SEARCHING FOR A CURE HOPE FOR OUR CHILDREN

Propionic Acidemia Foundation

VOLUME 1, ISSUE 32 SPRING 2022

2022 HCU/OAA/PAF Family Conference

Register online at http://www.pafoundation.com/2022-conference/

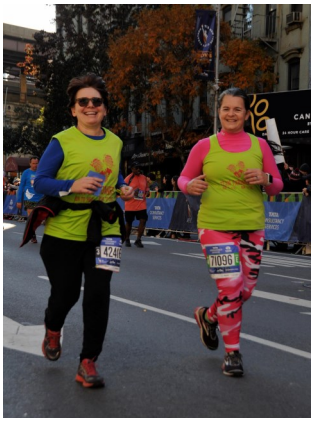
View the full conference schedule on pages 6—7

Announcing the PAF Marathon Team!

Would you like to run the best Marathon in the world?

Join **Team PAF** to run the New York City Marathon

See page 11 for more details!



PA Registry

Help move research forward for propionic acidemia. Participate in the Propionic Acidemia International Registry.

As of February 15, there are 114 participants. For more information on joining the registry, or to update your information, go to www.paregistry.org.

INSIDE

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.

BRYAN'S STORY

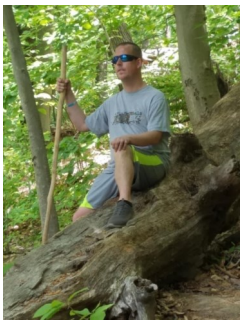
Hello everyone. I am 35 years old and I have Propionic Acidemic. Life with Propionic is not always easy. I was diagnosed late which caused me to have a stroke at a very young age. After years of a wheelchair and walker I made a somewhat normal recovery.

Around 2012, a few days after one my kickboxing classes, I noticed my knee was swollen. I had thought it was from my kickboxing class but turns out it was Lyme disease. Something that greatly effects me today. I get flare ups where my ammonia skyrockets, and I get incredibly fatigued and my muscles get pain that I can't describe.

In 2015 I was having the weekend of my life at my brother's campground, until I woke up in the ICU that is. I decided to throw caution at the wind and tried my hand at alcohol. It led to me having a metabolic acidosis. I was lucky not to suffer any serious side effects.

That's the thing between the Propionic and Lyme disease, you just never know what could happen! On top of my health issues I still have to deal with other real life events. Things like my parents getting divorced, the passing of my grandfather, and Covid-19.

I've always been into doing mindful things such as yoga and taking care of myself in general. However, it wasn't until my parents' relationship started to get worse that I found mindfulness meditation. Even though I saw the writing on wall, it deeply saddened me.



I remember stumbling upon Rebekah Borucki (BEXLIFE) on YouTube. She was a meditation teacher. My favorite Mantra of hers was *"I am like a boat on the ocean. My thoughts they rock me just a bit, but they never carry me away. I am anchored in the here and now!"* There was something about that saying that just put my mind at ease.

From that point on I became obsessed with how the mind works and the benefits of mindfulness meditation. I learned that once you realize all you can control is yourself, your reaction, emotions, and that happiness is a choice, it's only then will you find inner peace.

Fast forward to 2020, I had been stuck with a job that I was content with, but not happy with. I was working as a cashier at a food store which for me was physically exhausting. Then what turned into somewhat of a blessing, the virus hit. I knew that with my health issues, retail was no longer a option for me.

Instead of going though depression and anxiety over the virus, I decided to continue my mindfulness journey. After taking multiple classes on mindfulness and meditation I couldn't explain to how much it change's your life! No longer do I stress about things I can't control. I now have my own mindfulness routine that consists of nature walk, yoga and meditation. I can honestly say that I enjoy life to fullest. Moment by Moment. *www.bepresentlifestyle.com*

ALLISON'S STORY

Allison (PA), turned 16 in November. She is doing well. We recently stayed at Give Kids The World and visited several theme parks in Orlando.

