



# PROPIONIC ACIDEMIA FOUNDATION

SPRING 2024

SEARCHING FOR A CURE HOPE FOR OUR CHILDREN

## FEBRUARY 29, 2024



RARE DISEASE DAY®

On February 29th, our families “Showed their Stripes” for Rare Disease Day, an international day to highlight rare diseases. Propionic Acidemia is considered a rare disease. The incidence rate is 1:105,000–130,000 people in the United States (highest amongst the Amish populations), 1:1000 in Inuit of Greenland, and 1:2000-28,000 in Saudi Arabian populations. It is caused by a mutation in either the PCCA or PCCB gene. PA is autosomal recessive which means both parents carry a mutation.

Thank you to everyone that shared your stories, wore rare gear, reached out to someone that is “rare” and helped spread the word.



### PA Registry

Help move research forward!

Participate in the Propionic Acidemia International Patient Registry.

For more information on joining the registry, or to update your information, go to [www.paregistry.org](http://www.paregistry.org)

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**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.

## PAF AWARDS \$46,000 RESEARCH GRANT

### DETAILED CARDIAC FUNCTIONAL AND ELECTRICAL PHENOTYPING IN PROPIONIC ACIDEMIA

Bart Bjinens  
ICREA Research Professor  
Universitat Pompeu Fabra, Barcelona, Spain

Experience has shown that individuals with Propionic Acidemia (PA) can get Heart Failure (HF) or experience a Sudden Cardiac Death (SCD), induced by cardiac arrhythmias. Given the rarity of PA, little is known about how having the disease, or being a carrier of PA, affects the heart, so treating cardiologists often rely on general guidelines for Heart Failure, associated with the enlargement of the heart and potential decrease in Ejection Fraction; or SCD, often associated with a prolongation of the QT interval on the electrocardiogram (ECG).

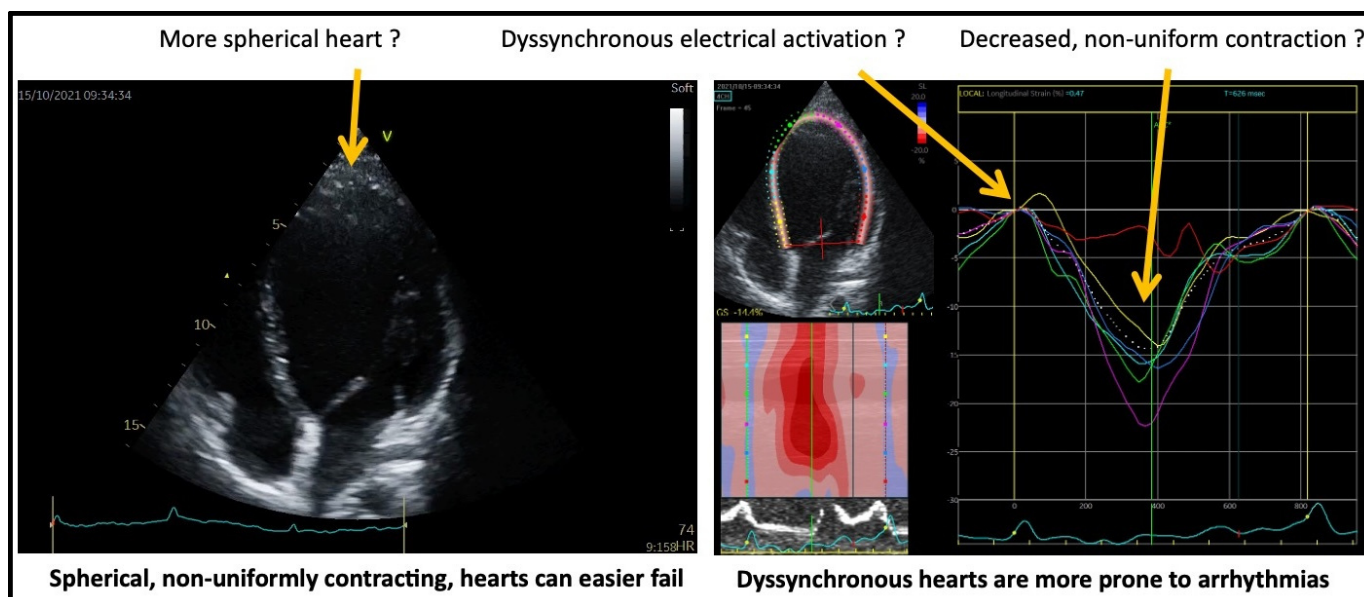
However, preliminary assessment of more detailed echocardiographic studies, and individual experience about the lack of improvement using standard therapies, suggests that the PA heart might not behave in a similar way as the majority of HF and SCD patients. Therefore, we have started with the collection of an extended cohort of PA patients,



