

MAKING AN IMPACT FOR RARE

2026

NORD: Supporting Individuals Living with Supporting Individuals Living with Organic Acidemia

Organic Acidemias are a group of rare inherited metabolic disorders that affect the body's ability to properly break down certain nutrients for energy. Individuals living with these conditions often require ongoing treatment, specialized dietary management, regular monitoring, and close engagement with healthcare providers to help maintain metabolic stability and reduce the risk of serious health complications.

Managing Organic Acidemia frequently involves a lifelong commitment to care. For individuals and families navigating these complex disorders, access to treatment, nutrition support, metabolic care, and ongoing monitoring can create significant financial challenges over time.

Through its Organic Acidemia Patient Assistance Program, NORD helps reduce financial barriers that can interfere with access to healthcare coverage, treatment, and other essential resources needed to support long-term disease management. The program is currently supported through the generosity of the Organic Acidemia Association, whose commitment helps make this assistance possible.

Alone we are rare. Together we are strong.®



NORD®
National Organization
for Rare Disorders

Patient Assistance Program Utilization

Organic Acidemia



Providing support through 33 Organic Acidemia assistance approvals in 2026



More than \$26,000 committed to helping individuals and families manage the financial challenges associated with Organic Acidemia in 2026.

The need for assistance within the Organic Acidemia community remains greater than the program is currently able to support. While the generosity of the Organic Acidemia Association has helped provide critical assistance to patients and families, additional funding would help expand support to meet growing community needs.

Financial Assistance and Support in 2026

Helping individuals living with Organic Acidemia maintain access to:

- Prescription therapies and medications
- Medical formulas necessary for daily disease management
- Essential supplements and vitamins

Looking Ahead: Maintaining Metabolic Stability

For individuals living with Organic Acidemia, maintaining metabolic stability is an important part of daily life. Ongoing treatment, dietary management, specialized care, and regular monitoring help individuals and families navigate a condition that requires continuous attention and long-term disease management.

For many families, maintaining access to that care can create significant financial challenges over time.

The Financial Impact of Long-Term Metabolic Care

Individuals living with Organic Acidemia often face ongoing healthcare expenses associated with metabolic care, prescription therapies, specialized nutrition support, monitoring, and long-term disease management. Even with health insurance, deductibles, coinsurance obligations, and other out-of-pocket healthcare expenses can create substantial financial strain.

As healthcare costs continue to rise, these expenses can place increasing pressure on families managing a lifelong metabolic disorder.

Access to Care Supports Metabolic Stability

For individuals living with Organic Acidemia, ongoing access to treatment, monitoring, and metabolic care plays an important role in supporting long-term health. Regular follow-up care helps patients and healthcare providers monitor metabolic health and proactively address challenges that may arise over time.

Financial barriers can make it more difficult to access the care and resources needed to remain engaged in treatment. Maintaining access to consistent care helps support better health outcomes throughout the disease journey.

Why Charitable Support Remains Essential

NORD's Organic Acidemia Patient Assistance Program helps bridge the gap between insurance coverage and the real-world costs associated with managing a lifelong metabolic disorder. Assistance helps individuals and families maintain access to treatment, metabolic care, and other essential resources needed to support ongoing disease management.

The generosity of the Organic Acidemia Association has helped make this support possible. However, the need for assistance within the Organic Acidemia community continues to exceed currently available resources. Continued donor support remains essential to helping more individuals and families access the care they need to manage these complex metabolic disorders.