Allison's Make-A-Wish was to meet Belle. Originally she was to go in March of 2020 to dress like Belle and have lunch with her in the castle. Then came COVID… Fortunately, we got to reschedule the trip. With all of us being vaccinated, we were able to go. Characters aren't meeting the way they used to, but Allison did get to see Beauty and the Beast live (front row!) and attend Beauty and the Beast sing-a-long.

She saw many princesses and characters, including Cinderella in the Castle. She enjoyed rides, and firework shows. We did the Magic Kingdom, Epcot, Disney Springs, Hollywood, & Universal Studios. It was a very busy 4 days! The 5 nights we stayed at GKTW Village were amazing. So much to do, a Carousel, magic tree house (where the wish kids make a star that the fairy adds to the night sky), great food, ice cream, activities, gifts every day…even a spa! Allison got her hair done (pink), nails (polka dots) and even glitter tattoos. We were treated like royalty and it was just an amazing trip.

We are back to reality & ready to schedule many follow up appointments with not only genetics, but orthopedic surgeon for her scoliosis, ophthalmologist for optic atrophy, dermatologist, dentist, etc…

Michelle Ellis

IN MEMORY OF MAX

Maxwell Weinzerl - 10/4/09 - 1/28/22

Our sweet Maxwell was born 10/4/09 in Peoria, Il. Four days after birth, we were rushed to a hospital in Chicago, where we received Max's diagnosis of PA, which results had shown on his newborn screening. After two weeks there, we came home to begin our beautiful yet challenging life.

The first three years were riddled with hospital stays, and doctors' appointments, and therapy sessions – but Max smiled through it all. He was our strength in any moment of despair. He had a gtube placed at eight months old, and continued to rely on that for nutrition throughout his life. He was diagnosed with asthma after multiple hospital visits due to croup/respiratory issues, and starting a daily inhaler ultimately fixed those issues.

Aside from the occasional short hospital visit, he was relatively healthy. He was very quiet the first few years of his life, but his eyes said everything for him. He was a "soul-gazer". His big beautiful brown eyes could capture every bit of your essence, and he wouldn't break his stare until you had seen his soul as well.

Then, the big hospital stay happened- the worst we ever had. In 2015, something happened, that we still can't explain. He got extremely sick, and we ended up spending seven weeks in the hospital, fighting for his life. He was paralyzed, intubated, placed on an oscillating ventilator, received multiple blood transfusions, special TPN IV, dialysis, picc line, daily xrays, among many other invasive procedures. Even with everything the doctors were doing, we thought he was going to lose his life. While my family and I were by his side constantly, he felt us. His heart would race when he heard us laughing (as hard as it was to laugh in those moments, we found comfort somehow). We made sure to turn Ellen on every single day at 4pm – Ellen was his FAVORITE! Her smile, her laugh, her positive energy- he loved her! And then finally, he started getting better, slowly but surely.

The day finally came when he was extubated. I said previously that he didn't talk much prior to this hospital stay. That changed the second they took out the breathing tube- he literally said "HELLO" over and over right after they took it out! And from that moment on, he was our chatty little buddy! Always talking, always laughing, always something to say. It was incredible to see his progress after that stay. Something clicked, and he decided nothing was going to stop him.

"Monster Max" as he was affectionately known, was an enormously vibrant boy who lit up any room with his infectious smile, contagious laugh, and mischievous dimple. He was as social as they come, and his ability to befriend anyone was admirable. His unending happiness, and love of music and dance were a few of the many ways he brought unforgettable joy to others. No words can explain the amount of beauty he brought to this world and how very missed he will forever be. He taught every single person that he met what kindness and patience are.

I have no doubt he will live forever in the kindness every one of those people will continue to give to the world. He didn't judge, he knew no differences, he only knew friends- and a friend he made in everyone.

Maxwell passed away in his sleep on 1/28/22, so peacefully, at his grandparents' house, feeling warmth and love surrounding him. As sad as we are, we will continue to find joy in every day, as Max had more "joy of life" than anyone. Spread joy wherever you can, and remember to "Be Kind".

We want to hear from you!

Have a PA story to tell, event to promote or news?
Spring newsletter submissions due by August 1, 2022.

