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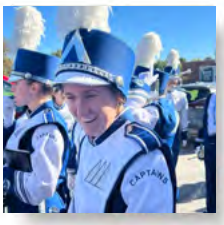
Organic Acidemia Association



OAA Newsletter • Family Stories • Family Matching • Family Conferences • Research Funds Awarded • National Advocate for Newborn Screening

Parent Support, Education & Awareness www.oaanews.org

A support group for families living with methylmalonic, propionic, isovaleric, and other organic acidemias

Happy Holidays!

This issue of the OAA newsletter is packed with exciting developments, information you can use, and moving stories.

Save the dates … June 28 and 29 2024 in Pittsburg, PA … for our next FOD/OAA Family Forum. You'll find registration and hotel reservation links on Page 3 with more detailed information to come.

OAA board member, Cay Welch recently toured the Coughlin Lab at the University of Colorado. https://www.coughlinlab.org/ Curtis Coughlin II is an Associate Professor in the Department of Pediatrics and the Center for Bioethics and Humanities. His research focuses on inborn errors of metabolism that result in neurologic dysfunction such as pyridoxinedependent epilepsy (PDE-ALDH7A1) and glutaric aciduria type I (GA I). His laboratory utilizes model organisms to characterize the role of metabolites in disease pathology. He is also an OAA Medical Advisor.

This issue includes our annual financial summary that details how our dollars have been put to work to support and promote the mission of the OAA around the world.

As you have likely heard, our pharma partners Hemoshear and CoA Therapeutics have stopped their clinical trials on new treatments for MMA and PA. We all had high hopes that these breakthrough treatments would offer a new life for those afflicted with MMA and PA disorders (and other OA disorders in the future). But like everything else in the world, it all comes down to business decisions. We should note that in the case of CoA Therapeutics, they indicated their inability to sufficiently enroll participants lead to the closure of the trial. There were many factors contributing to their enrollment challenges, but let us remember that since these are rare disorders, with a small population, our community has a responsibility to support these trials whenever possible.

The OAA Natural History Registry is being migrated to a new NORD platform during 2024. We are delighted to have two OAA members step forward to help us with this important effort. You can read more about them in this issue.

Martha is an adult with Propionic Acidemia. She has two girls, ages 16 and 14 and resides in Portland, Oregon. Professionally, she is a dietitian who, prior to having her own children, worked in a genetics clinic. Since having kids, she has had a number of part-time jobs most in schools, primarily to revolve around the school year calendar. With both girls in high school, she is looking to work more. In addition to helping OAA out with this project, she is working part-time in the local NICU. There isn't much spare time, but when there is she enjoys musical theater with her children, completing puzzles and Diamond Dotz artwork and snuggling any of the three cats or two guinea pigs that will let her.

Meher is a stay-at-home father of a 12 year old boy with Methylmalonic acidemia. Before having children, Meher was involved in the software, animation and visual effects industry. He currently spends his spare time volunteering for the OAA and the local maker groups in Piedmont, California.

Finally, in this issue you'll have a chance to read about several brave and talented young adults with organic acidemia disorders. Michael shares his new adventure as an author and developer. Raechel is a member of a marching band and section leader, despite being visually impaired due to having MMA CblC. And Karli has successfully "left the nest" having moved to a new city and secured a great job based on her self-advocacy. Each story is an inspiration for OA parents wondering about their child's potential in the future. As these three show, the future can be very bright.

On behalf of the entire OAA family, I send best wishes for a safe and happy holiday season.

Kathy

In this issue

Organic Acidemia Association

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Medical **Advisors**

FOD/OAA Back Together Again!

We are excited to partner again with the FOD Family Support Group for this year's event. We will be at the Wyndham Hotel University Center in Pittsburgh, PA.

Registration Link: https://www.eventbrite.com/e/fod-and-oaa-family-forum-tickets-718153495437?aff=oddtdtcreator

Hotel Reservations Link: https://www.wyndhamhotels.com/wyndham/pittsburgh-pennsylvania/wyndham-pittsburgh-university-center/overview?checkInDate=06/27/2024&checkOutDate=06/30/2024&groupCode=062724OAA

OAA Family Forum Website: https://oaanews.org/conferences/2024-fod-oaa-family-forum/

OAA Online Shop Offers Awareness Items

Visit oaanews.org/donation/oaa-store/

Financial Report

As is our custom, each year after filing our annual 990 report with the IRS, we publish the organization's financial status.

During 2022, the OAA collected a total of $109,117 in contributions and earnings on our investments. Not shown in this amount are contributions previously made in support of our 2020 family conference which was postponed due to the Covid pandemic.

For 2022, we published two issues of our newsletter, read by thousands around the world. This vital communication tool distributes information to parents and health professionals on updates, editorials, and letters from and for affected families. We also actively participated in facilitating communication through our public/public Facebook group as well as other social media platforms such as Twitter, Instagram, and LinkedIn.

