



**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,
Pennsylvania

- Kailey Danks, Toronto, Canada
- Whit Davis, North Carolina
- Nicole & Lillian DeJean, Louisiana
- Debra Fox, Arizona
- Rev. David Hamm, Maryland
- Christy Koury, North Carolina
- Terry Livingston, Florida
- David McNeas, Ohio
- Linda Ramsey, New York
- Jennifer Schwartzott, New York
- Sharon S. Reeder, 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.umdf/AACTconnect@umdf.org

AACT - ADULT CORNER PAGE

KAILEY AND DEVIN'S FAMILY STORY ACCT COUNCIL MEMBER AND CANADIAN AMBASSADOR

My husband Devin and I, met in University through a mutual friend. We dated for three years and then got married. I actually met him after my first muscle biopsy. After graduation we moved to Toronto and continued with further education. I completed my post grad certificate in Career Counseling and he completed a post grad in HR. We got our first jobs together and then purchased a condo in Toronto.

I started seeing Dr Mark Tarnopolsky of McMaster University for further testing and another biopsy in my 20's and after almost 10 years was given a specific diagnosis CPEO+ (a form of Karynes Sear Syndrome). I wanted to start a career after University and College and was hired by a non profit as an Employment Consultant and later an Employment Counselor.

In my late 20's, I met with Dr Tarnopolsky for further testing and worked with a Genetic Counselor at McMaster. My condition is sporadic so Devin and I decided that we would love to start a family. I had the support of my family doctor, neurologist, and a fertility specialist.

Once I was pregnant I was referred to SunnyBrook Hospital in Toronto as high risk Obstetrical Case. Because of my muscle weakness and chronic fatigue, it was decided that I would have a planned cesarean section. I was able to work until around 7 months and then decided to take my vacation time to rest.



We delivered a very healthy and happy little guy in June 2015 by c-section with no complications. Sometimes, I have to do things differently or be creative with Jude when I am having hard days. But, we live close o family so they are supportive. Since I can't drive, my parents have a car seat for Jude. I plan many activities and play dates for Jude each week and I am fortunate to have such great friends and neigl my house as it's easier!

My husband Devin, is a wonderful partner and dad. He is very involved and does a lot of the more physical activities with Jude like swim lessons, walks, and playing at the park - we make a great6 team!

To save energy, I have a house cleaner come in once a month and food prep every second week. We attend programs at the Library and at the Early Center. Jude is a very social but chill guy. If I am having a hard day, he loves to read books, listen to music, draw, etc. I am currently 20 weeks pregnant with our second child so I am considering a part time nanny or mother's helper for support. We are very excited to welcome our new arrival soon!



In conjunction with UMDF, we are excited and pleased to preview the Adult and Young Adult Program that will be presented at Mitochondrial Medicine 2018: Nashville.

Thursday, June 28, 2018 - 5:30pm-8:00

12th Annual Adult Gathering 6:00PM to 8:00pm

Symposium Mitochondrial Family "Mixer" Reception.

Friday, June 29, 2018

Ask the Mito Doc Panel - UMDF Staff Panel Speakers: Zarazuela Zolkipli Cunningham, MD; Mary Kay Koenig, MD; Andrea Gropman, MD;

Navigating Social Security Disability Panel

Moderator: Donald E. Garrison, JD

Panel Speakers: Carol Rabideau, LCSW; John P. Garner, JD, Social Security Disability Attorney; Tim Takacs, JD, Certified Elder Law Attorney; and Joy and Bryan Krumdiack.

Saturday, June 30, 2018

Genetics 101 Talk - Speaker: Tyler Reimschisel, MD.

Other sessions of special interest....

Independent Living

ALL – Mitochondrial Disease of Non-Genetic Origin

Speakers – Kendall Wallace, PhD and Bruce H. Cohen, MD

Cardiology

We look forward to seeing you in Nashville!

**SPECIAL ANNOUNCEMENT....
CALLING ADULTS AND YOUNG ADULTS FOR
UPCOMING WEBINAR**

**“THE IMPORTANCE OF SLEEP”
PRESENTED BY DR. BRUCE COHEN, MD, FAAN**

During this 90 minute webinar, we discuss:

- How to get a good night's rest
- The importance of good sleep for patients.
 - Sleep studies

You can watch the replay at
www.umdf.org/aact/webinars



Dr. Bruce Cohen- MD, FAAN

“Always discuss your diet with your physician or provider. Diets are different for people with gastrointestinal disorders and low muscle mass. For those that are overweight, the use of a modified low-carbohydrate diet is reasonable. These would include the “Eat-Fat, Get-Thin Diet” by Mark Hyman, MD, but there are others. Portion control diets (Nutrasystem, Weight Watchers) do work.

I talk to my patients about the No-White, Rainbow Diet: Stay away from food that comes in cardboard boxes, fresh fruits and veggies are best. If the base of the food is white (rice, grain, wheat, potato, sugar, corn syrup) then avoid. If the base of the food is full of color (dark green, orange, yellow, red, purple) then consider it a friend. High quality meats and fish are fine. Some people do better with small frequent meals. Calories do count. But calorie restriction without a plan for the long term is usually not successful in the long run.

<https://www.healthline.com/health-news/hacking-cells-to-reduce-diseases-of-aging#1>