UCSF Memory and Aging Center
Family Advisory Council
2015

Family Advisory
COUNCIL
UCSF Memory and Aging Center

FAMILY PARTICIPANTS

Robert Blomberg

After returning from Peace Corps service in Peru in 1965, I (finally) completed my undergraduate degree at UC Berkeley in 1966. I later returned for a master's degree and a doctorate in Public Health, both with an emphasis in health behavior and reproductive health/demography. Between the latter academic sojourns, I worked for the Ford Foundation in Bogotá, Colombia as a Population Program Advisor for three years, 1970–1973, providing grant development for initiatives in Colombia, Venezuela, Ecuador, Peru and Bolivia. Upon completing my doctorate, I worked for three years at the West Coast Cancer Foundation where I served as assistant director of the Behavioral Health Division and headed a research project on the psychosocial aspects of cancer care. I subsequently served as director of the Western Region Office of the Planned Parenthood Federation of America, providing technical support and guidance to Planned Parenthood affiliates in 14 Western states; I retired from that position in 2006 after 27 years of service. Throughout my career I worked as an occasional consultant on the development and evaluation of reproductive health programs in Africa, Asia and Latin America. I met my future wife, also a Peace Corps volunteer, in 1963; we were married in 1966. She was a schoolteacher who decided to become a university professor of education. After completing her doctorate at UC Berkeley, she participated in a variety of research projects before taking a position on the faculty at the Graduate School of Education at San Francisco State College where she became a full professor and served for 20 years. She died of primary progressive aphasia in October 2014. I/we have two adult children (both of whom live in Berkeley) and two grand children.

John Elliot

My wife Sarah was diagnosed with Alzheimer's disease nearly ten years ago and has been in a care facility since April 2010. I usually see her twice a day. We have lived in San Jose/Carmel for 53 years. I was with Morgan Stanley for 40 years, having managed the San Jose office for 15 years, before retiring in 2002. Dr. Miller and his UCSF staff have been a true blessing in this AD battle.

Sharon Farber

My name is Sharon Farber, and I reside in Westlake Village, California. My husband, Bob, was diagnosed in 2011 with corticobasal degeneration (CBD). He was a strong, vital, handsome, healthy 60-year old man, who held the position of CEO of a security software company here in Westlake Village. We were married 45 years; he was my high-school sweetheart. Our marriage was a love story of two teenage kids who met, fell in love, got married at 19, and gave birth to our only child, Bobby, one week shy of our 20th birthdays!

Our story was never meant to end the way it did.

I became a caregiver prior to the diagnosis, as there were “signs” that my family and I had noticed that were of concern. At the time of diagnosis, my life changed forever. I had no idea what I was up against. This disease has not one adjective to describe it! Nothing that anyone, but me did for him, was ever good enough. I exhausted every single possible “solution” to make his last years filled with quality, dignity and my unending presence in his life. I am, to this day, never completely assured that I accomplished these things, although I have been told by everyone that “I did everything I could have done!” It was a losing proposition from the beginning.

My hope now is to help other people on this journey that they are about to embark upon. If I can do one thing, for one person, to make their life easier, more comprehensible—to hold their hand through the awful times, I will have accomplished what I always hoped I could, and tried to do for my husband and myself.

Adele Kellman

My husband, Jeff, and I live in Los Altos Hills and have been married over 33 years. We have three children—two girls, ages 27 and 25, and a boy aged 20. Jeff was diagnosed with progressive nonfluent aphasia two years ago, retiring immediately thereafter. Last year, he was also diagnosed with corticobasal degeneration. He is still relatively independent but no longer drives. He has had increasing difficulty speaking fluently to the point that I often interpret what he wants to say, and he is generally silent in a group of friends. He relies on me to speak for him when we are in public. Overall, he has a good attitude.

Carol Lei

I was a caregiver to my husband, Ray, who had early onset Alzheimer's disease. He was diagnosed in 2010 and passed away in 2014 at age 64. I have two daughters, currently in the 8th and 9th grades, and I work full time for the City and County of San Francisco as a program manager.

Linda Woo-Lim

My name is Linda Woo-Lim and my husband, Wally Lim, was diagnosed with early onset Alzheimer's Disease 15 years ago at the age of 50. It has taken me a long time to write this bio. Every time I start to write about my husband and how this disease has affected him and our family, I become so distraught that I am unable to finish. What has been most difficult for me is to see how the progression of this disease has changed Wally from an outgoing, intelligent, active individual to someone whose mental capacity is gone and whom I know is suffering physically. Despite the stress and turmoil this disease has caused our family, our children have grown up to be wonderful human beings. Hopefully, there will be a breakthrough in treating this devastating disease in the very near future.

Charlie Maguire

My wife, JoEllen and I, both San Francisco natives, were married in 1963. We were blessed with three sons and eight grandchildren. JoEllen was diagnosed with primary progressive aphasia in January 2007, about 1½ years after first noticeable onset. We first came to the Memory and Aging Center clinic the following year and immediately decided to be a part of the FTD research study. I was able to care for JoEllen at home until June 2011 at which time she became a resident at Silverado Senior Living in Belmont until her death on July 3, 2014. I often wonder how I would have ever made it through those dark years without the MAC and its incredible staff.

