

The Organic Acidemia Natural History Registry

Sponsored by the Organic Acidemia Association

The Organic Acidemia Natural History Registry, established in 2017, is an online registry and natural history study for people with organic acidemias. It is sponsored by the Organic Acidemia Association (OAA) and hosted by the National Organization for Rare Disorders (NORD®) on their IAMRARE® platform. There is no geographic eligibility criteria. Surveys take ~30 minutes to complete.

Our Goals

- Support the design of clinical trials that explore new organic acidemia treatments;
- Understand the variability and stages of organic acidemias;
- Learn about clinical practice patterns and variations over the course of treatment;
- Help to develop best practices, management guidelines, and recommendations;
- Identify people with organic acidemias who might be willing to take part in other research studies or clinical trials.

Our Surveys

- Socio-demographics
- Medical history and diagnostics
- Treatment and disease progression
- Nutrition, diet, and exercise
- Insurance and management of care
- Quality of life
- Clinical trial participation
- Genetic testing



>200 participants



12 organic acidemias represented



~400 survey entries

How families can participate

- Register online at <https://oaaregistry.iamrare.org/>
- Register through the NORD® IAMRARE® app
- Email research@oanews.org with any questions