PAF REQUEST FOR PROPOSALS

Submission Deadline: October 1, 2022
Awards announcement: January 15, 2023
Funding begins: Upon execution of grant agreement

Primary Research Mission

PAF is a non-profit organization whose primary mission is to help advance research devoted to finding treatments and a cure for propionic acidemia. By funding research, we aim to accelerate new knowledge, discovery, development and/or evaluation of therapeutics leading to better treatment and a cure for all individuals affected by PA.

Application categories:

1) Research Projects – Basic and Clinical research including initial grant request or continuation grant supporting projects designed to understand the molecular basis of the PA pathology and explore possible therapeutic avenues for the treatment of this condition. Past awards have ranged from $3,000-50,000 per year and may last 1 or 2 years upon competitive renewal.

2) Post-Doctoral Fellows Program - This program provides financial support up to $50,000 per one year for a metabolic/genetic fellow working on a research project in PA. This salary is intended to supplement any existing institutional support

PAF is particularly, but not exclusively, interested in the following areas of research:

- Development of chelating compounds for PA toxicity
- Risk factors for development of brain damage, pancreatitis, kidney disease, cardiomyopathy and/or arrhythmias,
- Disease modifiers in PA
- Development of new animal or cell/tissue-models for the study of PA
- Improved treatment including nutrition

Grants will be evaluated by the PAF Medical Advisory Board and Board of Directors based on the scientific validity and merit of the proposed research; technical feasibility; impact on accelerating discovery, development or evaluation of therapeutics; potential translation to humans; innovation; and ability to complete the research within the funding period.

Additional evaluation criteria include the relevance of the proposed research to PAF goals, specific research priorities and how the project fits with the current project portfolio.

If you have any additional questions regarding applications and funding regulations, please email research@pafoundation.com.

APPLICATION GUIDELINES

Applicants are invited to submit a full proposal (single-spaced with 0.5" margins using no less than 11 point Arial fonts). Full proposals should include the following in order and be submitted in one electronic document in the order listed below to research@pafoundation.com

- Project Title
- Principal Investigator Name, title, address (institution), phone, and email
- PAF Grant Type: initial research grant, a continuation grant, or a Fellowship
- Abstract/Summary of the Project (1 technical and 1 for the lay audience)
- Introduction
- Hypothesis to be tested
- Significance of proposed research to individuals with PA
- Specific Aims/Objectives
- Preliminary Studies if applicable

PAF REQUEST FOR PROPOSALS (CONTINUED)

- Methods and procedures
- Proposed results and potential challenges
- Project timeline
- Detailed Project Budget of total direct cost estimate for all categories of requested support including justification in U.S. dollars. *Indirect costs will not be payable through the grant.* Include total proposed by year if project period is longer than 1 year in scope.
- Biosketch for all key scientific and technical personnel. The NIH or other standard biosketch format is acceptable.
- Relevant Publications during the past five-year period. For continuation applications, list research articles submitted during the current grant period (published or in press).
- Assurances and Collaborative Agreements including Letters of Intent to Collaborate and Letters of Agreement from consultants
- Other Sources of Support including current and pending research support of all key scientific and technical personnel. Identify other support for the proposed project(s) including title, abstract, annual and total amount of the grant, inclusive funding period and percent of effort of the applicant. If there are no other grants, indicate "none."

Number of awards each cycle is dependent on the number of applications, outcome of review and the availability of funds. PAF is not obligated to make awards following each grant cycle.

Applicants without a faculty appointment (e.g., post-doctoral level) must also submit a letter of support from their project mentor.

Please contact PAF with any questions at research@pafoundation.com or 877-720-2192