carriers and non-carrier family members, in which we performed comprehensive echocardiograms and ECGs, as well as extended genetic testing.

In this study, we propose to analyze the available imaging and electrical information in detail to study if indeed there is a specific PA cardiomyopathy, that explains both HF and SCD, and how this is expressed in different individuals. To ensure the most comprehensive quantification, we will use contemporary Machine Learning, besides classical cardiological parameters.

If successful, this could open possibilities for a better and more personalized assessment of the PA heart, as well as improved follow-up and (medical and dietary) management to reduce the risk of HF and SCD.



## SEBASTIAN M. (2/27/13 -11/14/23)

It's always hard to put into words just how wonderful your child was. Sebastian didn't know a life without Propionic Acidemia and while it did impact him physically, he didn't let it impact his spirit.

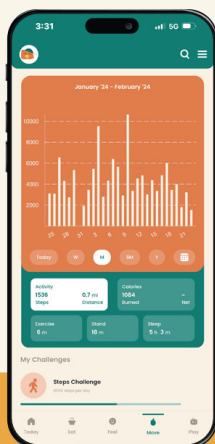
Sebastian loved to be with his people, especially MawMaw, PaPa, Uncle Kyle and LaLa. He enjoyed riding the train at the St. Louis Zoo, cheering for the St. Louis Blues, swimming and going down the purple slide. He even got to go to "Mickey's House" a.k.a. Disney World this past September. He was so excited to be practicing with his team again for Special Olympics basketball, he was the king of the grandma shot and always cheered for himself as the ball flew through the air. Sebastian loved his life and all of the people in it. He enjoyed routines, cleaning, folding clothes and loading the dishwasher, he was his future wife's dream man.

On November 14th, Sebastian passed away and left those here on earth missing him. Though he is no longer physically here, he left pieces of himself scattered for each of us to find on those days when we miss him most and memories to share with each other for years to come. It would be easy to lose hope with yet another child dying from Propionic Acidemia, however, I think that Sebastian's life, though short taught us that there is always joy and hope to be had, sometimes we just have to look a little harder to find it.



## FLOK FAMILY CAMP AND APP

### flok Together: Camp and App with Us!



flok is advancing research and care for people with Propionic Acidemia. **The flok app** helps you track how you eat, feel, move, and play to offer new insights into our conditions.

Attend our in-person **flok Family Camps** in Oregon and New Hampshire! Our metabolic community members, family, and friends are all welcome for 3 days of fun, learning, and social connection.



Visit [flok.org](https://flok.org) for more information on the flok app and Family Camp registration

Share



We want to hear from you! Have a PA story to tell, event to share or news?

Fall newsletter submissions due by August 1, 2024

## MELBOURNE AND ELISE

Greetings PAF Friends and Families –

We are the Russell Family: Mel, Nicole, Melbourne (13), Elise (12), Silvia (10), Aston (3) we are from Brookfield, Wisconsin. Our family is honored to share our PA story and for those that have come to know us over the years, an update on the kids.

