

New Patient Guides:

- UMDF - https://www.umdff.org/wp-content/uploads/2022/09/New-Patient-Guide-for-Mitochondrial-Disease-2022_MasterDoc.pdf
- UMDF (Spanish version) - https://www.umdff.org/wp-content/uploads/2023/02/New-Patient-Guide-for-Mitochondrial-Disease-2022_MasterDocSpanish.pdf
- UMDF Patient Toolkit - <https://www.umdff.org/patient-resources>
- Mito Action - <https://www.mitoaction.org/education/new-patient-kit/>

Understanding Mitochondrial Disease:

- UMDF Mito University - <https://www.umdff.org/mito-university/>
- What is Mitochondrial Disease Video - <https://youtu.be/vMu0DbyQ0-E?feature=shared>
- Wellcome Center for Mitochondrial Research - <https://www.ucl.ac.uk/genomic-medicine-neuromuscular-diseases/partner-institutions/uk/newcastle-university/wellcome-centre-mitochondrial-research#:~:text=The%20Wellcome%20Centre%20for%20Mitochondrial,mitochondrial%20disease%20and%20mitochondrial%20biology>
- Genetics101 - geneticsupportfoundation.org - <https://geneticsupportfoundation.org/genetics-101/>. They have basic genetic info, a list of all states' genetic testing (NBS)
- Types of Mitochondrial diseases - <https://www.umdff.org/what-is-mitochondrial-disease-2/types-of-mitochondrial-disease/>
- Recent developments in mitochondrial medicine (part 1) - https://www.4open-sciences.org/articles/fopen/full_html/2021/01/fopen210001/fopen210001.html
- Recent developments in mitochondrial medicine (part 2) - https://www.4open-sciences.org/articles/fopen/full_html/2022/01/fopen210011/fopen210011.html

For Caregivers:

- UMDF Mito University - <https://www.umdff.org/mito-university/>
- Conserving Energy for the Mito Patient and Caregiver - <https://www.umdff.org/ask-the-mito-doc-january-2023/>
- **Finding a Caregiver**
 - Tips and choosing the right caregiver - <https://callemmy.com/tips-tricks-finding-right-special-needs-caregiver/>
 - Vitalxchange - Blog with many helpful resources <https://vitalxchange.com/tips-for-a-special-needs-caregiver>
- Cerebral Palsy Guide - <https://www.cerebralpalsyguide.com/community/parents-caregivers/>
- Circle of Care Guidebook for Caregivers of Children - <https://www.caregiving.org/guidebook-for-caregivers-of-children-with-rare-serious-illnesses/>

- Tips for Family Caregivers - <https://www.caregiveraction.org/resources/10-tips-family-caregivers>
- Caregiver stress - <https://csch.uconn.edu/wp-content/uploads/sites/2206/2019/11/CSCH-Brief-Caregiver-Stress-November-2019.pdf>
- Parental well-being - <https://www.curemito.org/caregiver-wellness-guide#:~:text=Foundational%20ideas%3A,health%20of%20the%20whole%20family.>

For Physicians:

- UMDF Clinician Resources - <https://www.umdf.org/clinician-resources/>
- Neurology new visit toolkit (Eng and Spanish) - <https://www.childneurologyfoundation.org/child-neurologist-new-visit-toolkit/>
- Mito Patient Care standards - <https://bit.ly/2ZQFbwD>
- Article on patient-partners as educators: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10286174/>
- Article on parents' experience when communicating with healthcare professionals: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6599337/>

Getting Help:

- UMDF Patient Resources - <https://www.umdf.org/patient-resources>
- UMDF Mito University - <https://www.umdf.org/mito-university/>
- Easter seals - <https://www.easterseals.com/support-and-education/finding-a-caregiver-for-a-child-with-special-needs.html> finding a caregiver for special needs
- Child Welfare Information Gateway - <https://www.childwelfare.gov/topics/systemwide/service-array/services-disabilities/youth/grandparents/>
- Kids Waivers by state - www.kidswaivers.org
- List of disability organizations - https://www.childwelfare.gov/organizations/?CWIGFunctionsaction=rols:main.dspList&rolType=Custom&RS_ID=84
- Financial assistance resources –
 - ReThink Medicaid – Slides from MitoMed2023 – Jenny Hobbs - https://drive.google.com/file/d/1XJZym2U3IbQZ-Ud6LOkC-iquMhv2vtBl/view?usp=drive_link
 - Medicaid Glossary – provided at MitoMed2023 - https://drive.google.com/file/d/1BDrYvuGtSaa55eNKZ67vOEGHhcYu1EjN/view?usp=drive_link
- Global Genes: Tool kit along with the following link - <https://globalgenes.org/toolkit/2022-fair-toolkit-family-planning-and-financial-considerations/>
- Family to Family Health Information Centers - <https://familyvoices.org/felsc/whataref2fs/> - (F2F) (family-led organizations that support families of children and youth with special health care needs (CYSHCN). They help families navigate health systems.

- Parent Information and Training Centers (PTI) - <https://www.parentcenterhub.org/find-your-center/> - (work with families of infants, toddlers, children, and youth with disabilities, birth to 26, helping parents participate effectively in their children's education and development, partner with professionals and policy makers to improve outcomes for all children with disabilities. They help families navigate education systems.
- National Disability Rights Network - <https://www.ndrn.org/about/ndrn-member-agencies/> - NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP).
- **Centers for Independent Living (CILs)** - <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory> - (serve people with all types of disabilities and provide peer support, information and referral, individual and systems advocacy.)

