

Propionic Acidemia Foundation

PAF is a 501(c)3 nonprofit organization dedicated to finding improved treatments and a cure for Propionic Acidemia by funding research and providing information and support to families and medical professionals.

Started in 2003 by a handful of family members whose children were affected, PAF has grown to be an international leader in the fight to conquer Propionic Acidemia (PA). PAF is run exclusively by volunteers.

What is Propionic Acidemia (PA)?

Propionic Acidemia is a rare metabolic disorder. Individuals with PA cannot break down parts of protein and some types of fats due to a non-functioning enzyme called PCC. This inability to break down propionic acid, which can cause damage to multiple organs and be life threatening.

FOR MORE INFORMATION



Propionic Acidemia Foundation
P.O. Box 151
Deerfield, IL 60015-4421



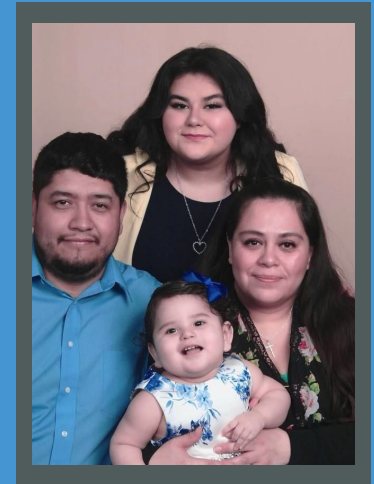
The Propionic Acidemia Foundation website and print materials are designed for informational purposes only and are not intended to serve as medical advice. The information provided should not be used for diagnosing or treating health problems nor disease. It is not a substitute for professional care. If you suspect that you or your child may have Propionic Acidemia, you should consult your healthcare provider.

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FOR THE FAMILY



**PROPIONIC
ACIDEMIA
FOUNDATION**



**Funding Research
Providing Support
and Education**

*Searching for a Cure
Hope For Our Families*

Current PAF Programs

Research

Propionic Acidemia International Patient Registry (paregistry.org)

The registry will help characterize PA, uncover unknown characteristics, and increase understanding of the different ways it may be affecting adults and children. The data collected in the registry will help identify patterns and trends that often go unnoticed in such a small patient population. The goal of this registry is to stimulate, advance and accelerate PA clinical and translational research that will lead to new treatments, improved outcomes and a cure.

Research Grants and Fellowship Grant Opportunities

PAF evaluates research and fellowship applications each fall and typically announces awards in January. Research grants in the past have led to more knowledge about PA, publications, patent filings and NIH funding. Applications are due October 1st.



Outreach to families and the community

- Educational conferences
- Family Day Events
- Bi-annual newsletter
- Private social media group for families
- Public social media page

Resources

- A Care Notebook to help keep track of important medical information (English or Spanish)
- Website with information linking to valuable resources
- E-mail newsletter with research updates & events
- Emergency Preparedness Guide
- Warrior Birthday Club, birthday greetings are sent to affected individuals and their siblings/children
- Information on Clinical Trials and Research Studies

Participation Matters

Learning more about PA is empowering and will help families on their journey. There are many ways that families can participate including the PA International Patient Registry, sharing their story on our website and/or in the newsletter, and joining our private social media group. Volunteers are always needed.

Currently, there are several clinical trials and studies that are actively recruiting. Contact PAF for more information.

Connect with us:

-  pafoundation.com
-  paf@pafoundation.com
-  Patient Registry: paregistry.org
-  877-720-2192
-  [/propionicacidemia](https://www.facebook.com/propionicacidemia)
-  [/company/propionic-acidemia-foundation](https://www.linkedin.com/company/propionic-acidemia-foundation)
-  [/propionic_acidemia/](https://www.instagram.com/propionic_acidemia/)