In June we held our previously delayed bi-annual family conference in Bethesda Maryland. The well-attended meeting included participants from HCU Network America and the Propionic Acidemia Foundation.

We continue to give visibility to organic acid disorders through our presence at key conferences. In 2022, we participated in Moderna's "Voice of the Patient" and then at the CHARLIE consortium conference in Barcelona, Spain.

During the year we hosted a number of webinars including: a session for ORCAM, a device for the visually impaired (something very important to our MMA members who often struggle with their sight), and a program advancing interest in research for MMA and PA.

We continue to make investments in maintaining our global presence with our first major update of the OAA internet web site in 10 years! We also executed a social media campaign created with collaboration from students at the University of Minnesota.

We proudly awarded research grant to National Research Council's Institute of Biophysics in Palermo, Italy who are working to identify potential treatment for cobalamin C (cblC) deficiency. We also awarded a research grant to the Healthwell Foundation to assist family's copayments. And finally, we again participated with Rare Science Inc. to distribute their very popular "Rare Bears" to our OAA kids.

As shown in the chart below, we ended 2022 with a balance of $688,418 in our investment accounts.

Financial Summary

REVENUE	FY2022
Donations/Contributions	$109,117
EXPENSES	
Grants	$14,500
Management	$48,863
Conferences, Meetings & Travel	$44,464
Family Support & Programs	$5,565
Website Refresh	$8,877
Office Expenses, Accounting, Insurance	$6,297
Newsletter	$7,618
Telephone/Internet	$3,463
	$139,647
FUND CHANGE (Revenue-Expenses)	-$30,530
ENDING FUND BALANCE	**$688,418**

We have a new way for you to support OAA financially!

Donating appreciated investments, rather than cash, can be a tax-efficient way of accomplishing your charitable goals. When you contribute non-qualified, long-term appreciated investments to charity, you avoid paying capital gains tax on the appreciation of that investment. As a registered 501(c) (3), OAA will also not pay any capital gains tax either. This also may provide additional tax benefits. You may be entitled to a charitable deduction equal to the fair market value of the investment on the day its donated, up to certain maximum amounts allowed determined by the IRS. Please contact a CPA to see how this might impact your own tax situation.

If you are interested in finding out more about this, feel free to contact our financial advisor,
Adam Jaehnke at 763-542-3715 or
jaehnkea@stifel.com.

Angel Flight NE

Good Afternoon Members of the Organic Acidemia Association!

I am writing to introduce you to Angel Flight NE, a 501(c)3 nonprofit organization that coordinates free air and ground transportation for medically stable patients seeking medical care for healthcare conditions including rare and ultra-rare diseases that requires them to travel hundreds if not thousands of miles for the specialized care they need.

Here is a link to our website – www.angelflightne.org. We also have a recent video that features just a few of the patients we have assist - https://angelflightne.wistia.com/medias/ce612qu7ii.

Our vital mission is made possible thru the generosity of our volunteer pilots and commercial aviation partners who fly medically stable children & adults for FREE. We have been humbly providing our services for 27 years assisting more than 108,000 patients who have flown over 15 million miles to 750+ medical facilities throughout the United States. We also provide our services to patients who need to travel internationally to receive specialized care.

Over the last several months, there has been an increase of flight requests for patients - children and adults - diagnosed with rare and ultra rare diseases. Our mission/flight coordinators, who are available 24x7, use our web-based system to schedule flight made possible by our 400+ volunteer pilots or commercial airline partners. These flights are completely FREE of charge to the patient & family for as long & as often as they need to fly.

Having seen the recent spike in requests from people diagnosed with rare diseases, we've begun an initiative to reach out to rare diseases organizations and groups, like yours, to let them know about our services. My hope in reaching out is that you will consider adding Angel Flight NE to your "resources" list so patients are aware of our ability to provide FREE air and ground transportation. As a small thank you, we would also add your organization to our website & share your information.

Please feel free to reach out to me at rsica@angelflightne.org or via phone at (978) 794-6868 if you have any questions.

Regards,

Robert Sica
Community Outreach Associate
Angel Flight NE
(978) 794-6868
angelflightne.org

OAA Race Car Wins Track Championship!!

We wrapped up our first season of racing the Organic Acidemia Association car today with a win and the track championship for 2023. Our season results were 12th, 2nd, 1st, 1st, 3rd, and 1st. I want to thank everyone who added a name on the car and I hope this gave everyone some joy and happiness to have their child or themselves on the car for awareness of these diseases. In all of my post race interviews I made sure to point out that I was running for the Organic Acidemia Association to raise awareness of all of these rare diseases. Thanks also to Kathy Stagni for allowing me to bring this awareness and use her organization's name.