PAF AWARDS $40,300 NEW RESEARCH GRANT

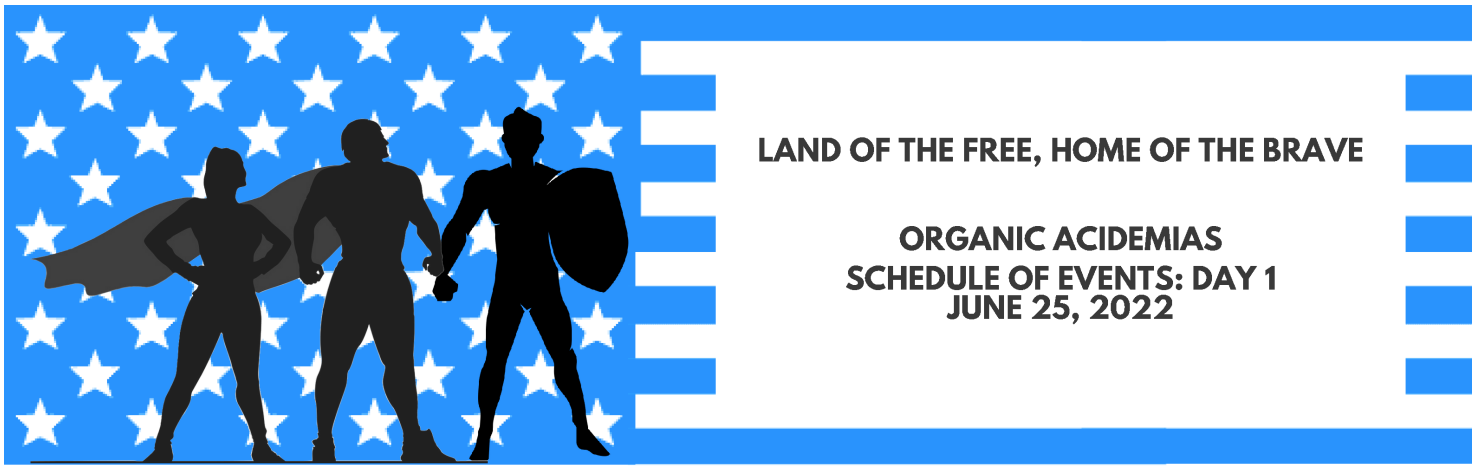
"Elucidation of cardiac electrophysiological alterations in propionic acidemia: Towards the identification of targets for therapeutics"

PI : Eva Richard, Associate Professor, Universidad Autónoma de Madrid, Spain
PI: Eva Delpon, Professor, Universidad Complutense de Madrid, Spain

Cardiac complications in propionic acidemia (PA) disease have increasing prevalence with age. Affected patients are prone to life-threatening cardiomyopathies, frequently alterations in cardiac rhythm (arrhythmias), a major cause of morbidity and mortality. In order to treat and prevent these cardiac problems, we must first understand the underlying mechanisms. In this line, our project pursues the understanding of the mechanisms of these cardiac alterations as a first step to develop future therapeutic strategies. Although a PA mouse model has been used to study some aspects related to the cardiac phenotype, differences in heart rate and in the ionic currents underlying the generation of action potentials, makes it unsuitable for more in depth studies. Our aim is to elucidate the electrophysiological alterations in a human PA cellular model, differentiating patient-derived induced pluripotent cells (iPSC) generated in our lab, to mature cardiomyocytes. The study of iPSC-derived cardiomyocytes from two PA patients with different cardiac phenotypes will provide a deeper understanding of the molecular mechanisms responsible for cardiac electrical defects responsible for life-threatening arrhythmias in PA and identify potential targets for therapy.

For this PAF-funded project, two groups of scientists with complementary expertise are actively collaborating to ensure success in the study of PA-related cardiac alterations. Our laboratory expertise is in PA disease and in the generation and use of iPSC -derivatives. We collaborate with Professor Eva Delpon's group at Universidad Complutense de Madrid with expertise in cellular cardiac electrophysiology and cardiovascular pharmacology. Preliminary results have confirmed the generation of mature PA iPSC-cardiomyocytes that represent a promising model for investigating the pathological mechanisms underlying PA cardiomyopathies.

We would like to sincerely thank the Propionic Acidemia Foundation for supporting our research to working together toward a common goal in Propionic Acidemia disease.



