

# ANNUAL REPORT 2021-2022

**MISSION:** The Propionic Acidemia Foundation is dedicated to finding improved treatments and a cure for Propionic Acidemia by funding research and providing information and support to families and medical professionals.

**VISION:** To create a future where Propionic Acidemia can be prevented, and any affected individual can be cured and live a productive life.



**PROPIONIC  
ACIDEMIA  
FOUNDATION**

## 2021-2022 Financials

### Revenue:

Contributions	\$133,032
Interest	\$87
<b>Total Income</b>	<b>\$133,119</b>

### Expenses:

Program services	\$103,857
Management & General	\$2,444
Fundraising	\$2,881
<b>Total Expenses</b>	<b>\$109,182</b>

Cash Assets 8/01/2021 \$431,754

Cash Assets 7/31/2022 \$455,691

## Letter from the Board of Directors

We are happy to share with you our annual report.

This past year PAF has begun to go back to more “normal” pre-pandemic activities. We gave a small grant to the Community Health Clinic to host a PA Family Day activity for support in the Amish & Mennonite community. We also joined with HCU & OAA in hosting our first in-person conference since the onset of COVID-19.

PAF received our first education grant to work on developing new educational and support materials for families. The first two projects are expected to be completed in the fall of 2022.

We have been working with some new volunteers who are helping to expand PAF’s reach and support to those who do not have English as a first language.

We thank you for your continued support for PAF as an organization and families touched by PA.

## Board of Directors

Jill Chertow, President

Brittany Smith, Treasurer

Angela Waits, Secretary

Maria L. Cotrina

# PROGRAM ACCOMPLISHMENTS

## Grants Awarded

- Awarded \$40,300 grant to Eva Richard & Eva Delpon, at Universidad Complutense de Madrid, Spain as a new grant for the project entitled: “Elucidation of cardiac electrophysiological alterations in propionic acidemia: Towards the identification of targets for therapeutics.”
- Awarded \$50,000 grant to Ken Maclean, PhD, at the University of Colorado Denver, USA as a continuation grant for the project entitled: “Chemical Chaperone Treatment to Restore Enzyme Activity in Folding Mutations of Propionyl-Co-A Carboxylase: Towards a Personalized Therapeutic Strategy in Propionic Acidemia (PA).”
- Awarded \$842 grant to Community Health Clinic in Topeka, Indiana, USA to hold an education event in the Old Order Amish (OOA) community.

## Support Activities

- In June 2022, PAF held a joint conference with HCU and OAA for “Land of the Free, Home of the Brave. Video recordings of the speakers are available for families to view online.
- Distributed fall and spring newsletters to affected families, clinicians, and donors
- Coordinated the Propionic Acidemia Foundation’s Warrior Birthday Club in which students and staff at Oak Lawn Hometown Middle School and St. Linus School, Illinois, USA make birthday cards for those affected by PA, their siblings, and children.



## Registry

114 Participants in the PA International Patient Registry. The Registry is an IRB-approved research project and the data collected will help characterize the condition of people living with PA.

## Other Activities

- PAF received an educational grant from a pharmaceutical company for \$8,500. The funds are being used to develop new educational & support materials for families affected by PA.
- Continued partnerships with other rare disease groups including: NUCDF, HCU, OAA, and NECPAD.
- Worked with pharmaceutical companies who are developing new treatments for PA and some who are currently holding clinical trials .
- Continued partnership with NHGRI Organic Acid Research Section who is performing a study entitled: Natural History, Physiology, Microbiome and Biochemistry Studies of Propionic Acidemia and developing a gene therapy for PA.
- Refreshed logo and Registry website.

Propionic Acidemia Foundation

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