Melbourne and Elise both have Propionic Acidemia. Although they were born 18 months apart, both were diagnosed with PA at the same time. Melbourne was born healthy and unremarkable as doctors might say. He thrived for a very long time while on breastmilk. Once we introduced food and switched to whole milk, we began to see changes. Around 7-8 months he began to rapidly decline and eventually went from the ~90th percentile to below 10th percentile. As any decent parent would do, we sought help in many places, different doctors, specialists, ERs, and we were told many different answers; he had a virus, was constipated, etc. as he continued to decline. Some days were better than others, but our instincts told us otherwise.



In September of 2011, we welcomed a beautiful baby girl, Elise. Like Melbourne, Elise thrived. Days after coming home from the hospital we received a call from the children's pediatrician's office telling us that we should bring Elise in for a check-up to discuss her test results. We followed instructions and went to the office. Our pediatrician informed us that on occasion tests come back and a retest proves nothing is wrong. We reminded her that Melbourne had a retest after birth, and we were told his results returned normal. She pulled Melbourne's file, confirmed with us that it was indeed similar and then informed us to go to the local Children's Hospital to meet with genetics.



We of course followed instructions and met with genetics where they retested Elise. At the time I was not aware of what the test was but came to know it was the state newborn screening. Days later, we woke as any normal day. I tended to Elise while Dad picked up Melbourne from his crib and laid him down with his sippy cup of whole milk. But things were different, we noticed

that Mel was not able to hold his cup on one side of his body and when we picked up his leg it immediately fell as if it were numb. Melbourne had a metabolic crisis/stroke, and that is when we discovered that he and Elise both have PA.

At that time, the lives that we thought we would have together became unclear and dark. For any parent hearing about a diagnosis that predicts their child's short life expectancy is unimaginable. When the diagnosis came through, we were informed that there was a "failure in the system" and Melbourne's test had slipped through the cracks. Doctors advised us not to research and ignore the internet, but how could we?

A short time later we realized that we were Mel and Elise's only advocates - not the system that failed them, not a hospital that has only ever seen PA a handful of times. We researched everything, met amazing PA parents and caregivers, visited the NIH, attended conferences out of state, went to the state lab that failed our family and demanded answers, and lastly went to court to make sure that our voice was heard.

It has been 12 years since we received their diagnosis, and they are both thriving. I attribute their wellness to a decent variant of PA, healthful living and God's will. It is not popular with everyone, but we opt to treat them more holistically through daily supplements (Aspire, Fish Oil, CoQ10, and Dose for their liver) They are both on levocarnitine to help them cleanse and a low dose of Enalapril to prevent known heart issues in PA patients. Aside from that we try to eat healthy and exercise. In some ways it is easier that they are older and understand how their bodies feel when they consume too much protein or if they have a cold and need extra sugar to feel better. In other ways it is more difficult to not be able to control portions and keep them away from some of their favorite foods.

Mel is a teenager and about to enter high school. He has many friends, braces, a cell phone, loves sports cars, politics, video games, and is always the funny guy. He will try any food and will take on a spicy food challenge.



(Cont. PAGE 5)

## MELBOURNE AND ELISE (CONT. PAGE 4)



Elise is in 6th grade, she has an amazing circle of best friends. She also has braces, a cell phone, enjoys reading, sewing, art, performing in school plays, and is an avid equestrian.

In addition, we have two other amazing children that do not have PA. They however have other

conditions that keep us on our toes: Silvia (Cystic Fibrosis) and Aston (Peanut Allergy).

Our family will never let PA define who we are, it is just something that we deal with. For now, they are normal children with a healthy lifestyle and forever connected through a miracle that has kept them together beyond the statistics.

If there is anyone that would like to know more about how our family manages PA, we are happy to share our lessons in advocating for children, holistic living, PGD IVF, Brain Balance, or whatever else – lets connect.