Dylan, brother to Brandon, Christian and Jake (Isovaleric Acidemia)

My Newest Adventure

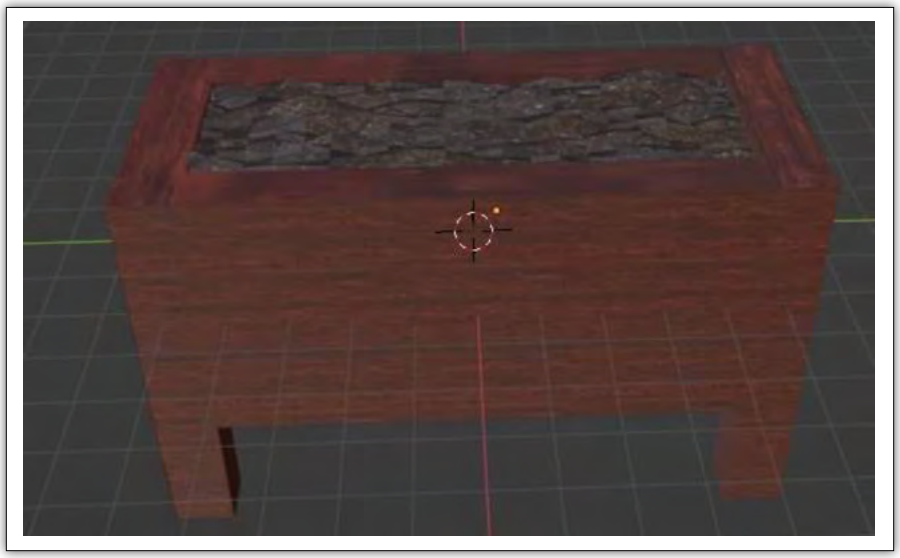
Michael Clapcich
michael.clap@gmail.com

Have you ever dreamed of watching over your city like a guardian angel? Defending it like the Avengers, or protecting the galaxy as the Guardians of the Galaxy do? How about being the chosen one like Harry Potter? Even better, protecting the mythology universe like Percy Jackson, or become a part of a legendary team like the power rangers?

If you are a Hero in the making, THEN STAY TUNED...

While the writing of my book has been completed, I am on another journey that ties in with my book. Last year, thanks to the help of my supports coordinator, I was introduced to an online class given by Game -U University. This is where I discovered videogames could be created. I came up with the idea of creating video game to go along with my book. About a year ago I enrolled in this class and started to create. I started out with a one hour class once a week but that soon changed to two days a week. I quickly became interested in what my instructors, Dustin and Jovan had to show me. Construct, one such program is how I used animation to bring characters to like while Blender, another type of program, is used for 3D creation. Another type of program that I was exposed to was Paint. net. Something else that had been fun to learn is making storyboards, like in comics. In Blender I've made a tea set for a table setting as well as the table. I also was able to create the texture of our dining room chairs and used it in my program. I have created such animals like a horse, a wolf, and currently working on a greenhouse. The different programs allow me to do different things. For example I started animating a chapter of my book where I have to get the dragon in a certain position. Seeing this creation in 3D was amazing. Game U University offers workshops to all interested. Please check out their website, www.game-u.com. I have taken a sprit animation and a comic book workshop which I'm hoping gives me a a better way to incorporate storyboards in my book illustration.. I am going attempt to convert a comic strip that my brother did when he was younger into storyboards. For those who are reading this I am on social media where I do show off my work as well as stream. My YouTube channel is https://youtube.com/@michaelclapcich6353?si=mkXPVQKM_atX7E-o

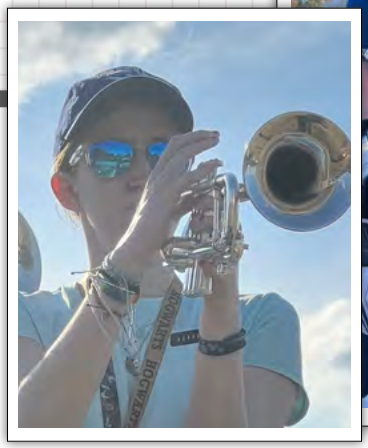
Thank you for allow me to share my story.

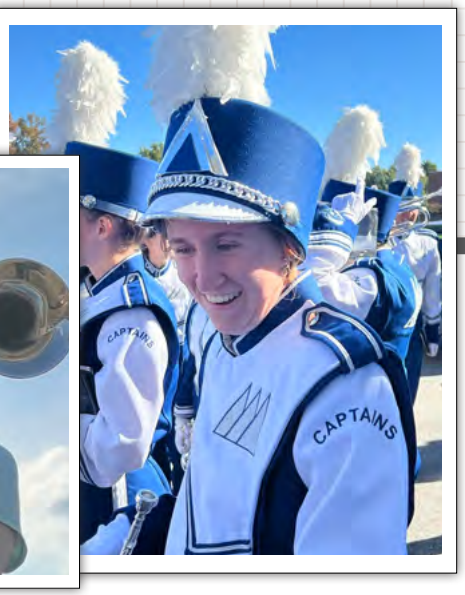


Raechel

MMA, Cobalamin C

Age 20





Raechel is a 20 year old sophomore at Christopher Newport University in Virginia. She was born with MMA CblC, before it was part of the newborn screening panel. She was actually diagnosed day two after birth by sheer luck by her caring and curious cardiologists who had followed her since 20 weeks gestation for a cardiac anomaly. But that is a whole story in itself.

