



UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®

WELCOME AND MEET

THE ADULT ADVISORY COUNCIL TEAM (AACT)
ESTABLISHED 2006



AACT Co-Chair

My name is Joy Krumdiack, and I live in Bellingham, Washington. I was diagnosed with mitochondrial disease in 2000, and I am the UMDF Ambassador for Northwest Washington. I joined the Adult Advisory Council Team in January of 2013.

AACT Co-Chair



My name is Gail Wehling, and I live in St. Charles, Illinois. I was diagnosed with CPEO (Chronic Progressive External Ophthalmoplegia) a form of Kearns Sayre Syndrome at age 16. I have been involved with UMDF since 2000 serving on the Chicago Chapter and as Co-Chair of the Adult Advisory Council Team. I am enrolled in a number of mitochondrial disease patient registries, including the newly created UMDF Mitochondrial Disease Community Registry (MDCR). In addition, I have participated in a number of studies and clinical trials.



Young Adult Chair

My name is Devin Shuman, and I am currently living in Las Vegas, NV working as a prenatal genetic counselor. I was diagnosed with mitochondrial DNA depletion syndrome in 2010. In 2014, I joined the Adult Advisory Council Team as the Young Adult Coordinator. I have also been a Youth Ambassador for UMDF since 2011.



My name is Mia Bell and I live in Adelaide, Australia. In 2003 I was diagnosed with Mitochondrial Myopathy 3302 A>G while I was living in the UK and under the care of Professor Poulton in Oxford. This is a maternally inherited mitochondrial disease. I moved back to Australia 12 years ago and was re-diagnosed. I am passionate about using my limited energy to support others in the Mito community, and to raise awareness, share information and contribute to research about the disease.



My name is Kailey Danks, and I live in Toronto, Canada. I was diagnosed with CPEO+(Chronic Progressive External Ophthalmoplegia) a form of Kearns Sayre Syndrome in 2008 after over 10 years of testing. I am new to the Adult Advisory Council Team and I joined in 2014. I am also a Peer Support Volunteer for MitoCanada and am very excited to be a part of the Adult Advisory Council Team.



My name is Whit Davis, and I live in Collegeville, Pennsylvania. I was diagnosed with Kearns Sayre Syndrome in 1981. I joined the Adult Advisory Council Team in 2011.



My name is Deb Fox and I live in Sedona, Arizona. I was diagnosed with Mitochondrial Myopathy in 2008 after numerous lifelong misdiagnoses. I have served on the Adult Advisory Council Team as the Adult Liaison Coordinator since 2009.



My name is Rev. David Hamm, and I live in Severn, Maryland. I was diagnosed with MELAS (Mitochondrial Myopathy, Encephalopathy, Lactic Acidosis, Stroke) in 2005. I have been a member of the Adult Advisory Council Team since April 2007.



My name is Christy Koury, and I live in the suburbs of Charlotte, NC. I have a clinical diagnosis of mitochondrial disease. Two of my children are affected as well. I have worked with the UMDF in various capacities since my oldest daughter was diagnosed in 2006.



My name is Terry Livingston, and I live in Seminole, Florida (Tampa Bay area). I was clinically diagnosed over 35 years ago with Chronic Progressive External Ophthalmoplegia (CPEO) Plus/Mitochondrial Myopathy. I joined the Adult Advisory Council Team in 2014.



My name is David McNeas, and I live in Chardon, Ohio. I was diagnosed with Complex IV Deficiency, Mitochondrial Myopathy, Neuropathy, and Dysautonomia in 2011. I am a Montessori teacher, and I joined the Adult Advisory Council Team in January of 2013.



My name is Linda Ramsey and I live outside Buffalo, New York. I have been involved with the UMDF since 1997 after my son passed away from what we learned later was a rare inherited condition of Leigh's Syndrome. Since then I have lead support groups, chaired and co-chaired fundraisers and events, and remain committed to increasing awareness and providing support for families affected by mito.



My name is Jennifer Schwartzott, and I live in North Tonawanda, New York. I was diagnosed with Mitochondrial Myopathy in 1990. I have been involved with UMDF since 1998 and previously served at the co-leader of the NY Chapter and co-chair of the Energy For Life Walk-NY. I joined the Adult Advisory Council Team in June of 2012 and became co-chair in May of 2014. I am a UMDF Ambassador and also serve as a Patient Representative for Mitochondrial Disease for the FDA.



My name is Sharon Shaw. My motto is "be of service and part of the solution", and you just mind find this to be the best medicine of all! I was diagnosed with mitochondrial disease in 1999 and live in Tucson, Arizona. I have served on the UMDF's Board of Trustees for over a decade; currently holding the position as "member liaison" and Secretary. I have been involved with The Adult Advisory Council since its inception. I serve on the FDA's first Mitochondrial Patient Advisory Committee. I was newly appointed onto The Department of Defense "D.O.D" first Mitochondrial Patient Advisory Committee. I keep my mental focus positive by helping UMDF in their mission to educate, help patients and families and raise money for research.



My name is Gregory Yellen, and I live in Pasadena, Maryland. I was diagnosed with Kearns Sayre Syndrome in 1989, and I have been learning about mitochondrial disease ever since. I became involved with the Adult Advisory Council Team in 2007.

IN MEMORIAM

Robert "Bob" Brieff
1944 – 2015

Bob was a proud New Yorker and Wisconsin Badger. He had a great mind, sense of humor and many interests. He was also very kind, giving and generous. With tireless dedication, Bob was one of the vital, original UMDF AACT Council Members instrumental in its development, mission and purpose. And, he was deeply committed to carrying out UMDF's mission - even until the time of his passing. He loved life and fought valiantly with courage and dignity. We will miss him greatly.

Thank you, Bob.
Shalom.