## Clinical and Laboratory Research on Propionic Acidemia: A Post Covid Update from the National Human Genome Research Institute at the National Institutes of Health

On behalf of the Organic Acidemia Research Section team at the NHGRI, NIH, I wanted to provide a brief update on some of our clinical and laboratory research programs focused on propionic acidemia. Our clinical protocols, while always open, had many restrictions on in-person travel and participation at the NIH Clinical Center during the COVID pandemic, when COVID-focused research studies took priority. However, we were fortunate to have met many new patients and families via telehealth between 2020-2023 and were able to remain in close virtual contact with many patients who had enrolled previously. We are excited to fully return to pre-COVID operating procedures and without any doubt, affirm we are OPEN and excited to meet new participants and re-engage with existing patients.

Since our last update, we have continued with very active clinical and laboratory research efforts. We are delighted to welcome a new attending metabolic physician to the team: Dr. Carolina Galarreta Aima. She writes:

“It is a pleasure to join this wonderful team, I am a pediatrician and metabolic geneticist, I had the fortune to have Dr. Venditti and Dr. Manoli as my mentors during my biochemical genetics training. I went on to practice as a metabolic physician in California’s Central Valley. I am delighted to be back at NIH and contribute to the organization mission and team efforts particularly focusing on PA.”

En Espanol: “Es un placer unirme a este maravilloso equipo, soy pediatra y genetista metabólica, tuve la fortuna de tener al Dr. Venditti y al Dr. Manoli como mis mentores durante mi formación en genética bioquímica. Continué ejerciendo como médica metabólica en el Valle Central de California. Estoy encantada de estar de regreso en NIH y contribuir a la misión de la organización y los esfuerzos de este equipo, centrándome especialmente en la Acidemia Propiónica. Me encantaría también contribuir ayudando a disminuir las barrera de language y culturales y permitir que más pacientes hispanohablantes tengan la oportunidad de participar en nuestros estudios. ....SE HABLA ESPANOL !!”

Since the inception of our natural history studies for MMA and cobalamin disorders (2004-current) and later, PA (2016-current; “Natural History, Physiology, Microbiome and Biochemistry Studies of Propionic Acidemia” (ClinicalTrials.gov Identifier: NCT02890342)), we have enrolled >730 participants, including 336 affected individuals with organic acidemias including >50 with PA, and supported over >1300 in person patient/family visits to the NIH. We have published more than 100 papers, review articles, commentaries and book chapters on our research.

Our recent PA clinical research includes an important paper on autism and PA (reference 1) and can be fully accessed here: <https://www.nature.com/articles/s41380-023-02385-5> (cont. PAGE 6)

## NIH UPDATE (CONT. PAGE 5)

We are supporting many active projects including: analyzing the cardiac phenotypes in PA; describing the expanded outcomes PA post solid organ transplantation; delineating the natural history of chronic kidney disease and ophthalmological phenotypes in patients with PA; characterizing the obstetric, gynecological, and reproductive/endocrine phenotypes in PA patients; and describing immune syndromes in patients with PA.

Our laboratory investigations have also continued with full effort as we work to develop gene therapy for both genetic subtypes of PA (PCCA, PCCB) with support from the Platform Vector Gene Therapy initiative (reference 2; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10031144/>) and the BESPOKE gene therapy consortium (<https://fnih.org/our-programs/accelerating-medicines-partnership-amp/bespoke-gene-therapy-consortium-bgtc/>). Some of our recent papers are listed below for those who might want to read further about a new mouse model of, and gene therapy for, PA caused by PCCA deficiency (reference 3; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10512014/>); and a review that overviews mouse models of organic acidemias, including PA, and preclinical gene therapy (reference 4; <https://onlinelibrary.wiley.com/doi/10.1002/jimd.12665>).

On behalf of the NIH team, I want to close this short update by expressing our deep appreciation to all the families who have participated in our research and supported our continuing quest to develop better treatments for those affected by PA. If any readers are interested in learning about our clinical and/or laboratory research, please call or write me an email to start the conversation.