She is legally blind, but is in the CNU marching band as a trumpet player, and she is majoring in American Studies Major with a double minor in Philosophy of Law and Criminology. The University did a feature on her and you can see it here: https://cnu.edu/news/2023/10/25-sswa-s26-erler/#skipheader

Yes, I am proud of her and all she overcame – the 8 weeks in the NICU after birth, the 12+ weeks of hospitalizations over her first 9 years, the battle with protein and medications and finding the right balance of each. (Again- a whole novel could be written about this.) What I am most proud of is how she is growing despite her disabilities and disorder, and she wants to make a difference in her future and the future of others, and she will not let anything stop her. She asked me to share her college application essay with this audience (and she was accepted to every college she applied to, by the way). So here it is. Thank you, our OAA family, for reading.

I'm a miracle child. I wasn't supposed to be born, let alone writing this essay to apply to college. I was born with a genetic disorder called MMA, which affects my vision, metabolism and my heart. When I was in the womb, my heartbeat was very irregular and had poor function. My mom says that it sounded like a badly played drum. The doctor said that because of my heart, I would never be born. Then something miraculous happened. At 35 weeks, my heart started working normally, and at 38 weeks, I was born. But that was only the start of my obstacles.

I was hospitalized over a dozen times before I turned nine, and I experienced two emergency helicopter rides to the hospital. Now, of course, I don't remember what happened, but I've heard one of the stories multiple times. My mom was at work when she got a call from my nanny, Elizabeth, who said I was very sick. Although my temperature was only 101, a temperature at which one should be conscious, I wasn't moving. When my mom got home, she discovered that my nanny had misread the thermometer, and it was really 107. Immediately, my mom called 911, and I was airlifted to Children's Medical Center. The doctors tried everything, but they couldn't get my temperature down. My mom kept trying to persuade the doctors to get ice packs to put under my arms, but they kept saying that it wouldn't work. Finally, the doctors gave her ice packs, and within 20 minutes, my temperature came down. Once again, I shouldn't have survived.

Even though I haven't gotten that sick or been hospitalized in a long time, I still face obstacles every day. My heart doesn't pump as strongly as it should, and I have no central vision. I take medicine each day and have regular doctor's visits. But I will not let this or anything stop me. I love music, so I joined my high school band and marching band. Since I don't see as well as most people, I am unable to site read music, so I have to have someone record the music and send it to me so I can memorize it. When I am learning my position for a marching band show, I ask someone to help me find my spot since I can't see my position sheet, and then I memorize where I need to go. Despite all of my obstacles, I was recognized as the best freshman marcher. I've been a part of the band for 8 years and marching band for 4, and I enjoy every minute of it. If the doctors hadn't caught my disorder when they did, I'd have a lot more problems than I do and probably wouldn't be participating in either band or marching band, or even school.

It's hard to pick just one lesson that my disorder has taught me, but the most important one is that people shouldn't let a disability get in their way. Even with my disorder, I've never let anything stop me. If I want to do something, I find a way to do it. I not only marched with the band, but I auditioned for section leader and succeeded in getting one of the two section leader positions. The other lesson I learned from what I've experienced is that sometimes in life people have to reach for their goals no matter how hard they may seem, because a person never knows when their life may end. Even though I know there are goals I will never be able to obtain, I reach far because I want to make my life the best it can be.

Raechel (and mom Melanie)
Virginia
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Karli

Propionic Acidemia

Age 34

My name is Karli, and I am now 34 years old. I live in my own apartment in Winona Minnesota. My OAA Story had gone out in the OAA Newsletter in 1998 and I would just like to give an update on where I am today.

I was first diagnosed with Propionic Acidemia (PA) when I was ten months old. And wow have I come a long way. When my story came out in the 1998 newsletter, I was taking 32g of protein a day and most of that was through formula which I call bug juice. Today I am taking 55g of Protein from food intake and about 200z of formula (Bug Juice). I still get tired very easily of course with my low stamina and muscle tone. But I live each day to the fullest doing the best to my ability.

I graduated from High School in 2007. I did some volunteering at a local nursing home in the summer helping with the afternoon activity. I did try a couple of online college courses after high school, but it wasn't the right fit for me.