Susan Matteucci

Susan Matteucci is the eldest of four children whose beloved mother has late-stage Alzheimer's disease. Her father is the primary caregiver, and she and her adult siblings are the "secondary" caregivers. Susan has worked in journalism and refugee policy in Washington DC and in international marketing and Internet startups in Silicon Valley. She has an MA degree in international relations from Johns Hopkins University School of Advanced International Studies and an MA degree in theology from Fuller Theological Seminary. She resides In Burlingame, California, with her husband and 12-year-old son.

Lyle McCarty

My wife has frontotemporal dementia (FTD). While officially diagnosed five years ago at age 50 we can trace symptoms back 15 years ago, right after the birth of our youngest child. Sadly her earliest symptom was a loss of empathy and sympathy followed by ever increasing outbursts of anger and contempt directed at our children and me. We had many rough years as her disease ripped our family apart. The turning point was the diagnosis of FTD by the doctors at UCSF—at least we knew what we were dealing with. Today my wife's dementia has progressed to the point where her personality is totally flat, as she is unable to feel or understand any emotions, which, sad to say, is a huge relief. We moved her into a dementia care home last September, which was been a huge improvement for everybody.

Helen Bundy Medsger

I have been advocating for family members suffering from neurological disorders since I was an adolescent. Growing up with a mother who had suffered a catastrophic cerebral aneurysm, I found that her mother's health care network was unwilling to provide supportive services to a young family dealing with the overwhelming task of in-home caregiving. This experience continued when my father was diagnosed with dementia with Lewy bodies, immediately resulting in placement in skilled nursing for the remaining five years of his life and requiring Medi-Cal funding to pay for his care. Currently, I am the primary caregiver and health care advocate for her sister who also has a diagnosis of dementia with Lewy bodies. With additional family members who have been diagnosed with Parkinson's disease, I believe that research will provide answers and have been principal in linking my family to research projects in genetics, Parkinson's diseases, and dementia in multiple states. As a member of the Family Advisory Council to the UCSF MAC, I hope that my years of experience in dementia care and health care advocacy will give voice to families who have received a life-altering diagnosis of dementia and provide them with the avenue to a supportive care system much different from the crisis management response I have dealt with for decades.

Pamela Roberts

My husband self-diagnosed his memory issues. In 2002 my husband was fully retired, and I was working in San Francisco. Since I was not at home during the day, I was not aware of issues my husband was beginning to experience regarding losing things and misjudging spatial relationships. He complained to our doctor, who arranged for Dave to be evaluated at UCSF Memory and Aging Center where after very extensive testing he was diagnosed with MCI (mild cognitive impairment), and his diagnosis remained as MCI for about six years, during which time we participated in several studies and were visiting UCSF about every two months or so. In mid-2009, the diagnosis changed to Alzheimer's, consistent with what the staff explained was the typical progression from MCI for usually more than half of those with MCI. In 2005 I was able to move my work to our home so that I could observe and assist Dave as things became more challenging for him. I cared for Dave at home until March 2, 2015 when he moved to an all Alzheimer's facility nearby. The first 5–6 weeks he was there he seemed to be experiencing normal decline moving into the later stages of the disease. Then he started to decline rapidly. On Memorial Day, Hospice indicated that Dave could possibly pass away that week. The children and his sister were able to come and together we were able to be with him over his last days, and we were all there when he died in the morning of May 29.

Suzanne Tay-Kelley

Myles and I met in 1984 at San Jose State, marrying four years later. Myles grew up raising Appalachian Blue Ribbon racehorses on a thoroughbred ranch in Georgia. He served as a police officer, then physiology professor in the Bay Area until his corticobasal degeneration diagnosis in 2012; he no longer works, but enjoys his loves of gardening, history, and animals in our studio on the peninsula.

I was a journalist for eight years (Los Angeles Times, Oakland Tribune), a healthcare management consultant for five (PricewaterhouseCoopers, Kaiser Permanente), then an acute care nurse at UCSF for a decade. In 2010 I collaborated with clinical nurse specialists in geriatrics at Kaiser to improve inpatient dementia care. In 2013 I co-founded and was Clinical Nurse III resource for the Mount Zion palliative care council; I served on the UCSF Spiritual Care Services professional advisory group, and completed CSU Palliative Care Institute certification for advanced practice nurses.

Currently, I continue to practice palliative care and strive toward streamlining care delivery as a GI-Oncology nurse practitioner with Stanford in my perennial quest to discover truth, ease suffering, and clarify meaning in our journey.