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 Web: <http://www.genome.gov/27529399>

### SELECTED RECENT PUBLICATIONS

1. Shchelochkov OA, Farmer CA, Chlebowski C, Adedipe D, Ferry S, Manoli I, Pass A, McCoy S, Van Ryzin C, Sloan J, Thurm A, Venditti CP. (2024) Intellectual disability and autism in propionic acidemia: a biomarker-behavioral investigation implicating dysregulated mitochondrial biology. *Mol Psychiatry*. 2024 Jan 11. doi: 10.1038/s41380-023-02385-5. Epub ahead of print. PMID: 38200289. PMCID: in progress
2. Lomash RM, Shchelochkov O, Chandler RJ, Venditti CP, Pariser AR, Ottinger EA; NIH PaVe-GT Team (2023). Successfully Navigating Food and Drug Administration Orphan Drug and Rare Pediatric Disease Designations for AAV9-hPCCA Gene Therapy: The National Institutes of Health Platform Vector Gene Therapy Experience. *Hum Gene Ther*. 34(5-6):217-227. PMCID: PMC10031144.
3. Chandler RJ, Di Pasquale G, Choi EY, Chang D, Smith SN, Sloan JL, Hoffmann V, Li L, Chiorini JA, Venditti CP. (2023) Systemic gene therapy using an AAV4.9 vector rescues a neonatal lethal mouse model of propionic acidemia. *Mol Ther Methods Clin Dev*, 30: 181-190. PMID: 37746248 PMCID: PMC10512014
4. Chandler RJ and Venditti CP. (2023) Gene therapy for organic acidemias: Lessons learned from methylmalonic and propionic acidemia. *J Inherit Metab Dis*. Aug 2. doi: 10.1002/jimd.12665. Epub ahead of print. PMID: 37530705



From Left to Right: Susan Ferry, Carolina Galarreta Aima, Irini Manoli, Maria L. Cotrina (PAF Board Member and mom), Gabe Lopez (PA Adult) and Charles P. Venditti

## REQUEST FOR PROPOSALS

REQUEST FOR

**RESEARCH  
PROPOSALS****PAF: ADVANCING RESEARCH AND IMPROVING LIVES**

PAF is a non-profit organization that is committed to advancing research and finding better treatments, and ultimately a cure, for propionic acidemia. Our primary aim is to fund projects which will accelerate new knowledge about PA, promote the discovery of biomarkers and co-morbid conditions, and develop and evaluate therapeutics that can help improve the lives of those affected by PA.

PAF will entertain any proposal with the potential to advance treatments and improve the lives of those with PA

**APPLICANT QUALIFICATIONS:**

To be considered, candidates must possess a PhD, MD, or equivalent degree, and currently hold a full-time position at an established academic or research institution, regardless of their current rank (post-doctoral, research scientist, professor, etc.).

**DEADLINE: OCTOBER 1, 2024****GRANT SPECIFICATIONS**[www.pafoundation.com](http://www.pafoundation.com)[paf@pafoundation.com](mailto:paf@pafoundation.com)

877-720-2192

## REGULATING PCCA GENE EXPRESSION BY MODULATION OF PSEUDOEXON SPLICING PATTERNS TO RESCUE ENZYME ACTIVITY IN PROPIONIC ACIDEMIA

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Department of Biochemistry and Molecular Biology  
University of Southern Denmark, Odense, Denmark

Prof. Lourdes R Desviat, PhD  
Ainhoa Martínez-Pizarro, PhD  
Eva Richard, PhD  
Centro de Biología Molecular Severo Ochoa UAM-CSIC  
Universidad Autónoma de Madrid, Spain



This summary highlights the key findings from a recently published collaborative research article (Spangsberg Petersen et al. 2023), resulting from the synergy between two research groups with expertise in RNA splicing and disease and in propionic acidemia. In this manuscript, we joined forces to delve into a potential treatment strategy for propionic acidemia patients with certain mutations. Our goal in this newsletter article is to explain how these findings can lead to positive impacts within the patient community.

