



**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**

**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 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.umdf.org/AACT

connect@umdf.org

AACT-ADULT CORNER PAGE

SUMMERTIME TIPS



Kailey, Toronto, Canada

Summertime cool beverage; Passion Fruit Iced Tea Lemonade. Use passion fruit tea (caffeine free). Brew tea and cool. Add lots of ice and a splash of organic lemonade.



Whit, North Carolina

When traveling to other time zones I've found it helpful to adjust yourself to the new time zone a day or so before you leave home, e.g. wake time, meal times, bed times, etc. It lessens the shock to your system once there. Summertime travel can be a little more stressful...bigger crowds so don't forget to pack your patience! With warmer weather I also eat lighter meals and more frequently than otherwise to help digestive challenges.



Nicole & Lillian, Louisiana

We live in the deep South where heat and humidity are worn like a part of our wardrobe! This is also the time of the year when we see the greatest decline in mine and Lillian's activity level. To maximize our functioning we do some of the following:



We do our shopping early in the morning before the asphalt can heat up. Shopping in the afternoon or evening is out of the question because the sun has heated the asphalt all day. At stores we don't always use the handicap parking spots because we choose spots that are under trees (unfortunately, those are rarely near the door). We drop Lillian off at the door to avoid the additional walking and heat exposure.

In our area, we do a lot of traditional cooking outdoors. In order for Lillian to enjoy being outside with us, we use a portable AC. This allows her to be part of the traditions of our family and community.

Deb, Arizona

If you have to go outside, be cautious. Stay out of the heat and in the air conditioning.



Rev David, Maryland

Great time to take up six-string guitar! Helps to improve brain function by learning new things like notes and chords. Helps to improve hand coordination by playing the instrument with both hands. Take the guitar outside while practicing but remember;



Sit under an umbrella on hot, sunny days and drink plenty of water for hydration; wear a wide-brimmed hat for additional protection of the face from the sun; wear sunglasses for protection of the eyes from the sun's harmful rays; use suntan lotion with an SPF rating of 40 to protect the skin from the sun's harmful rays.

Joy, Washington

For a treat to keep cool, freeze watermelon or other fruit in ice cube trays and you can use them to chill your drinking water. The frozen fruit could also be put in an infuser bottle.



Terry, Florida

Use cooling towels/headbands similar to the kind used by athletes.



David, Ohio

The Buddha said: *"in the end, only three things matter: how much you loved, how gently you live, and how gracefully you let go of things not meant for you."*



Our common processes with mitochondrial disease unfurl our capabilities to love and be loved, while also nudging us toward a gentle life that we can sustain.

The long daylight hours of summer are conducive to sitting in the shade, watching nature flourish and gracefully letting go of what has been difficult for us. Ponder this, and realize what blessings have been gained through your journey!



Linda & Jennifer, New York

Stay in AC if possible. Stay extra hydrated. IV hydration with electrolytes if possible. Eat watermelon. More frequent naps. Cooling neck wraps. Self-assess.



Sharon, Arizona

Hydrate and schedule your outings around the hot sun!



Devin, Nevada

If cooling vests are too heavy/expensive, try using a simple bandana with an icepack wrapped inside of it around your wrists and the back of your neck. It's cheap, and if the icepack is small enough you can simply spin the bandana around between your hands to secure the icepack within and tie it to your wrist/neck.



Gail, Illinois

Growing up and living in the Chicagoland area, our summers are short, too short. Summer is a time for me to reset and reinvigorate my body, mind and spirit. Depending upon Mother Nature, I love to do some of the following things...

Parks: All of us have many local area parks to enjoy. Sit and/or walk along their paths, pack a picnic, and/or use them as a powerful place and time to connect with nature (meditation, journaling, etc.)

FYI...The National Park Service oversees over 400 natural and historic areas, and offers free admittance to any U.S. citizen or resident with a permanent disability via its Access Pass. Parks and the great outdoors are accessible for people with disabilities no matter our mobility level.

Fairs & Festivals: I love to attend with family and friends. They are always lots of fun and a great way to spend a day outside. It's also a wonderful opportunity to connect with and support your local community.

Farmers Market: Simply, the best! There is nothing better than selecting healthy locally grown and sourced goods. Plus, it's a great way to support our local area farms and businesses.

Travel: Do not be afraid to travel - long or short trips! It's important at times to get away. Plan ahead and be well prepared for expected and/or unexpected situations. To help, make a detailed list of all things you will or may need, including local area hospital contact information.

Summertime has so many benefits for us to enjoy, including being more active - on any level - which helps our mitochondria! And, it's a great time to naturally boost our Vitamin D levels. Many of us have low or deficient Vitamin D levels which can cause fatigue, on top of our chronic fatigue. Next time you see your doctor, you may want to have your Vitamin D level checked.

Happy Summertime... Get Outside... Have Fun & Enjoy!



Greg, Maryland

Plant a small garden. Many benefits include helpful occupational therapy, enjoying your grown goods, and a great way to spend some time outside.



Amy Goldstein MD, Pennsylvania

CHOP & AACT Medical Advisor

Make your own cooling vest. Buy a fishing vest with many pockets from a sporting goods store and place lightweight freezer packs in every pocket.

Visit www.UMDF.org/AACT soon for links to symposium recordings.

AACT CO CHAIR HONORED



Gail Wehling of Wayne, IL, was awarded the prestigious Stanley A. Davis Leadership Award. The award is presented to a UMDF volunteer leader who exemplifies dedication to the UMDF. The award was created to honor the organizations late Board Chairman, Stanley A. Davis. Wehling truly exemplifies the spirit of the award. She is a leader that put others before herself. She has made a difference in the Chicago area and nationally for the mito community.

LEAP AWARD



At Mitochondrial Medicine 2018, the United Mitochondrial Disease Foundation recognized Andy Garrison of Franklin, TN, with the UMDF Leap Award. The award is presented to an individual who is living positively with mitochondrial disease. As a result of his persistence, he has gone river rafting, kayaking, and snorkeling, camping, and even surfing. He attained the rank of Eagle Scout with the help of an encouraging scoutmaster. He has participated in therapeutic horseback riding for over 20 years. He attended college, living on campus for 2 years. And when that ended, he knew he wanted to live independently, which he now does with help from roommates and aides.