LAND OF THE FREE, HOME OF THE BRAVE

ORGANIC ACIDEMIAS
SCHEDULE OF EVENTS: DAY 1
JUNE 25, 2022

TIME	EVENT	SPEAKER
07:00-08:30	Registration, Vendors Open Breakfast Open	
07:50-08:00	Kids Zone (Ages 3-12) (Kids will eat lunch with their guardians)	
08:00-08:30	Welcome Message	
08:30-09:30	Keynote Dr. Gerry Berry, MD	
09:30-10:00	Vendor Break	
10:00-11:00	The Anatomy of a Metabolic Crisis: Why the Physiology is Important to Both OA and HCU Patients	Dr. Mark Korson, MD
11:00-12:30	Lunch	
12:45-01:45	Natural History Study of Propionic Acidemia	Dr. Oleg Shchelochkov, MD
01:45-02:00	Vendor Break	
02:00-03:00	**Main Ballroom:** Organic Acidemias Disease and Therapies Overview	Dr. Kimberly Chapman, MD, PhD
	Suites: Low Protein Breakout Sessions by Age	
03:00-03:15	Vendor Break	
03:15-04:15	The Translational Approach to Develop new Therapies for Organic Acidemias and Cobalamin DIsorders*	Dr. Charles. Venditti, MD, PhD
04:15-05:15	Novel Therapies for Branch Chain Organic Acidemias	Dr. Jerry Vockley, MD, PhD
05:30-06:30	Cocktail Hour (Cash Bar)	
06:30	Dinner Reception	

***Denotes Sessions Specific to Combined Cobalamin Disorder**

ALL GROUPS
SCHEDULE OF EVENTS: DAY 2
JUNE 26, 2022

TIME	EVENT	SPEAKER
07:00-08:00	Breakfast and Vendors Open	
08:00-08:30	Group Picture (Children will depart for Kids Zone from Pictures)	
08:30-9:30	Combined Young Adult Panel	
09:30-10:00	Vendor Break	
10:00-10:15	Rare X Presentation	TBD
10:15-10:30	Coriell Institute	TBD
10:30-10:45	Vendor Break	
10:45-11:45	Navigating Health Insurance	Raenette Franco
11:45-12:00	Closing Remarks	
12:00	Lunch	

REMEMBERANCE POSTER

Dear Families,

On behalf of the HCU Network America, Organic Acidemia Association and Propionic Acidemia Foundation, we offer our deepest condolences on your loss.

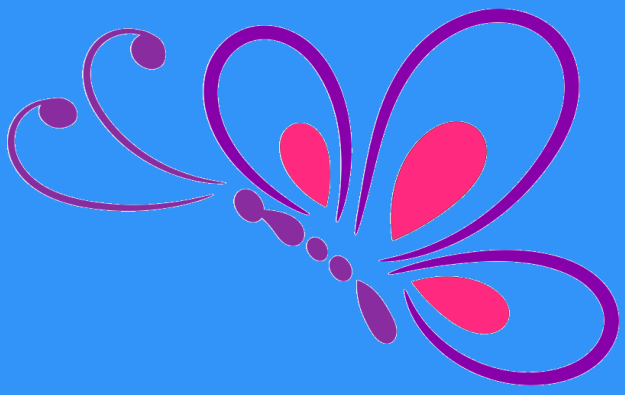
We would like to honor your loved one during the upcoming 2022 HCUA,OAA & PAF Conference by having a Hero Remembrance photo poster displayed during the conferences dinner banquet. If you would like to share a picture of your hero, please email Raymonde Degrace, degracemr@gmail.com. Please include your Hero's first name, genetic disease, birthdate , Angel date, state and/or country. Photos must be received by Friday, June 3,2022.

With Love,

Danae Bartke
HCU Network America

Kathy Stagni
Organic Acidemia Association

Jill Chertow
Propionic Acidemia Foundation



CARDIAC COMPLICATIONS IN PA: RESPONSE TO TREATMENTS

Propionic Acidemia is characterized by the accumulation of propionic acid, its derivatives, and ammonia. It is a multisystem disorder; it affects every organ in the body. However, one hallmark of the disease is the complications that arise in the heart. We know now that PA may cause cardiac disease in between 22-70% of patients, depending on the cohort (Park et al., 2020) manifesting mostly as cardiomyopathy and long-QT syndrome. In some PA patients, the cardiac defect has been discovered even before the genetic diagnosis of PA is made.