Propionic acidemia is genetically heterogeneous, and can occur by deleterious sequence variation, with missense variants being prevalent in both genes PCCA and PCCB encoding both subunits of the propionyl-CoA carboxylase enzyme (PCC). However, splicing variants, though less explored, are progressively gaining significance.

Pre-mRNA splicing is a crucial cellular process that takes place in the nucleus of eukaryotic cells, where genetic information is transcribed from DNA to precursor messenger RNA (pre-mRNA). This pre-mRNA is initially synthesized as a sequence containing both coding regions (exons) and non-coding regions (introns). The primary objective of pre-mRNA splicing is to remove the introns and join the exons together, forming the mature mRNA that serves as a template for protein synthesis. The splicing process is executed by a complex molecular machinery called the spliceosome that recognizes specific sequences at the boundaries between introns and exons, resulting in the excision of the intron and the ligation of adjacent exons. Sequence variations in these regions or in auxiliary splicing regulatory elements (enhancers and silencers) disrupt this splicing process and can lead to diseases.

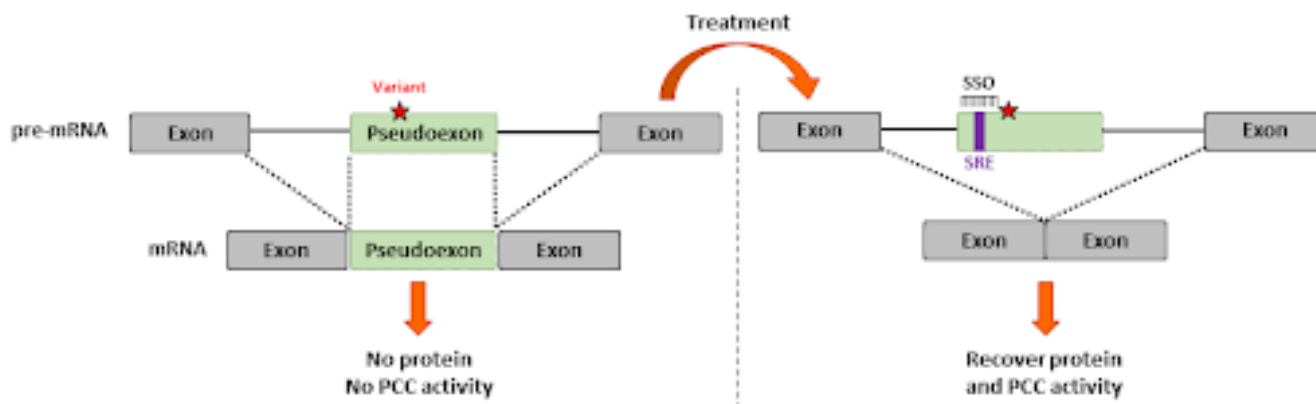
In some cases, aberrant splicing can result from deep intronic variants activating or creating potential splice sites, which are used in combination with other cryptic splice sites nearby leading to the exonization of intronic regions, known as pseudoexons. Pseudoexons share characteristics marking them as high risk sites in the human genome, where single nucleotide variants (SNVs) may cause disease through their activation.

In this work we have focused on the deep intronic variant PCCA c.1285-1416A>G activating a pseudoexon. This variant disrupts a splicing silencer while simultaneously creating a splicing enhancer element. This dual effect leads to the inclusion of a pseudoexon, which results in the absence of PCCA protein and PCC activity.

