Who is OAA?

The Organic Acidemia Association (OAA) is a parent-led 501c3 nonprofit dedicated to supporting individuals and families affected by organic acidemia metabolic disorders.

Our Board

The OAA Board of Directors consists of dedicated parents that have children with an organic acidemia. Each member volunteers their time to empower families and healthcare professionals with knowledge in organic acidemias. OAA also has a medical advisory board that actively contributes to updating medical guidelines and conducting research.

Our Mission

OAA's mission is to empower families and healthcare professionals with knowledge in organic acidemias. We support early intervention through expanded newborn screening, and distribute funding to support research. OAA has played a vital role in newborn screening advocacy, contributing to the addition of nine organic acidemias to the Recommended Uniform Screening Panel (RUSP).

Creating Community

The Organic Acidemia Association (OAA) provides families with meaningful connection, support, and resources. Through the biennial Family Forum, individuals and families affected by organic acidemias can connect with caregivers, patients, clinicians, and researchers to share lived experiences, provide guidance, and build community. OAA also offers a private Facebook group and newsletter to keep families connected, informed, and supported year-round with educational updates, shared stories, and announcements.

Support family outreach, education, and research programs that will help improve lives and create hope for the future.

DONATE ♥

Organic Acidemia Association

organic_acidemia_assn

oaanews.org

ORGANIC ACIDEMIA ASSOCIATION

we care for the rare

WE ARE PARENTS, AND WE ADVOCATE.

OAA is a 501c3 non-profit volunteer parent and professional support group.

What are Organic Acidemias?

Organic acidemias are a group of rare, inherited metabolic disorders in which there is a defect in protein metabolism where an essential enzyme is absent or malfunctioning. This defect results in a build up of toxic organic acids, on one side of the metabolic blockage and a deficiency of chemicals vital to normal body functioning on the other.

These disorders are typically inherited in an autosomal recessive pattern, meaning that an individual must have two non-working copies to have the disorder. Due to this type of inheritance, the cells of the body do not produce all of the enzymes that are needed to complete metabolic processes.

The severity of OA disorders is dependent on the level of enzyme deficiency. In more severe cases, the disorder is apparent in the first few days of life when the newborn shows classic OA symptoms such as general malaise, reluctance to feed, breathing problems, vomiting, hypotonia (floppiness) and/or spasticity (stiffness).

Resources

OAA offers trusted resources to support families, patients, and healthcare professionals throughout every stage of the journey.

Newsletter

OAA also publishes The Cofactor, a monthly newsletter dedicated to sharing family stories, research updates, updated clinical guidelines, educational resources, and community news to keep families informed and connected.

Nutrition Resources

Many organic acidemia patients need a low protein diet to prevent buildup of toxic organic acids. Others need additional supplements like carnitine. OAA has educational tools and resources to inform patients and caregivers on the science behind the diet and supplements.

Patient Assistance Program

Many organic acidemia patients depend on medical forumla and special persciption supplements that can be very costly. NORD's new Organic Acidemia Patient Assistance Program, made possible by the Organic Acidemia Association, provides financial support for essential medications, medical formulas, and supplements.

Organic Acidemia Research

Research plays a vital role in improving treatments and moving toward better therapies for individuals living with a rare disease. OAA is committed to supporting and advancing research through collaboration with families, physicians, and researchers.

- Member of the NIH funded Rare Organic Acidemia Research (ROAR) Consortium
- Attend conferences and nework with leading experts
- Fund scientific and clinical research
- Consult on clinical study design
- Updates on new and current clinical trials

Organic Acidemia Natural History Registry

One of the most important ways that families can contribute is through the Organic Acidemia Global Registry, where patients and caregivers can share their experiences and health information. This registry helps researchers better understand the natural history of these disorders. OAA also connects families to current clinical trials and emerging research opportunities in an effort to expand access to therapies.

https://oaaregistry.iamrare.org.