

# Management of Long-Chain Fatty Acid Oxidation Disorders: Pharmacist, Provider & Patient Perspectives.

## *PowerPak Podcast*

### REFERENCES

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2. Modifications to the ICER value assessment framework for treatments for ultra-rare diseases. Institute for Clinical and Economic Review. November, 2017
3. NICE and NHS England consultation on changes to the arrangements for evaluating and funding drugs and other health technologies assessed through NICE's technology appraisal and highly specialised technology programmes.: National Institute for Health and Care Excellence; March 15, 2017.
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### WEBSITES

**FAOD In Focus:** <https://www.faodinfocus.com/>

**The International Network for Fatty Acid Oxidation Research and Management (INFORM):** [www.informnetwork.org](http://www.informnetwork.org)

**Egg Whites Only:** [www.eggwhitesonly.com](http://www.eggwhitesonly.com)

**FAOD Family Support Group:** [www.fodsupport.org/newborn-labs.htm](http://www.fodsupport.org/newborn-labs.htm)

**Global Genes:** [www.globalgenes.org](http://www.globalgenes.org)

**The Metabolic Foundation:** [www.themetabolicfoundation.com](http://www.themetabolicfoundation.com)

**MitoAction:** [www.mitoaction.org](http://www.mitoaction.org)

**New England Consortium of Metabolic Programs:** [www.newenglandconsortium.org/for-families/](http://www.newenglandconsortium.org/for-families/)

**Genetic Metabolic Dieticians International (GMDI):** [www.gmdi.org/](http://www.gmdi.org/)

**MetabolicPro:** [www.metabolicpro.org/](http://www.metabolicpro.org/)

**Patient Advocacy at Ultragenyx:** [www.ultrarareadvocacy.com](http://www.ultrarareadvocacy.com)

**Save Babies:** [www.savebabies.org](http://www.savebabies.org)