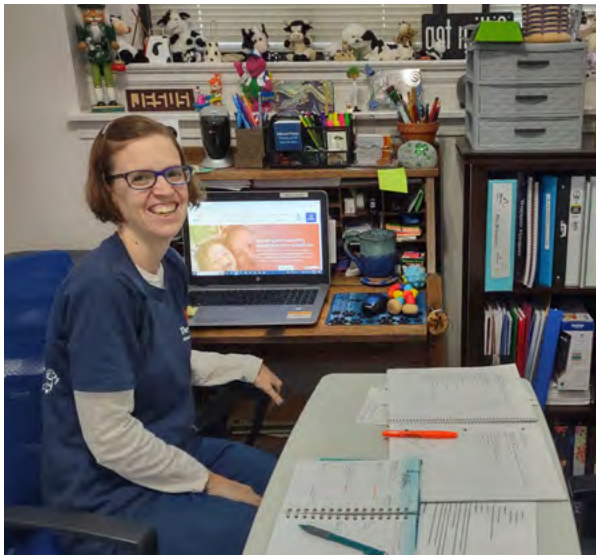
In 2009 I started working at ABC Woodland industries/Twice is Nice. This is a place where it gives people with disabilities a chance to work. I worked mostly in the secondhand store. Which gives each individual the opportunity to try different areas to see what the right fit is for them. I worked as a cashier, working on pricing/tagging/ hanging clothes. I was paid by subminimum wage, but I was still working and was feeling proud of my accomplishments. Woodland connected me with workforce Development which helps people with disabilities find jobs in the community that is the right fit for them. I felt I was capable of so much more and wanted to prove that to myself and others. They helped me create a resume, cover letter and help me figure out what my skills and strengths were. In my assessment I was found to be very social, enjoyed working with others, and loved working with the public. Workforce development continued helping me apply for employment at many community businesses. I ended up getting my first Job at Alco Department store. Things we going smoothly for approximately 6 months until my supervisors became less understanding of my needs and stamina. So I ended up putting in my two weeks' notice and then was on the job hunt again, working with workforce development. I resumed my twice is nice position while I continued the job search.

With my sister in college, and my younger brother making plans to attend college after his senior year, I felt it was time for me to spread my wings and leave the nest. However we needed to come up with a plan, where both my parents and I would be comfortable with me living on my own. We ended up getting in contact with the Arc of Minnesota after my dad read an article about a new program called "Housing Access Services." And it was an answer to a prayer. We met with the team and we went over what I was looking for and what kind of place I would like. I was ready to move out but still wanted my parents close in case of emergency. After contacting the Arc of Minnesota and Housing Access Services things moved pretty quickly. I was able to find a place about 5 minutes away from my parents. But I was still going to be independent and living on my own. I was the 1st individual from the state of MN to receive assistance. Housing Access Services also helped me find different programs to help me financially. For example, getting me in contact with Sec 8 and an energy assistance program.

With the Arc of Minnesota, I became involved in SAM (Self-Advocates of Minnesota). With being involved in self-advocacy I have blossomed and this program has helped make me the unique individual I am today. I learned to speak up for myself to let others know what I want, but I also have the chance to give others a voice who aren't able to get their voices heard. I have been involved in self-advocacy ever since, going on 14yrs now. With being involved in SAM I have taken many leadership positions in the self-advocacy group. I had started off as the Media/Legislative reporter and moved up to Historian, later to Vice Chair and then Chair.

In 2016 I ended up getting a job at Sterling Drug Store in Caledonia MN. And everything was going so smoothly. Co-workers and supervisors were amazing and understanding. I was working as a cashier there. The job was also slow paced.

In 2017 I started getting lonely in my apartment. I was coming home at the end of a workday to an empty and quiet apartment. I needed to find a nice companion. Someone who would be there



to greet me when I came home from work every day and that is where my dog Ms. Lady Pugglesworth came into my life, she was a blessing in disguise. I would come home from work and there is now someone to greet me, and I talk to her and tell her about my day. She is a great cuddler too.

Now when I moved out in 2009, I was living in Eitzen MN which is a very small town. And even though I now had a dog to keep me company I didn't have much of a social life. My social life was considered going out to eat with my parents. I needed a change. In 2019 I used the Arc of Minnesota's "Housing Access Services "Program again and moved to Winona MN. Although when you move to a new town you need to have a plan. Mom and dad were going to be an hour away instead of 5 minutes away. So I needed to have a good support system. We ended up getting connected with Cardinal of Minnesota where I have staff that come in about 4 times a week to help with errands, med check, or just a check in to see how things are going. Besides that, I still have my independence. The reason I chose Winona was because I already had a connection with SAM Members there who were part of my self-advocacy group. I am now involved with Winona People's 1st which is a local self-advocacy group. I am going bowling every week through project compass through Winona Community Ed. So, my social life is pretty busy. Sometimes it gets so crazy that mom has a hard time of keeping track and some months I even need to print out a calendar.

Today I am working at my dream job at the Arc of Minnesota as a Self-Advocacy Associate. I help host and support at self-advocacy meetings. I help create and present workshops for self-advocates and provide information, resources, and training about self-advocacy, and so much more. The work I do has impacted others and their life situations in the easiest way. I started this job in December of 2021, and I am currently in that same position. My hours for my job have increased. I started off at 10hrs per week and am now up to 12hrs per week. I am loving every minute of it.