We explored the therapeutic potential of blocking this regulatory region, and thereby the inclusion of the activated pseudoexon, using splice switching antisense oligonucleotides (SSOs) (Figure 1). SSOs are small RNA molecules designed to modulate splicing by sterically blocking splice sites or splicing regulatory sequences in the pre-mRNA. This can result in exon exclusion, a strategy applied in Duchenne muscular dystrophy (DMD), to skip mutated exons and/or recover the open reading frame. In contrast, blocking splice silencers may instead promote exon inclusion, a therapeutic strategy employed in spinal muscular atrophy (SMA). Therapeutic SSOs for DMD and SMA have received approval from the Food and Drug Administration (FDA) and European Medicines Agency (EMA). SSOs have also been extensively used to prevent aberrant pseudoexon inclusion in the mRNA. (cont. PAGE 9)



## REGULATING PCCA GENE EXPRESSION (cont. PAGE 8)



**Figure 1.** Pseudoexon activation by deep intronic variant and its treatment using SSO. SRE: splicing regulatory region.

In our study, we demonstrate that blocking the regulatory element within the PCCA pseudoexon with SSO increases both PCCA and PCCB protein levels (as PCCB protein is unstable without PCCA), resulting in an increase in PCC enzyme activity, both in patient fibroblasts and in a cellular model with the variant created by CRISPR/Cas gene editing. Most relevant is the fact that the PCCA pseudoexon shows relatively high inclusion levels even in the wild-type context, and blocking its inclusion effectively upregulates PCCA gene expression levels, thus resulting in increased PCCA and PCCB protein levels. Therefore, this approach offers a potential treatment strategy for propionic acidemia, not only for patients with pseudoexon activation but also for those with missense PCCA and PCCB variants that retain some residual enzyme activity, as we demonstrate using patients' fibroblasts.

We acknowledge the continuous support of the Propionic Acidemia Foundation and the essential role that patients and their families play in the research in this rare disease. We look forward to continuing to be part of the propionic acidemia research community advancing towards a better understanding and treatment of this rare genetic condition.

### Reference:

US Spangsborg Petersen, M Dembic, A Martínez-Pizarro, E Richard, LL Holm, JF Havelund, TK Doktor, MR Larsen, NJ. Færgeman, LR Desviat, Brage S Andresen. "Regulating PCCA gene expression by modulation of pseudoexon splicing patterns to rescue enzyme activity in propionic acidemia". *Mol Ther-Nucleic Acids* (2023) Dec 13;35(1):102101.

## WARRIORS BIRTHDAY CLUB

This year birthday cards will be made by students at Oak Lawn-Hometown Middle School and St. Linus for participating families. We are thankful they have volunteered to do it again this school year. Please sign up a patient or sibling for the Warriors Birthday Club at <http://www.pafoundation.com/warriors-birthday-club/>.

If you signed up last year, you will need to sign up again, so we have current information.



# 2024 TCS NYC MARATHON - NOVEMBER 3, 2024



Join Team PAF to run the  
2024 TCS New York City Marathon



**Raise funds for a cure! Raise awareness!**  
**Have the most fun in the world!**  
**Runners of all levels welcomed**  
**Interested? Contact Marisa Cotrina at [TeamPAR4@gmail.com](mailto:TeamPAR4@gmail.com)**  
*Searching for a Cure, Hope for our Children*

**Eat Well, Live Well. Cambrooke is Committed to Families Living with Metabolic Conditions**



Eat Well, Live Well is our mission and we recognize how the support of our low protein foods and resources can make a difference in your lives.

For over 2 decades, Cambrooke has worked diligently to provide the most nutritious and delicious low protein foods for the metabolic community.

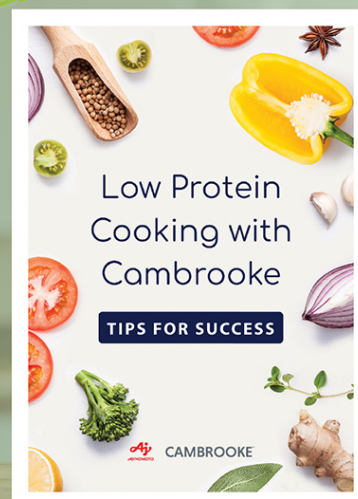
Over the last couple of years, many of our external vendors and suppliers have had challenges. This has led to some discontinuations of our products, temporary out of stock, or changes to some of the shapes, taste and textures.