Louise Tilston

My husband was diagnosed with dementia in 1998. I was fortunate to be able to have him at home for many years, at first on his own and later with the use of an Adult Day Care Program and in home help. Finally it became unsafe for him to remain at home and I put him in a Memory Care Facility about 6 years ago. This journey of dementia will be different for everyone, but the constant will be the need for compassionate and understanding physicians and staff to guide and support us on this unfamiliar and unchosen path. My husband and I have been fortunate to have four amazing children who have stood by him and helped us both as our story continues to unfold.

MAC STAFF PARTICIPANTS

Lena Driscoll

I am a full-time nurse in the Memory and Aging Center Clinic. I completed my master's degree in nursing at UCSF School of Nursing. Prior to being a nurse, I worked for biotechnology companies doing research in skeletal and neurological diseases. I'm happy to be part of the MAC team! In my free time you can find me gardening or hiking around San Francisco.

Rosalie Gearhart

I am a Gerontological Clinical Nurse Specialist and have a master's in degree in nursing administration at UCSF. I serve as Administrative Nurse for the Memory and Aging Center and oversee center operations. I work closely with both faculty and staff on quality of care initiatives and program development focusing on optimizing the functional status of each patient and maintaining the quality of life for both the patient and caregivers. I live in the Bay Area with my husband, two daughters, and golden Labrador.

Julia Heunis

I was born and raised in Cape Town, South Africa. I graduated from UC Berkeley in May 2014 with a bachelor of arts degree in integrative biology, with a special focus on human biology and health sciences. As an undergraduate, I volunteered as a research assistant in Alison Gopnik's Cognitive Development Lab, where she investigated the acquisition of infants' ability to understand others' preferences, as well as other childhood cognitive developmental processes. During my time at Cal, I also choreographed hip-hop dances and was a member of a competitive hip-hop team. I joined the Memory and Aging Center in November 2014 as a clinical research coordinator and Care Team Navigator for the CMS-funded Care Ecosystem. In my free time, I spend time with friends, exploring beautiful San Francisco, and continuing to pursue my passion for dance. I am also currently applying to medical school to fulfill my lifelong dream of becoming a physician.

Jennifer Merrilees

I am a Clinical Nurse Specialist in Geriatrics and have been with the MAC since 2001. In 2010, I completed my PhD in nursing. I participate in the leadership of the MAC clinical services and am involved in several projects focused on dementia family caregivers. I am a co-investigator for two NIH-level funded project focused on dementia family caregivers: both studies focus on emotions. One seeks to characterize the nature of emotions experienced by dementia family caregivers and the other aims to increase positive affect as a strategy for coping with stress. I live in Moss Beach with my husband Neil: we have two daughters, age 18 and 21, who are both in college.

Bruce Miller

I hold the A.W. and Mary Margaret Clausen Distinguished Professorship in Neurology at the University of California, San Francisco (UCSF) and direct the UCSF Memory and Aging Center where patients in the San Francisco Bay Area and beyond receive comprehensive clinical evaluations and participate in research. My goal is to foster model care to patients with dementia and their families. I am a behavioral neurologist focused on dementia with special interests in brain and behavior relationships as well as the genetic and molecular underpinnings of disease. I have a special interest in the association between neurodegeneration and creativity. I live in San Francisco with my wife Deborah. We have two children. I am also a proud grandfather.

Georges Naasan

I received my medical degree from the American University of Beirut in Lebanon and then completed internship and neurology residency at Case Western Reserve University. As a neurologist, I evaluate patients and research participants with various neurodegenerative disorders through a multidisciplinary approach and provide follow-up care. My particular interest is the psychotic manifestations of neurodegenerative diseases such as hallucinations and delusions.

Kate Possin

I am an Assistant Professor at the Memory and Aging Center within the UCSF Department of Neurology. I am the Associate Director of the CMMI Healthcare Innovations Award “The UCSF and UNMC Dementia Care Ecosystem: Using Innovative Technologies to Personalize and Deliver Coordinated Dementia Care.” Dr. Possin’s research also examines the neural bases of cognitive changes in neurodegenerative diseases including Parkinson’s disease, Alzheimer’s disease, Huntington’s disease, and frontotemporal lobar degeneration. I develop cognitive measures that are sensitive to the earliest cognitive changes in these disorders and that can assist with early diagnosis and disease monitoring. With Quest Diagnostics, I am developing a Neurobehavioral Screen to support early dementia diagnosis in primary care. This screen is being programmed in the TabCAT framework, which is a platform I designed for tablet-based assessment. My research is funded by a National Institute on Aging K23 Career Development Award and by grants from the Michael J. Fox Foundation, the Hellman Family Foundation, and the Alzheimer’s Association. I live in Marin with my husband and adorable son who recently turned one.

Cathy Wang

I earned a master's in social work from Columbia University in New York. I have worked with adults and seniors in hospitals, patients' homes, and clinics. I am also a consultant, training and supporting social workers in long-term care facilities to maintain state licensure and accreditation. Before joining UCSF, I was a social work discharge planner, ensuring patients have services in place upon leaving the hospital. I am an advocate for patients, families, and caregivers through supportive education and linking them to appropriate resources to meet their needs.