

Parenting a Child with a Rare Disease Tip Sheet and Resource Page for Mito

1. Helpful Books to educate your children about their body

- a. "Cells and Systems" by Holly Wallace: <https://www.thriftbooks.com/>
- b. "See Inside Your Body" by Katie Daynes and Colin King (found through amazon or thriftbooks.com)

2. Educational Sites for Adults

- a. Medical Journal Articles: <https://pubmed.ncbi.nlm.nih.gov/> (some articles are free, others you can access for free at Medical Libraries at local colleges, or at children's hospitals!)

3. When Can I Use FMLA Leave?

- a. If you work for an employer that is covered by FMLA, and you are an eligible employee, you can take up to 12 weeks of FMLA leave in any 12-month period for a variety of reasons, including: Serious Health Condition
- b. You may take FMLA leave to care for your spouse, child or parent who has a serious health condition, or when you are unable to work because of your own serious health condition.
- c. Whether you are unable to work because of your own serious health condition, or because you need to care for your parent, spouse, or child with a serious health condition, the FMLA provides unpaid, job-protected leave. Leave may be taken all at once, or may be taken intermittently as the medical condition requires.
- d. For more information about FMLA go to:
<https://www.dol.gov/sites/dolgov/files/WHD/legacy/files/employeeguide.pdf>

4. Insurance Jargon Quick Reference

- a. *Premium*- The amount you pay (yearly or monthly) to have your health insurance.
- b. *Deductible*: The amount you have to pay before your insurance kicks in and starts covering costs.
- c. *HMO*- An insurance plan that usually limits coverage of doctors to those who are specifically contracted with the HMO. Out-of-network costs may only be covered in an emergency, and sometimes you must have a referral to see specialists.
- d. *PPO*- An insurance plan that has both "in-network" and "out-of-network" doctors and services you can use. This insurance plan will often cover both types of expenses but will charge more to see an "out-of-network" specialist.
- e. *High Deductible Plans*- Lower premiums, but higher deductible. Best for people who don't have many healthcare expenses.
- f. *In-Network Expenses*- Facilities that your insurance company has contracted with are considered "in-network." These expenses are often cheaper for patients.
- g. *Out-of- Network Expenses*- Services that are not within your network that have accrued cost. (Depending on whether you have a PPO or HMO your plan may cover some or none of these expenses.)
- h. *Out of pocket maximum*- The most you pay to providers during a policy period (usually a year) before your insurance company covers the cost at 100%.

- i. *Pharmacy vs. Durable Medical Equipment*: Normally pharmacy covers drugs/medicines and Durable medical equipment cover medical supplies such as wheelchairs, oxygen etc. BUT medical formulas, medical foods, medical oils can technically be covered under either!

<https://www.cms.gov/CCIIO/Resources/Forms-Reports-and-Other-Resources/Downloads/uniform-glossary-final.pdf>

<https://www.medmutual.com/For-Individuals-and-Families/Health-Insurance-Education/Compare>

3. Look at how the “No Surprise Act” may help you cover the cost of your insurance bills!

<https://www.kff.org/private-insurance/fact-sheet/surprise-medical-bills-new-protections-for-consumers-take-effect-in-2022/>

<https://www.cms.gov/newsroom/fact-sheets/what-you-need-know-about-biden-harris-administrations-actions-prevent-surprise-billing>