



**UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®**

ADULT ADVISORY COUNCIL TEAM

EST: 2006

AACT TEAM

**Joy Krumdiack, Co Chair
Washington**

**Gail Wehling, Co Chair, Illinois
Devin Shuman, Young Adult Chair,
Nevada**

**Mia Bell, Adelaide, Australia
Kailey Danks, Toronto, Canada
Whit Davis, North Carolina
Debra Fox, Arizona
Rev. David Hamm, Maryland
Christy Koury, North Carolina
Terry Livingston, Florida
David McNees, Ohio
Linda Ramsey, New York
Jennifer Schwartzott, New York
Sharon Shaw, Arizona
Gregory Yellen, Maryland**

MEDICAL ADVISORS

**Bruce Cohen, MD
Amy Goldstein, MD**

AACT Purpose

To represent and serve the unique needs of the affected adult community and to ensure that those needs are adequately represented to UMDF resulting in enhanced services to the affected adult population. AACT is a liaison to the UMDF Board of Trustees whom will assess and evaluate, provide advice and guidance, and make recommendations to UMDF on all adult related issues and/or needs.

www.umdff.org/AACT

connect@umdff.org

AACT- ADULT CORNER PAGE

UMDF AACT is very excited to announce a new member to the Council, Mia Bell. Mia is our first International Council Member from Australia! Currently, AACT has 15 Council Members serving throughout the United States, Canada, and now Australia.

Hi everyone!

My name is Mia and I live in Adelaide, Australia. I was recently nominated as the Mito Foundation's Australian representative to AACT, and am very pleased to have 'met' some of the AACT Committee over Zoom and be involved with the work of the AACT group.



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. We have several excellent Mito specialists (as well as paediatric Mito specialists) here in Adelaide.

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.

I am currently the Chair of the Mito Foundation's MCAP (Mito Community Advisory Panel), and set up the first support group for Mito patients in Adelaide. That group now has around 30 members. This year I have been involved with advocating for mitochondrial donation (or Mitochondrial Replacement Therapy) which is currently legal in the UK but not in Australia.

When I was initial diagnosed with Mito there was not a lot of information about how to manage the disease, and very little support. Even having a diagnosis, I didn't know anything about mitochondrial disease and I didn't know how to manage the symptoms. At that time it was common for patients to receive a diagnosis of mitochondrial disease and simply be sent home without any further information. It wasn't until eleven years after my diagnosis that I met anyone outside of my family who had Mito.

Once I was able to learn about how to manage my symptoms - through a combination of supplements, tailored nutrition, appropriate exercise and sufficient rest - I have been able to improve my health and my lifestyle. I work part time, raise my kids, volunteer in the community and have a full life, while living with Mito.

I am passionate about helping other people to do the same, through access to excellent medical care, informed and appropriate therapies, and plenty of useful and reliable information about mitochondrial disease and how to accommodate it within your life.

This would not be possible without the medical and scientific research into Mito, and the tireless work of both the UMDF and the Mito Foundation.