Building Your Support Network

Living with a rare condition can feel isolating. Most people you encounter are not likely to have heard of long-chain fatty acid oxidation disorders (LC-FAOD), and many won't understand what it's like to manage a chronic or life-threatening condition. These are some reasons why it's very important to ***find and connect with organizations and people who share similar experiences*** and challenges, and who can offer support.

Because LC-FAOD are a type of fatty acid oxidation disorder, some people may refer to them as FAOD for short.

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MRCM-UX007-00288 February 2022

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How to Use this Resource

You can find support in many ways, such as through patient advocacy organizations, your physician or healthcare providers, academic institutions, online or in-person support groups and social media forums, and professional organizations.

Patient advocacy organizations are non-profit groups dedicated to helping patients and caregivers navigate life with a condition or diagnosis. To achieve their goals, advocacy organizations work in a variety of ways, such as:

- Hosting events and networking opportunities to bring patients and families together, both in person and online.
- Serving as a source of disease and treatment information.
- Promoting disease awareness, hosting support programs or sharing resources.
- Raising money to fund research for a disease or group of related diseases.
- Advancing public policy to meet the needs of patients with rare disease and their families.
- Supporting disease research by collecting medical history and health data from patients.

Organizations may focus on some or all of these areas, or even just one single area. They can be specific to LC-FAOD or one type of LC-FAOD, serve a related rare disease with similar symptoms or management needs, or support the common needs of people living with any rare disease. ***The following support resources focus not only on FAOD, but on mitochondrial disorders, metabolic diseases, other rare conditions, and topics that may impact all rare families.***

When reading or using any resource, keep in mind that medical research moves quickly and information on the internet can become outdated. Remember to check the date of publication and always bring questions and new ideas to your healthcare team.

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Metabolic Disorder Organizations

INTERNATIONAL NETWORK FOR FATTY ACID OXIDATION RESEARCH AND MANAGEMENT (INFORM) FAMILIES

Primary focus: FAOD disease-specific research and education
Website: informnetwork.org/inform-families

INFORM is a global scientific organization that focuses on FAOD and related metabolic disorders. Its main goals are to provide education and encourage or support research on these disorders. INFORM also hosts a FAOD conference each year for researchers.

INFORM Families is a dedicated part of the organization that provides families with information on newborn screening, diagnosis, and treatment of FAOD. They also include ***patient stories, information on clinical trials, and an "Ask the Experts" discussion forum.***

MITOACTION

Primary focus: Mitochondrial disease education and awareness
Website: mitoaction.org

MitoAction's mission is to improve the quality of life for children, adults, and families living with mitochondrial disease, including FAOD, through support, education, outreach, advocacy, and clinical research initiatives.

- The organization helps patients and caregivers manage their day-to-day journey with mitochondrial disease, as well as helps clinicians and researchers better understand the burdens of living with the disease.
- MitoAction offers monthly ***educational webinars, one-on-one support*** through the Mito411 support line, weekly support teleconferences, ***financial assistance*** for families in need, ***college scholarships*** for students with mitochondrial disease, opportunities to attend summer camp, a physician locator, ***clinical protocols*** to help with disease management, and a state-of-the- art ***mobile platform.***

MITOCANADA

Primary focus: Awareness, education, support, and funding research for mitochondrial disease in Canada
Website: mitocanada.org

MitoCanada is a Canadian-based organization offering support to ***patients with mitochondrial disease,*** their families, and caregivers. It also strives to increase public awareness of mitochondrial disease, ultimately advancing research towards disease prevention and cure.

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Umbrella Rare Disease Organizations

CANADIAN ORGANIZATION FOR RARE DISORDERS

Primary focus: Rare disease public policy, education, and patient support
Website: raredisorders.ca

Canadian Organization Rare Disorders (CORD) is a national network for rare disease organizations. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. CORD works with governments, researchers, clinicians, and industry to promote research, diagnosis, treatment, and services for all rare disorders in Canada.

REGROUPEMENT QUÉBÉCOIS DES MALADIES ORPHELINES (Quebec Association for Orphan Diseases)

Primary focus: Rare disease education and support
Website: RQMO.org

RQMO offers educational and support services for patients, and helps raise awareness about rare diseases.

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Organizations Outside Canada

There are also several organizations outside Canada that might have relevant information or be useful if you ever decide to visit, live or work in another country. In some cases, international organizations may collaborate with Canadian-based organizations on global issues and initiatives.

NATIONAL ORGANIZATION FOR RARE DISORDERS

Primary focus: Rare disease public policy advocacy, education, and research
Website: rarediseases.org

NORD provides information, services, and support for patients and their families as well as patient advocacy organizations, medical professionals, and others seeking to develop new diagnostic tools and treatments for rare diseases.

EVERYLIFE FOUNDATION FOR RARE DISEASES

Primary focus: Rare disease public policy and legislative advocacy
Website: everylifefoundation.org

EveryLife Foundation for Rare Diseases provides training, education, resources, and opportunities to guide patients to be advocates for their needs with the intent to affect and change public policy in the United States. While the foundation focuses on the US, there may be opportunities to learn more about advocating for yourself and your community.

GLOBAL GENES

Primary focus: Rare disease education and support
Website: globalgenes.org

Global Genes is a global non-profit advocacy organization for individuals and families fighting rare, genetic diseases. The main purpose is to raise awareness and build community support of genetic disorders through social media, provide education to both the public and medical communities, and fund research focused on treating rare conditions.

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Organizations Outside Canada

CAREGIVER ACTION NETWORK

Primary focus: Caregiver support
Website: rarecaregivers.org

The Caregiver Action Network (CAN) is an organization focused on supporting people who care for individuals with chronic conditions, disabilities, disease, or age-related issues. CAN also offers a rare disease caregiver-focused site that provides education, peer support, and resources to family caregivers across the country free of charge. CAN offers support and information for all caregivers, regardless of the condition.

NATIONAL ALLIANCE FOR CAREGIVING

Primary focus: Public policy advocacy regarding caregiver issues
Website: caregiving.org

The National Alliance for Caregiving (NAC) conducts research, analyzes public policy, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Although not specific to LC-FAOD or rare genetic diseases, the NAC offers valuable resources and information to all types of caregivers. The NAC collaborated with Global Genes to publish Rare Disease Caregiving in America, a first-of-its-kind national research study capturing the experiences of caregivers of children and adults with a rare disease.

METABOLIC SUPPORT UK

Primary focus: Metabolic disease patient and caregiver support
Website: metabolicsupportuk.org

Metabolic Support UK is an organization supporting patients and families with inherited metabolic disorders across the United Kingdom. It offers a Family Advice Service and Metabolic Connect (a peer support matching service). Metabolic Support UK also sponsors conferences, workshops, and education days, among other programs.

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