-What is cardiomyopathy?
Cardiomyopathy is a general term used when the heart shows structural changes. In PA, the so-called dilated cardiomyopathy (enlarged heart) is the most frequently diagnosed heart defect. Some complications from cardiomyopathy are arrhythmias and heart failure (Figure 1).

-What is long-QT syndrome?
In the long-QT syndrome, the electrical activity of the heart is altered and results in a delay in the time it takes for the electrical system of the heart to recharge after each heartbeat. It is detected through the electrocardiogram (EKG). Long-QT syndrome can compromise the normal rhythm of the heart and lead to ventricular tachycardia (the heart beating too fast), arrhythmias, and even sudden death (Figure 2).

-Do PA patients respond to cardiac medications?
Coenzyme Q10 has sometimes been used successfully in PA patients with cardiomyopathy, but this therapy has not been standardized for the treatment of PA. For severe cases of cardiomyopathy, cardiac transplantation may be the only resource available to patients.

For long-QT syndrome, a class of medications called beta blockers (BB) are used to slow the heart rate and make the syndrome less likely to occur. Atenololol, propranolol, metoprolol and nadolol are the most frequently used medicines. The choice of medication will depend on the exact electrical alteration seen the patients (longer or shorter QT interval) and the gender, among other variables. In PA patients, both nadolol and propranolol have been documented to control long-QT syndrome. However, a thorough evaluation of which medication works best in patients with PA is still missing. Although the choice of BB highly depends on the individual patient, there is no evidence to suggest that these medications do not work in patients with PA who have long-QT syndrome.

-Future therapies that may aid the heart problems in PA
Liver transplantation has been successful in resolving PA cardiomyopathy in some cases. However, the cardiac defect may come back a few years after the transplant (Park et al., 2020).

We need new experimental tools to discover why PA diminishes heart function. Some of the animal models that have been developed to study PA also show cardiac alterations (Guenzel et al., 2013). These animal models will likely be a valuable tool to study how PA affects the heart. Isolated cardiomyocytes derived from patients with PA may also be a very useful tool to study the cardiac defects of PA cells and to screen compounds that could aid in the treatment of cardiac PA (Sala et al., 2019).

Additional Reading:

Guenzel et al., 2013. Generation of a hypomorphic model of propionic acidemia amenable to gene therapy testing. Mol Ther. 21 (7):1316-23.
Park et al., 2020. Cardiac complications of propionic acidemia and other inherited organic acidemias. Front. Cardiovasc. Med. 7:617451
Sala et al. 2019. Long QT syndrome modelling with cardiomyocytes derived from human-induced pluripotent stem cells. Arrhythm Electrophysiol Rev 8(2):105-110.

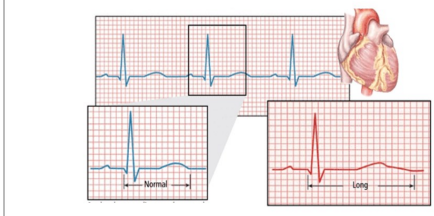


Figure 2. Long QT in the EKG. On the electrocardiogram, the normal QT interval is 350-460 milliseconds (ms). Prolonged QT is considered if QTc ≥450 ms (males) and ≥460 ms (female). *(Adapted from Levine et al. 2008).*

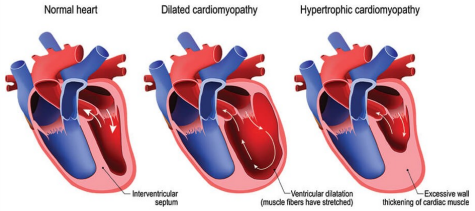


Figure 1. Different types of cardiomyopathy. *(From Advanced Cardiovascular Institute)*

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 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.*

CLINICAL TRIAL OPPORTUNITIES

HERO Clinical Study Updated - Recruiting Participants Now

HemoShear Therapeutics has modified their **HERO** (**H**elp **R**educe **O**rganic Acids) clinical study to ease the process for families to participate. The entry criteria have been broadened, the number of study visits to the clinical site have been reduced and there are no overnight stays required.