Over the years there have been blessings, struggles, ups and downs, and achievements. But with my faith and the support that I have been given by family, friends, coworkers and programs I have overcome many barriers and obstacles. My faith has become stronger, and I have become more confident in myself. I would not be where I am today without my faith. I live each day to the fullest and thank God for everything that he has blessed me with. I have been blessed with two amazing nephews who fill my heart with love and joy. My life has been like a transformation of a Butterfly. I used to be in my own little chrysalis and now have emerged into a beautiful butterfly and spreading my wings. I have accomplished and achieved many things. I am proud of who I have become with just putting my best foot forward and trusting in God. He is by my side to lead me on the path that he has chosen for me.

I have the Dream Job, great living space, social life. Everything is good. I can't wait to see what the future holds.

I am surrounded by love and support. My parents still live at the same address. My Sister is married and has 2 boys, and my brother just got engaged. With my faith and the love and support from my family I would not be where I am today

Karli
Winona, MN
karli.harguth@gmail.com

Fundraising for OAA

2024 OAA Calendar

The 2024 OAA Calendar is now ready to purchase at the link below! We showcase our beautiful children each year in our fundraising calendar. We thank Raymonde, a MMA Cbl C mom who creates this masterpiece each year!

Makes a perfect gift for family and also your medical team!

https://www.createphotocalendars.com/Shop/organicacidemiaassociation

Texas Roadhouse Holiday Fundraiser!

All funds will go towards scholarships to our 2024 OAA/FOD Conference!

https://txrhgiftcards.com/collections/txrh-5-100-no-brd?ref=261OrganicAcidemiaAssoc2023

If you purchase prior in November - the ecards will be sent on December 1 -- after December 1st - the ecards will be mailed December 20th.

Thanks for your support!

iGive.com®

1,800+ Online Stores Where Shopping Helps Our Cause

Raise Money for Organic Acidemia Association, Every Time You Shop Online

Now more than ever, smart shoppers are looking for ways to stretch every dollar. In these uncertain economic times, we all face hard choices as we plan for special occasions, holiday gifts, and charitable giving. With iGive.com, you don't have to choose between buying the things you need and supporting Organic Acidemia Association.

Now you can save money with exclusive coupons and deals at hundreds of online stores. And, you can feel good knowing that a portion of each purchase benefits our organization.

Create your free iGive account today, and start helping every time you shop. Over 1,800 stores participate in the iGive program, including Walmart, QVC, Staples.com, HSN, Kohl's, and Quill.com.

So why not avoid a trip to the mall, skip the long lines, and save some gas? You'll never pay more when you reach an online store through iGive.com, and up to 26% of each purchase benefits our organization!

Start helping today at: www.iGive.com/OAA

Up to 26% of each purchase benefits your favorite cause.

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Adagio Teas
Adorama
AJ Madison
Albertsons
Alibris
American Blinds
American Eagle Outfitters
Ancestry.com
Anker
Ann Taylor
Appleseed's
ASICS
Athleta
Aveda
Avon
Banana Republic
Banana Republic Factory
Bare Necessities
bareMinerals
Bass Pro Shops
BeallsFlorida.com
Bed Bath & Beyond
Bergdorf Goodman
Best Bully Sticks
Best Western
BestBuy.com
Better World Books
Bissell
BJ's Wholesale Club
Blair.com
Blick Art Materials
Blinds.com
Bloomingdale's
Bonobos
Booking.com
Booksamillion.com
Boscov's
British Corner Shop
Brooks Brothers
Cabela's
Canon eStore
Capitol Lighting
CardCash
Carhartt
Carolina
Carter's
Charles Tyrwhitt
Cheryl's
Chicago Steak Company
Chico's
Chico's Off The Rack
Choice Hotels
Clarks
Clinique Online
COACH
Coach Outlet
Collections Etc.
Columbia Sportswear
Craft Beer Club
Crate and Barrel
Crocs.com
Crowne Plaza
Crutchfield.com
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Darn Tough
Dell Technologies
Dermstore
Discount School Supply
Discount Tire
DiscountMugs
Dollar Tree
Draper's & Damon's
Eddie Bauer
EILEEN FISHER
Enterprise Rent-A-Car
Estee Lauder
EventDecorDirect
Expedia.com
EXPRESS
Famous Footwear
Fanatics
Fandango
FARFETCH
Food Lion
FragranceNet
From You Flowers
FSA Store
FTD.com
Gap Factory
Gap.com
Gardener's Supply Company
GiftCards
Gilt
GlassesUSA
GNC
Go Daddy
Greater Good Stores
Groupon
Guitar Center
Hanes
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HOBO Bags
Holiday Inn
Holiday Inn Express
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Lenovo US
Levi's
Life is Good
Lilly Pulitzer
Lindt Chocolates
LOFT
Lookfantastic
Lovesac
Macy's
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maurices
Merrell
MeUndies
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Omaha Steaks
One Hanes Place
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Orbitz
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Parachute Home
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Tempur-Pedic
TerraCycle
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The Container Store
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Tiger Direct
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Tractor Supply Company
Travelocity.com
Uber Eats
UGG
Ulta Beauty
UncommonGoods
UrbanStems
Vegas.com
Vera Bradley
Vevor
Vineyard Vines
Visible
Vistaprint
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Vrbo CA
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Industry Updates

