the recipient of The Americans with Disabilities Act Award, U.S. House Task Force on the Rights and Empowerment of Americans with Disabilities, Congressman Major R. Owens, Chairman (1991), and she was recognized and honored as a “Disability Patriot” by the President’s Committee on Employment of People with Disabilities (1991). In 2012, Dr. Nosek was honored with the Local Peacemaker Award by the Houston Peace & Justice Center for her advocacy for brothers and sisters with disabilities, for her determined leadership to remove physical barriers that deprive our brothers and sisters of the opportunity to participate fully in life, and for her just position in support of millions without health care by proclaiming health care as a right, not a privilege.

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Dr. Nosek is survived by her brother, scientific collaborator, and co-author Dr. Thomas M. Nosek and his wife Claudia of Berea, OH and Hilton Head Island, SC, nephew Thomas A. Nosek and his wife Kaycee of Sparta, NJ, and nephew Christopher M. Nosek, his wife Amy, and sons Quinton and Maxwell of Marietta, GA. She is also survived by her caregiver of 25 years, Perla Pedraza and her husband Gereasmo and their children Oscar, Aldo, Gina, and Edwin.

Those who would like to honor Dr. Nosek and help to continue her work in disability research and disability rights advocacy can donate to the Texas Exes Margaret A. Nosek Scholarship at the University of Texas, Austin (512-840-6195, www.texasexes.org/give/). This scholarship is awarded annually to students who are at the senior, master, or doctoral level - they must certify that they have a disability that causes a significant functional limitation in one or more major life activities and provide evidence that they have an ambition to pursue a career in research in any academic area. Preference is given to traditionally underrepresented groups. Donations can also be made to the Houston Center for Independent Living (713-974-4621, www.hcil.cc).

We will hold a celebration of Dr. Nosek's life over Zoom on Saturday, December 12th, 2020 at 2:00 PM EST (i.e.1:00 PM CST, 12:00 noon MST, and 11:00 AM PST). If you would like to attend the celebration, please email Dr. Nosek's brother Tom at tmnosek@aol.com and he will send you the Zoom link. Please let him know how you know Dr. Nosek. The celebration will be recorded and made available to those who are not able to attend.