"Participating in clinical trials is essential for making progress to advance potential new treatments," says Kim Chapman, MD, PhD, medical geneticist at Children's National Medical Center and lead Principal Investigator for the HERO study. "We also recognize that it can be hard for families to be able to commit to research. We believe our recent changes to the study design will help screening and for those enrolled, potentially reduce the impact on families while achieving our scientific goals."

HERO is actively recruiting children and adults with MMA (mutase deficient) and PA aged 2 and older who meet the study criteria. More information about what is involved is provided at MMA-PAHero.com.

Study Assessing Potential New Treatment

The HERO study is designed to assess the safety, effectiveness and metabolism of HST5040, an oral investigational drug developed by HemoShear to potentially reduce the toxins that cause harm in MMA and PA patients. HST5040 has the potential to be active throughout the body, including the brain, heart, liver, kidneys and muscles.

The investigational drug can be taken at home as a liquid formulation by mouth or through a gastric feeding tube. Study participants will have the opportunity to continue to take the study drug until it is available to the public or the study is ended.

Find a Site Near You

HERO is being conducted at several leading children's hospitals across the United States - and more sites are being added to the study soon. Ask your doctor about whether you could be a candidate to participate.

Transportation can be provided to travel to the study sites and stipends are available to cover meals. All study drugs, study visits and assessments will be provided at no cost.

Learn more at MMA-PAHero.com

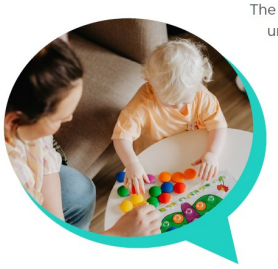
The safety and effectiveness of HST5040 for the treatment of MMA or PA have not been established.

MMA+PA IMPACT STUDY

HEMOSHEAR THERAPEUTICS

Share your Story!

Join IMPACT to share your experience with MMA or PA



The **IMPACT Study** is being conducted to understand what day-to-day life is like for people with methylmalonic acidemia and propionic acidemia.

It's Easy!

This study involves participating in up to two interviews via Zoom for up to two hours. No medication or clinic visits are required. Eligible study volunteers will be compensated.

Who Can Participate?

The **IMPACT study** is open to people with MMA and PA aged 8 and older as well as parents or caregivers of those aged 2 and older. Both transplant recipients and patients who have not received a transplant can join.

Visit MMA-PAImpact.com to learn more and sign up!

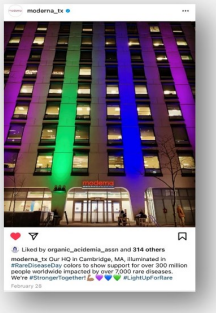
moderna

PA Clinical Trial Updates

Stronger Together!

For the past 10 years it has been Moderna's mission to advance mRNA as a potential therapeutic option for rare genetic diseases.

On Feb 28, 2022, Moderna headquarters proudly #LightUpForRare to help raise awareness and show our support for those living with a rare disease.



The **Paramount** Study is a Phase 1/2 study. It is designed to evaluate if an investigational treatment called mRNA-3927 is safe in individuals one year of age and older with PA. mRNA-3927 is an investigational intravenous (IV) infusion treatment that instructs a persons' body to make a PCC enzyme that works.

More information including full trial inclusion and exclusion criteria can be found at Moderna Paramount Study or by visiting ClinicalTrials.gov

paramount study

As a company deeply committed to developing life-saving medicines for patients around the world, we are pleased to share that Moderna completed Cohort 1 in 2021 an di sclose to completing enrollment of Cohort 2 in Phase 1/2 for Propionic Acidemia at research sites located in the United States, Canada, and the United Kingdom.

PAF EVENT & FUNDRAISING SPOTLIGHT

UPCOMING EVENTS

- **Fall 2022 - 17th Annual Tailgate Party & Corn Hole Tourney for PAF**

PAST EVENTS

- **Fall 2021 - Meigs High School UNICEF Club Corn Hole Tourney, raised $971**

GIFT MATCHING: This may enable you to double your donation. Check with Human Resources to see if your employer matches. It makes a big difference.

