

# 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.

FAOD

LC-FAOD

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

## 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or using any resource, keep in mind that medical research moves quickly and information on the internet can become outdated.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.**



# 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](http://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.*

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## MITOACTION

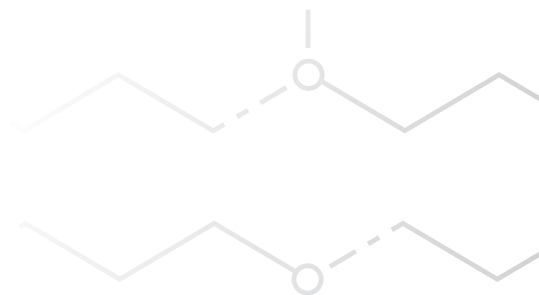


**Primary focus:** Mitochondrial disease education and awareness

**Website:** [mitoaction.org](http://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.*



# Umbrella Rare Disease Organizations

## EVERYLIFE FOUNDATION FOR RARE DISEASES



**Primary focus:** Rare disease public policy and legislative advocacy

**Website:** [everylifefoundation.org](http://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. Some programs include:

- **Rare Disease Legislative Advocates (RDLA)** is a collaborative organization that provides informational meetings, legislative resources, advocacy tools, and special events that support organizations and advocates working to promote rare disease legislation. RDLA offers travel stipends for a certain number of patients to attend Rare Disease Week on Capitol Hill.
- **Rare Disease Week** on Capitol Hill brings rare disease community members from across the country together to learn about federal legislative issues, network, and share their stories with legislators.
- **Rare on the Road**, a partnership with Global Genes, builds and activates the rare disease community at the local level by hosting regional one-day training sessions for rare disease patients, caregivers, and other advocates.
- **Young Adult Rare Disease Representatives** works to instill confidence in the next generation of rare disease advocates and provides support in the advocacy journey, especially during the transition from childhood to adulthood.
- **Rare Giving** financially supports individuals with rare diseases, as well as organizations that engage patients, caregivers, and others in the community in public policy.

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## GLOBAL GENES



**Primary focus:** Rare disease education and support

**Website:** [globalgenes.org](http://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.

- Its website includes **Global Genes Rare Toolkits and Rare University**, and features a portal where patients and caregivers can create a profile and connect with one other.
- Scholarships are also available for its **RARE Patient Advocacy Summit**, an annual event that brings together patients, caregivers, and other stakeholders to develop and take home actionable strategies to accelerate change.

## NATIONAL ORGANIZATION FOR RARE DISORDERS



**Primary focus:** Rare disease public policy advocacy, education, and research

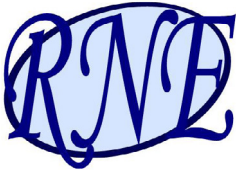
**Website:** [rarediseases.org](http://rarediseases.org)

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.

- NORD provides a network of patient organizations, information, resources, frequently asked questions, and **state-by-state advocacy information**. It also offers patient and financial assistance programs to help support a variety of disease-related patient costs.
- Its **network of ambassadors** – volunteers in leadership positions – aim to build a strong community of rare disease advocates in their state to help increase awareness of rare diseases and the challenges patients and their families face.

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## RARE NEW ENGLAND



**Primary focus:** Rare disease support and education throughout New England

**Website:** [rarenewengland.org](http://rarenewengland.org)

Rare New England (RNE) offers patients, families, and providers educational opportunities, resources, and support. The organization also provides information on genetic counseling, grief support, and regional and national events.

- Patients and families can watch episodes of **RNE's educational cable show series** about rare and complex diseases.
- RNE sponsors an **annual speaker series that connects patients and their families** with rare disease experts to discuss the diagnostic journey. These presentations cover the experience of living with a rare disease, coping strategies, how to navigate the challenges in the healthcare and/or educational systems, among other topics.
- RNE also hosts an **annual conference to provide resources, education, and networking opportunities** for the rare disease community.

# Caregiver Support

## CAREGIVER ACTION NETWORK



**Primary focus:** Caregiver support

**Website:** [rarecaregivers.org](http://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.

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## NATIONAL ALLIANCE FOR CAREGIVING



**Primary focus:** Public policy advocacy regarding caregiver issues

**Website:** [caregiving.org](http://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.**



## Organizations Outside the U.S.

There are also several organizations outside the U.S. 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 U.S.-based organizations on global issues and initiatives.

### METABOLIC SUPPORT UK

Your rare condition.  
Our common fight.

#### METABOLIC SUPPORT UK

**Primary focus:** Metabolic disease patient and caregiver support

**Website:** [metabolicsupportuk.org](http://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.



#### MITOCANADA

**Primary focus:** Awareness, education, support, and funding research for mitochondrial disease in Canada

**Website:** [mitocanada.org](http://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.



# Newborn Screening

Many people with LC-FAOD may have been or will be identified with a positive newborn screening test. A positive result means that the baby may have a higher risk of having one or more of the conditions included on the newborn screening panel. Confirmation of LC-FAOD diagnosis occurs with an additional blood, urine, or genetic test.

There are advocacy organizations that provide more information about the newborn screening process and mobilize patient advocates to influence newborn screening regulations and policies.

## BABY'S FIRST TEST



**Primary focus:** Newborn screening information and education

**Website:** [babysfirsttest.org](http://babysfirsttest.org)

Baby's First Test provides materials and resources about newborn screening at the local, state, and national levels. The organization's website features facts about the conditions screened and what to expect from the newborn screening process. Some topics include:

- Details on the newborn screening **tests offered in every state**
- **Tools for parents** including what to do after you receive newborn screening results
- **Condition-specific information** including causes, treatment, and family experiences

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## SAVE BABIES THROUGH SCREENING FOUNDATION



**Primary focus:** Newborn screening education and advocacy

**Website:** [savebabies.org](http://savebabies.org)

The Save Babies Through Screening Foundation **educates parents, pediatric healthcare providers, and policy makers** about the complexity of newborn screening, the importance of timely and early screening, and the importance of prompt testing to confirm a diagnosis. This confirmatory testing is a critical step and helps to allow for early treatment and management of rare disorders when indicated.

**In the U.S., adoption of newborn screening for LC-FAOD occurred in a few states in 1999, while most states adopted the screening between 2002 and 2008.<sup>1</sup>**



## REFERENCES

1. Mak CM, Lee HCH, Chan AYW, Lam CW. Inborn errors of metabolism and expanded newborn screening: review and update. *Crit Rev Clin Lab Sci.* 2013;50:142-162.