Hero Study Update

As you may be aware, the HERO study was recently stopped. The HERO study was in its open-label dose escalation initial stage evaluating the investigational therapy HST5040 for the treatment of methylmalonic acidemia and propionic acidemia. The data collected to date indicate that HST5040 was generally well-tolerated in patients. However, because the initial stage was designed to only identify an optimal dose for future studies, additional data would be required to prove the effectiveness of HST5040 in patients with propionic acidemia or methylmalonic acidemia. Such studies would require additional funding that could not be raised in the currently challenging capital markets environment. Accordingly, we will be taking down the HERO trial information website.

We know this is disappointing to the community as it is to us as well. We are extremely grateful to all the families and participants who invested time and effort into this project, sharing your stories and experiences along this journey, and to OAA for your partnership over the past 7 years.

Thanks for everything,

Mavis

AllStripes acquired by PicnicHealth

Hello! Please keep reading if you signed up to participate in research at AllStripes.

As you may have already heard, AllStripes has been acquired by PicnicHealth, the leading patient-centered medical records management platform. We're reaching out to make sure you've reviewed the recent user emails from AllStripes and PicnicHealth, and have taken action on your account.

If you activate your PicnicHealth account, you'll maintain access to the records that AllStripes collected for you to date. Begin by entering your email to get started: [Activate Account]

What does this acquisition mean for your AllStripes account?

PicnicHealth shares the AllStripes mission of empowering patients to easily access their medical records and participate in research. They have helped over 30,000 patients digitize and collect their complete medical records in one secure place. The AllStripes platform will be replaced by PicnicHealth, meaning you will continue to get access to a user-friendly platform to consolidate and manage records and securely share them with researchers if desired.

What will happen to my records?

- Your AllStripes account will be accessible until November 22, 2023
- Any medical records currently in your AllStripes account will be securely transferred over to the PicnicHealth platform in the next few weeks. Setting up your PicnicHealth account now will mean you'll have access to your records as soon as they're transferred.
- If you want to discontinue service and wish to close your account, please email support@allstripes.com

Can I keep participating in research?

Yes. Just like AllStripes, PicnicHealth is committed to accelerating research and empowering individuals impacted by rare and chronic health conditions. You'll be asked to sign PicnicHealth's informed consent when you create your account, and PicnicHealth will match you with research studies based on your diagnosis. You will still get a free PicnicHealth account regardless of whether you qualify for any active PicnicHealth studies.

If you have remaining questions about your account or data, you can review the FAQs at picnichealth.com/allstripes or reach out to their team at support@allstripes.com.

November 17, 2023

Re: Closure of the CoA-101 study

Dear Members of the Propionic Acidemia and Methylmalonic Acidemia Community,

CoA Therapeutics ("CoA") was founded in 2018 with the aim of developing novel therapies for difficult to treat and rare genetic disorders by harnessing advances in understanding of the CoA pathway. Our first investigational small molecule therapy, BBP-671, has been in development for individuals with propionic and methylmalonic acidemia (PA and MMA) and pantothenate kinase-associated neurodegeneration (PKAN) through research led by St Jude Children's Research Hospital in Memphis, Tennessee.

In June 2022, we launched the patient cohort of our CoA-101 study of BBP-671 (NCT04836494), which was designed to assess the safety and tolerability of BBP-671 in individuals with PA and MMA. More specifically, the patient cohort of our study was designed to look at the safety and tolerability of BBP-671 in up to 16 individuals with PA and MMA. The study was also designed to evaluate the potential effect of BBP-671 on selected exploratory disease-related biomarkers. Biomarkers are substances found in blood and other body fluids or tissues that can be used to see how the body responds to a treatment.