FACEBOOK: Thank you to all of our Facebook Fundraisers and people that donated to their fundraising pages for birthdays, #GivingTuesday or just because: Amy Fisher's birthday, Sarah Mullins' birthday, Elisa Huro's birthday, Elisabeta Riverqueen's Birthday, Selvi Pragasam's Giving Tuesday, Andrea Shewin's Giving Tuesday

STOCK DONATIONS: PAF is now accepting stock donations. Please email paf@pafoundation.com with any questions.

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**: Nila Branch, Garrett Hahamy, Dylan Jaehnke, Laura Lemire, Trent McKinley, Gwen Mouat, Nalani Johnson, Reuben Kleckley, Lenert's, Dania and Edgar Jr. Martinez, Trent McKinley, Gabrielle Millett, Brandon Napiwocki, Aidan Pragasam, Carolyn Schlein, Maren Stecken, Ben Sweetman, Chase Workman
- **In Memory Of**: Alice and John Dawe, Kerrie Fessler, Jordan Franks, Vincent Phillip Franze, Connor McKillop, Michael Messersmith, Nicholas Phillips, Andrew Popowicz, Abraham Sleiman, Amanda Sleiman, Talli Smith, Angelica Stageman, Kirstyn Tripp, Maxwell Weinzerl

STOCK DONATIONS: PAF is now accepting stock donations. Please email paf@pafoundation.com with any questions.

Matching Donations and Volunteer Hours: Some companies have a volunteer program and will donate based on your volunteer hours. PAF is always looking for volunteers. Please check with Human Resources to see if they have a program. In addition, some companies will match your donation.

INTERNET
Thank you for using Igive, Goodsearch and AmazonSmile and designating Propionic Acidemia Foundation as your charity and setting up Facebook Fundraising Pages. Every dollar counts.

Thank you for all donations and the kind notes we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration. PAF couldn't do what we do without your incredible support.

Thank you for making a difference.

MHS UNICEF

THANKYOU to the Meigs High School UNICEF club for sponsoring a corn hole tournament for PAF! The tournament had over 70 teams and raised over $900 for Propionic Acidemia Foundation! Congratulations to winners Bostic and Caleb! It was a great day!

Announcing the PAF Marathon Team!

Would you like to run the best Marathon in the world?

Join **Team PAF** to run the New York City Marathon

Raise funds for a cure! Raise awareness!
Have the most fun in the world!

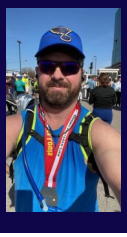
Runners of all levels welcome
Interested? Contact Marisa Cotrina at TeamPAR4@gmail.com

Searching for a Cure, Hope for our Children

JOHN'S TEAM PAF STORY

I'm running to raise money for PAF. There are many reasons to support PAF such as the research into cure's, formulas, and treatments. But most of all for me it's the communication and networking they provide anybody that has a family member with PA. When our twins Grant and Sebastian were born with PA we were fortunate to be in a hospital with a University, geneticist and insurance coverage. But as they started to crash even they had very little information about what they had, just a lot of scrambling to try and save them. It left us alone goggling to try and find out what they had. The PAF web site popped up and after an inquiry , Jill was on the phone with us in minutes and able to answer questions and explain it to us. I can only imagined what it would have been like to not be in a big city-university hospital and have no support. So I feel raising money for PAF is helping every parent with information and support that has a child with PA get the information they need and desperately want.

John



AUBREY'S TEAM PAF STORY

My name is Aubrey Delima. Our daughters, Jenna and Lauren were born with an inborn error of metabolism called Propionic Acidemia. As you may know, Lauren passed away at the age of 9 (in 2010) due to complications of this disease. By the grace of God, Jenna is stable and is now 23 years old! I wanted to raise awareness about this rare disease.

I will run the New York Marathon on Nov. 6, 2022 with a small group fundraising for the Propionic Acidemia Foundation (PAF). We are the PA-runners! Please help us by making a small donation to this very worthy cause. The money raised will go towards funding research and improved treatment of those living with this metabolic disorder.

Thank you in advance for your support. We sincerely appreciate every donation.

Aubrey

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Hope for Our Children

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PAF volunteers and board members are needed!

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