

OAA Support

The OAA offers a one-stop resource for information, education, networking and communications among those interested in OA disorders. Some of the services available include:

OAA Brochure: Overview of OA disorders that physicians can give to parents when children are diagnosed

OAA Newsletter: Primary source for news and information; published three times/year

Parent Connection: Matching parents with others seeking to share information or comfort/support

Conferences: Host or participate in national and regional conferences

Internet: OAA web site and discussion forum (Google Group) (<http://www.oaanews.org>)

Nutrition & Recipes: Ideas and information to help with OA child feeding challenges

Research Funds: Identify and fund medical research in support of improved OA treatments and a cure

Advocacy: Advocate for expanded newborn screening and other programs that can help improve diagnosis and management of OA children

We Need Your Help

The OAA needs your help to continue its mission. The cost of providing these services increases each year. We seek tax-deductible contributions from individuals and corporations who want to help the OAA deliver these support services and/or fund research.

Please Complete and Mail this form to:

Organic Acidemia Association

13210 35th Ave. No., Plymouth, MN 55441

Enclosed is my tax-deductible donation of \$ _____

Please distribute my contribution as follows:

OAA Operating Fund: \$ _____

OAA Research Fund: \$ _____

Name _____

Address _____

City _____ St/Prov _____

Zip/PostCode _____ Country _____

Phone _____ Fax _____

email _____



Organic Acidemia Association
P.O. Box 1008
Pinole, CA 94564

Organic Acidemia Association



Providing Awareness,
Information and Support

*Together, We Can
Make a Difference.*



"Your child has a rare metabolic disorder."

Imagine the horror you feel as a parent when a doctor speaks these words!

You knew your baby was sick, but never dreamed it was this serious. You and your family have never heard of metabolic disorders. Where do you turn?

The Organic Acidemia Association (OAA) was formed nearly two decades ago to provide awareness, information, and support for families whose children are afflicted with metabolic disorders, otherwise known as "inborn errors of metabolism." OAA is a non-profit organization (501c3) that is exclusively funded through the tax-deductible contributions of individuals and businesses. OAA is run by a volunteer board (no one receives any compensation for hours of dedicated work).



We have daily contact with care-givers, social-support teams and medical professionals from around the world through our newsletter and through the internet. We focus on sharing information about how our children and their caregivers cope with, and manage, life with these disorders. Our long-term goal is to increase awareness leading to early detection and treatment, minimizing the impact that these often devastating disorders impose on innocent children.



Organic Acidemia Disorders

Organic Acidemia (OA) disorders are a group of related medical conditions that are characterized by the body's inability to properly metabolize protein. Genes in each cell of our body produce enzymes. These enzymes work together to create a chain of chemical reactions called the metabolic process. Those with OA disorders have a defect in one or more of their genes. This defect is inherited from



both parents, even though neither of them may have the disorder themselves. As a result, cells do not produce all of the enzymes that are needed to complete the metabolic process. The result of this incomplete process is a build-up of toxins in each cell. These toxins flow through the bloodstream and attack the brain, liver, heart and other organs.

The severity of OA disorders depends on the level of enzyme deficiency. In mild cases where some enzyme activity exists, children appear normal until metabolic stress results in a crisis (and eventual detection of the underlying OA disorder). In more severe cases, the disorder is seen 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).

Treatment for organic acidemias is designed to minimize the toxins in the bloodstream and the resulting potential for damaging vital organs. Generally, treatment includes a carefully balanced, protein-restricted diet combined with vitamins, amino acid supplements, and medications such as L-carnitine, which helps excretion of toxins in the body's cells.



Since OA can cause permanent damage to vital organs, early detection is an important factor. Newborn screening tests can identify OA disorders in the first few days of life. OAA actively supports the American College of Medical Genetics (ACMG) recommendation to screen for 29 conditions, which include several organic acid disorders.

Organic Acidemia Research

In the medical research community, Money Talks.

That is because it takes money to fund research that is directed at a specific medical issue. All too often, rare disorders get little



Dr. Venditti and Johnny Tate

attention because there is insufficient funding to hire research assistants, build and execute experiments, or collect and analyze data.

The OAA is working to change that. We maintain the "Organic Acidemia Research Fund" which funds are distributed to researchers who have identified specific areas where their work can lead to improved treatments and eventually a cure for organic acidemia disorders.



Past recipients of research funding includes physicians working at the National Institute of Health and the Mayo Clinic .

Won't you help provide the financial support that is needed to offer a better future for our OA kids?