International Resources:

- International Mito Patients - <https://www.mitopatients.org/>
- Mito Foundation Australia: <https://www.mito.org.au/>
- Mito Canada: <https://mitocanada.org/>

Patient Rights and Responsibilities:

- Lists of patient rights and responsibilities - [American Medical Association](#)
It is both your right and your responsibility to understand. Whether a medical appointment or school meeting, do not leave the room if you don't know what your next steps are and who to contact with questions/concerns.

Rights/responsibilities

- The right to be believed
- Get information about your/your child's medical condition in words or a language you understand.
- See and understand your/your child's care and treatment plan.
- Be a part of the decisions made about your/your child's treatment.
- Be told what you need to know and what to do in follow up to the appointment or meeting.
- Have a reliable resource to get follow up information
- Coordinated care - looking at the whole person, not just the individual parts
- Information you need to convey necessary medical information to less knowledgeable providers (e.g. ER letters)
- Easy access to medical records, test results, etc.
- Timely response to questions, sharing of test results
- It essentially boils down to the right to a medical home:
<https://theppcc.org/content/defining-medical-home>
 - **Patient-centered:** A partnership among practitioners, patients, and their families ensures that decisions respect patients' wants, needs, and preferences, and that patients have the education and support they need to make decisions and participate in their own care.

- **Comprehensive:** A team of care providers is wholly accountable for a patient's physical and mental health care needs, including prevention and wellness, acute care, and chronic care.
- **Coordinated:** Care is organized across all elements of the broader health care system, including specialty care, hospitals, home health care, community services and supports.
- **Accessible:** Patients are able to access services with shorter waiting times, "after hours" care, 24/7 electronic or telephone access, and strong communication through health IT innovations.
- **Committed to quality and safety:** Clinicians and staff enhance quality improvement to ensure that patients and families make informed decisions about their health.

Genetics 101 Additional Resources:

- Diagnostics – MitoMed 2019 and Feb 2022 Ask Mito Doc – Austin Larson MD
 - <https://youtu.be/AjzN3qItDHC?feature=shared>
 - <https://youtu.be/-x7VvLtqyOk?feature=shared>
- Ted Talk on mtDNA - <https://www.youtube.com/watch?v=0obYR-nf45I&pp=ygUlbn90IHRoZSBETkEgeW91IGdldCBmcm9tIHlvdXlgcGFyZW50cw%3D%3D>
- More Genetic 101 Videos – Devin Shuman
 - <https://www.youtube.com/watch?v=DuY6pWbJRgw>
 - <https://www.youtube.com/watch?v=DLrBZxQI1IA>
- Unique has some great generic handouts if you sort through the gene specific ones: <https://rarechromo.org/disorder-guides/>
 - AR Inheritance - <https://rarechromo.org/media/singlegeneinfo/Single%20Gene%20Disorder%20Guides/Autosomal%20Recessive%20Single%20Gene%20Disorders%20FTNW.pdf>
 - Genetics 101/AD inheritance - <https://rarechromo.org/media/singlegeneinfo/Single%20Gene%20Disorder%20Guides/SingleGeneDisorders%20QFN.pdf>
 - Prenatal Testing Options - <https://rarechromo.org/media/information/Other%20Topics/Prenatal%20genetic%20testing%20and%20diagnosis%20FTNW.pdf>
 - Planning a Family - <https://rarechromo.org/media/information/Other%20Topics/Planning%20your%20next%20child%20FTNW.pdf>
 - About a Genetics Appointment - <https://rarechromo.org/media/information/Other%20Topics/A%20Clinical%20Genetics%20Appointment%20FTNW.pdf>
 - WES and WGS - [https://rarechromo.org/media/information/Other%20Topics/DNA%20sequencing%20\(whole%20genome%20and%20exome\)%20FTNW.pdf](https://rarechromo.org/media/information/Other%20Topics/DNA%20sequencing%20(whole%20genome%20and%20exome)%20FTNW.pdf)
- For those who really want to dig deep into Genetics – ClinGen has some great videos:
 - Genetics 101 - <https://www.youtube.com/watch?v=EL1N0x4tgMY>
 - Example Sequencing Report - <https://www.youtube.com/watch?v=01sfQLcFVuc>

- Example Microarray Report - <https://www.youtube.com/watch?v=aKcCMjyzzoM>
- Video on Mito <https://www.youtube.com/watch?v=ewlTUdw5Ah0>
- Types of Genetic Testing - <https://www.youtube.com/watch?v=zINh0uTCox8>
- Types of Variants #1 - <https://www.youtube.com/watch?v=OpYn-zrbz2Y>
- Types of Variants #2 - <https://www.youtube.com/watch?v=xnfdPOi1L38>
- Types of Variants #3 - <https://www.youtube.com/watch?v=EyK7Zgxl-9E>
- De Novo, Inherited, and Mosaic Variants - <https://www.youtube.com/watch?v=DEEDGqfs60A>
- Variant Classification - <https://www.youtube.com/watch?v=7mnFnoEBOW8>
- Inheritance - <https://www.youtube.com/watch?v=KVQzP9JKVi4>