

# Coffee & Conversation Resources

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### **General Resources**

- UMDF Website [www.umdf.org](http://www.umdf.org)
- UMDF Mito University [www.umdf.org/mito-university](http://www.umdf.org/mito-university)
- UMDF Facebook Page <https://www.facebook.com/theUMDF>
- UMDF Facebook Support Page <https://www.facebook.com/groups/umdfgroup>
- UMDF Support Ambassador Program [support@umdf.org](mailto:support@umdf.org)
- UMDF Support Meetings/Event Calendar [www.umdf.org/events-calendar/](http://www.umdf.org/events-calendar/)
- UMDF Monthly Ask the Mito Doc Webcast [www.umdf.org/events-calendar/ask-the-mito-doc-series/](http://www.umdf.org/events-calendar/ask-the-mito-doc-series/)
- UMDF YouTube Channel <https://www.youtube.com/c/theUMDF>
- UMDF Navigating Social Security <https://www.youtube.com/watch?v=pJNFpd-E6hE>
- Mito Care Network New Patient Guide <https://www.mitonetwork.org/patient-guide>
- Living Well with Mitochondrial Disease by Cristy Balcells
- International Mito Patients Page <https://www.facebook.com/search/top?q=international%20mito%20patients>
- NORD [www.rarediseases.org](http://www.rarediseases.org)
- Dream a Little Dream for Parents <https://dreamalittledreamnp.com/>

### **Medical Cannabis**

- Epidiolex <https://www.epidiolex.com/about-epidiolex>
- State Medical Marijuana Laws <https://www.ncsl.org/research/health/state-medical-marijuana-laws.aspx>



## ***IEP's/School Issues***

- [Center for Parent Information and Resources](#)
- [Family to Family Health Information Centers](#)
- [Understood](#)
- IDEA- <https://sites.ed.gov/idea/parents-families/>
- National Disability Rights Network- <https://www.ndrn.org/>
- ADA National Network- <https://adata.org/>
- Computers for the Blind- <https://www.computersfortheblind.org/>
- State Resources - Offices of Vocational Rehabilitation (VR), Assistive Technology Programs, Division of Services for the Blind, Division of Services for the Deaf and Hard of Hearing

## ***Coping Strategies***

- UMDF Ask the Mito Doc Finding Joy and Gratitude in times of Anxiety and Isolation - Beth Heuer, NP. CMHP  
<https://www.youtube.com/watch?v=hMrfB39NUKM&t=16s>
- Stress and Coping of parents caring for a child with mitochondrial disease. Brenda A Senger et al. Appl Nurs Res. 2016 Feb.  
<https://pubmed.ncbi.nlm.nih.gov/26856513/>
- Living Well With Mitochondrial Disease by Cristy Balcells
- UMDF Support Ambassador Program support@umdf.org

## ***Managing Fatigue***

- UMDF Adult Webinar- Sleep and the Mitochondrial Disease Patient - Bruce Cohen, M.D. <https://www.youtube.com/watch?v=iVtJv-ZRv7s&list=PLsLD0T1HtmGQrY6hLzS7M8U3CpUN20pHQ&index=3>
- Energy Management for people with Mitochondrial Disease. March 31, 2020. By Emily Malcolm, PhD in Health Insights  
<https://mitochondrialdiseaseneews.com/2020/03/31/energy-management-for-people-with-mitochondrial-disease/>
- [www.healthline.com](http://www.healthline.com) (search fatigue)
- [www.healthline.com](http://www.healthline.com) (search foods to eat to beat fatigue)



## **Grief**

- Compassionate Friends [www.compassionatefriends.org](http://www.compassionatefriends.org)
- Grief [www.grief.com](http://www.grief.com)
- <https://courageousparentsnetwork.org/topics/end-of-life-and-bereavement>
- UMDF Mito Grief Mentors  
<https://www.facebook.com/groups/1004271073047410>

