



Caregiver Summit Cumbre Para Cuidadores

December 1, 2018



Angela Roberts, Ph.D.
Assistant Professor

Dr. Roberts is an Assistant Professor in the Roxelyn and Richard Pepper Department of Communication Sciences and Disorders at Northwestern University. She is the Principal Investigator of the Language and Communication in Aging and Neurodegeneration Lab. Dr. Roberts has practiced as a speech-language pathologist for 23 years, working with individuals with neurodegenerative disorders including Parkinson's disease and Alzheimer's dementia. Her research and clinical work focuses on better understanding the nature of communication difficulties in Parkinson's disease, the impact of these difficulties on maintaining and creating productive relationships, and developing interventions that address communication challenges and caregiver burden.



Sheila Silver, MA, DHS, ACS
Clinical Sexologist

Dr. Silver is a board certified clinical sexologist in private practice in Portland, OR. She has a Masters degree in Marriage, Family, and Child Therapy, and earned her Doctorate in Human Sexuality. She is a trained sex counselor, group facilitator, sex educator, and has worked as a psychotherapist since 1988. In addition to her private practice, Dr. Silver acts a consultant to mental health professionals, medical doctors, physical therapists, and clergy on their cases relating to sexuality. She also presents nationally at professional conferences and offers workshops on the topic of maintaining physical and emotional intimacy, with a specific expertise in Parkinson's Disease.



Annie Wallis, MSW

Annie's primary focus as Associate Director of Education for the Parkinson's Foundation is providing quality informational programs and resources for people with Parkinson's disease, their caregivers and loved ones, and the professionals who are part of the medical and care team. In addition, Annie masterminds the production and distribution of educational materials in English and Spanish, serves as a liaison to the foundation staff working across the country, and works to outline the educational agenda and manage online and in-person educational courses. Prior to this role within the Foundation, Annie served for nearly three years as the Ohio Chapter Program Manager, where she was responsible for increasing the impact of the Parkinson's Foundation's mission throughout Ohio.



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Doug Zabor
Caregiver
Caregiver Summit Planning
Committee Member

Doug recently retired to an aging-in-place home in Pittsboro, NC with his wife, Magda. He married late at age 35 and quickly produced 3 wonderful boys in 3.5 years. Within 6 years of marriage, Doug began to see Magda's first PD symptoms. Sadly, she wasn't diagnosed for 10 years. In that time Doug was growing his marketing research business and watched from the sidelines as multiple doctors made wrong diagnoses, treatments.

Doug is active in multiple PD support groups. He serves as a Triangle Moving Day captain for Fearington Village, initiated "Parkinson's ... no walk in the park", to raise awareness and support for PD, and sits on the Community Grants committee to support new programs for patients and care partners. Since 25, Doug has been a 4 time entrepreneur. His medical marketing research firm studied early PD medications. Today, his research background helps him scour clinical trials for a science-based approach to collaborative care through exercise, nutrition, and home control. His most recent adventure is a DIY home assessment tool to help reduce fall risk and age gracefully at home. Doug remains active in United Church. He continues his love of music in 5 instrumental and singing groups. As a survivor of both a stroke and cancer, he attributes his robust health to the practice of collaborative care.



Caryn Balaban
Caregiver
Caregiver Summit Planning
Committee Member

Caryn has an extensive educational and professional background in medical market research. Prior to retiring, Caryn conducted qualitative market research for pharmaceutical companies, medical device manufacturers and suppliers, laboratories, hospital and healthcare organizations, advertising agencies, and insurance companies in the United States and the Europe. Caryn is a care partner for her husband Al, who was diagnosed with PD just over 3 years ago. She brought Rock Steady Boxing to the Valley, became a Board member of the Phoenix Brandeis National Chapter, is chairing an auction to benefit medical research into neurodegenerative diseases and is a member of the Parkinson's Foundation People for Parkinson's Advisory Council [PPAC].



L. Addison Diehl
Caregiver

Addison is in his eighth year of caregiving for a parent with PD, three of them full-time. He has designed, developed, and delivered curriculum for caregivers, specifically for those facing ambiguous loss—the experience of grieving the loss of someone both "here" and "not here"



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Lisa Seghetti
Caregiver
Caregiver Summit Planning
Committee Member

Lisa Seghetti has spent her entire professional career in public service. She began her professional career at the Illinois Department of Children and Family Services as a social worker. In 2001, Mrs. Seghetti relocated to the Washington, D.C. area after she accepted a position at the Library of Congress' Congressional Research Service (CRS). There she led a team of policy experts that provided research and analysis to Members and committees of the U.S. Congress on a variety of social policy issues. In 2016, Lisa accepted a leadership position with the Federal Judiciary. In her current capacity, she manages a Division that is responsible for producing analytic reports to the Judiciary, Congress and the public. She also oversees the efforts to assure the quality of judicial caseload data and the effort to make such data is more visible and accessible through data visualization tools. Lisa joined the Parkinson's Foundation Parkinson's Advocate in Research (PAIR) program in 2016. As an advocate, Lisa served on a panel that reviewed grant applications for the Parkinson's Foundation Summer Fellowship program. She also supported a bilingual Parkinson's Disease informational session. Prior to joining the Foundation, Lisa stood alongside her father who suffered from Parkinson's disease. Although officially diagnosed in 2008, her father had been living with the disease for many years. Sadly, he succumb to complications related to the disease in 2012.



Leslie Peters
Caregiver
Caregiver Summit Planning
Committee Member

Leslie Peters's journey with PD started in 1998 when her mother-in-law was diagnosed. In 2007 her husband developed his first symptoms. Leslie currently serves as the Co-Chair of the Parkinson's Foundation's People with Parkinson's Advisory Council (PPAC). Getting involved with the Parkinson's Foundation and advocating for people with PD has changed the course of her life. She is honored to be part of the care partner's summit.



Dean Clarke Taylor
Caregiver

Dean is a 68-year-old caregiver to his life partner, Bill Sabatino. Almost four years ago, Bill's numerous medical issues were misdiagnosed and improperly treated. Everything fell into place when Bill was finally diagnosed with Parkinson's Disease.

Bill and Dean are grateful for each day they are given to be together. Their journey is one of communication, compassion, collaboration, listening, and love.

Learning about PD and applying that knowledge to both their daily lives has brought a new dimension to the meaning of relationship, hope, help, respect, dignity, support, mortality, and gratitude.

"Each day is a gift. Each day is a gift. Each day is a gift. Repeat."