We continue to produce over 100 low protein foods. For more information visit our BLOG at [cambrooke.com](http://cambrooke.com)

**It is always our goal to make our foods easy to prepare.**

For resources, visit [Cambrooke.com](http://Cambrooke.com) Patient Support Resources

**NEW**



## PAF ACTIVITIES AND FUNDRAISING SPOTLIGHT

### UPCOMING EVENTS

- PAF is exhibiting and presenting at SIMD and GMDI Annual Meetings 4/14-4/20
- The TCS New York City Marathon 2024 - 11/3

### PAST EVENTS:

Thank to to the PARunners for raising over \$18,500 in the 2023 TCS NYC Marathon (see our 2023 runners on PAGE 10) and to our Ohio Families for their Fall Fest and Tara Gerlach's Marathon for raising over \$10,000. (see below)

### DEDICATED GIFTS FROM INDIVIDUALS:

Among the many contributions received, the following is a list of some that were dedicated to those who have inspired the giver.

- IN HONOR OF: Dylan Jaehnke, Laura Lemire, Kate Lowry, Trent McKinley, Gabrielle Millett, Carolyn Schlein, Kate Wanyan, Josiah Weaver, Lukas Weaver, Chase Workman, Brett Young
- IN MEMORY OF: Kevin Ancil, Sean and Courtney Callahan, Alexa Faith Cardone, Alice and John Dawe, Kerrie Fessler, Jordan Franks, Shirley Franks, Vincent Philip Franze, Mike Messersmith, Nicholas Phillips, Talli Smith, Angelica Stageman, Kirstyn Tripp, Maxwell Weinzerl

**FACEBOOK:** Thank you to all of our Facebook Fundraisers and people that donated to their fundraising pages for birthdays, #GivingTuesday or just because: Debbi Buck, Jill Chertow, Rachel Anne Ellis, Tara Gerlach, Ale Gamez, Claire Howard, Kathleen Rusch

**STOCK DONATIONS:** PAF accepts stock donations. Please email [paf@pafoundation.com](mailto:paf@pafoundation.com) with any questions.

### MATCHING DONATIONS AND VOLUNTEER HOURS:

This may enable you to double your donation. Check with Human Resources to see if your employer matches. Some companies have a volunteer program and will donate based on your volunteer hours. PAF is always looking for volunteers.

### INTERNET:

Thank you for using iGive, Goodsearch, and Bing; selling on Ebay and setting up Facebook Fundraising Pages and designating Propionic Acidemia Foundation as your charity. Every dollar helps.



### Ohio Families Fall Fest and Tara Gerlach's Marathon raise \$10,000



## Propionic Acidemia Foundation

P.O. Box 151  
Deerfield, IL. 60015



SEARCHING FOR A CURE  
HOPE FOR OUR CHILDREN

## PROPIONIC ACIDEMIA FOUNDATION

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### Connect with us:

-  [pafoundation.com](http://pafoundation.com)
-  [paf@pafoundation.com](mailto:paf@pafoundation.com)
-  Patient Registry: [paregistry.org](http://paregistry.org)
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-  [/propionic\\_acidemia/](https://www.instagram.com/propionic_acidemia/)

**A special thank you to Veronica Lopez for serving on the PAF Board.**

**Publication Note:** The PAF Newsletter is published twice a year. Readers may subscribe by writing to PAF, registering online or calling 877-720-2192. Letters and article submissions are welcome for consideration and may be sent to [paf@pafoundation.com](mailto:paf@pafoundation.com) or mailed to Propionic Acidemia Foundation, P.O. Box 151, Deerfield, IL 60015-4421. If you would like to be removed from our mailing list or receive the newsletter via email, please contact us.