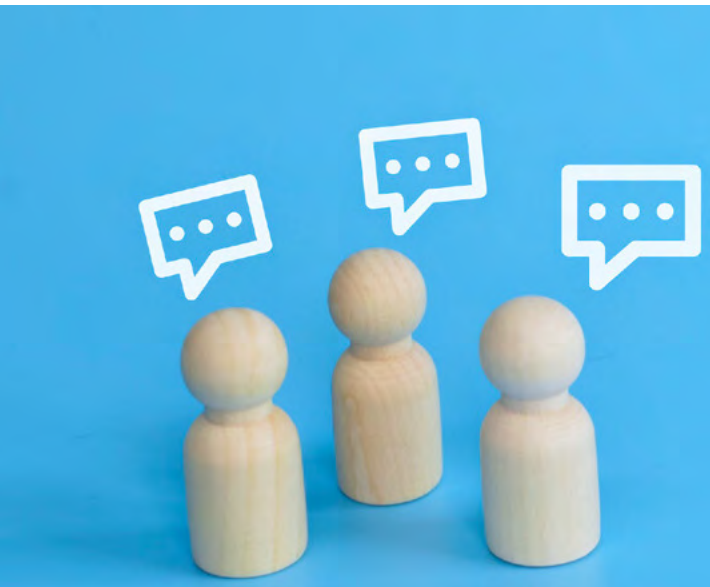
Due to the inability to sufficiently enroll the study since it was initiated over a year ago, we have been unable to gather enough data to evaluate the safety and tolerability of BBP-671 in individuals with PA and MMA. As a result, we have made the difficult decision to close our study in PA and MMA. We would like to sincerely thank the individuals who participated in the study and their families, our patient organization partners, as well as the study investigators and their teams who made the CoA-101 study of BBP-671 possible.

We will continue to keep the community informed of updated information on the development of BBP-671. We look forward to supporting developments in the field that may be able to address the unmet needs of PA and MMA patients.

Sincerely,

The CoA Therapeutics Team

BBP-671 is not approved for the treatment of PA and/or MMA or PKAN. BBP-671 is "investigational" which means that the potential therapy being studied has not been approved by any regulatory agency in any country.



Feedback Requested

Within CHARLIE, researchers in six counties work every day to learn more about the diseases PDE and GA1. The ultimate goal is to be able to offer patients more and better treatment options. Patient involvement is an important aspect of the CHARLIE-project.

Therefore, an online-survey about the needs and opinions of patients and caretakers is waiting to be completed. We hope that many patients and caretakers will participate in the survey. The survey is totally anonymous. This is being led by the support group in the Netherlands (VKS) and a representative from the Spanish GA 1 group (Albert).

https://charlie.science/patients.php

Now Available!

Betaine Anhydrous for Oral Solution 180 gm

An AB rated Generic version of Cystadane®
(betaine anhydrous for oral solution) with full
patient support services you might expect from a Brand†

Copay support

Eton Cares can help eligible, commercially insured patients get their medication for **as little as $0 per month***

Financial support

Patients who do not have insurance and meet certain financial requirements may be eligible for additional financial support from our **Patient Assistance Program***

*Restrictions, limitations, and/or eligibility requirements may apply. For patients who are not elibile for copay support or who need additional financial assistance, Eton Cares can help connect you with alternative forms of medication coverage or provide referrals to other possible sources of funding.

Eton Cares can provide copay and financial support.

Have your doctor complete the referral form to prescribe and enroll.

Click Here

IMPORTANT SAFETY INFORMATION

Warnings and Precautions

Hypermethioninemia in Patients with CBS Deficiency: Betaine Anhydrous may worsen high methionine blood levels and accumulation of excess fluid in the brain has been reported. If you have been told you have CBS deficiency, your doctor will be monitoring your methionine blood levels to see if changes in your diet and dosage are necessary.

Adverse Reactions

Most common side effects were nausea and gastrointestinal distress, based on a survey of doctors.
To report a suspected adverse event related to Betaine Anhydrous, contact Eton Pharmaceuticals, Inc. at 1-855-224-0233 or the U.S. Food and Drug Administration (FDA) at **http://www.fda.gov/MedWatch** or call 1-800-FDA-1088.

INDICATIONS AND USAGE

Betaine anhydrous for oral solution is indicated in children and adults for the treatment of homocystinuria to decrease high homocysteine blood levels. Homocystinuria is a rare genetic disorder in which there is an abnormal accumulation of the amino acid homocysteine in the blood and urine. The following are considered to be homocystinuria disorders:

- Cystathionine beta-synthase (CBS) deficiency
- 5,10-methylenetetrahydrofolate reductase (MTHFR) deficiency
- Cobalamin cofactor metabolism (cbl) defect

eTon PHARMACEUTICALS

Please see enclosed Full Prescribing Information for more information.

†Cystadane is a registered trademark of Recordati Orphan Drugs SAS, not affiliated with Eton Pharmaceuticals.

1402-v2

What's on the Horizon for Propionic Acidemia?

A useful metric of how much we know about a disease, biological process or molecule can be obtained from a quick search on Pubmed, which is accessible freely at https://pubmed.ncbi.nlm.nih.gov/. This lists all the scientific articles featuring a search term, and is the most frequently used website by scientists. We use it to keep track of the literature, find out what our colleagues are doing, and learn about new opportunities and breakthroughs. This year has had quite a few breakthroughs in PA, and one particular study that caught my eye was that lead by Chuck Venditti, a OAA supporter, on a gene therapy that produced excellent results in rescuing a lethal mouse model of PA. Congratulations to the team!

When I first became interested in understanding propionic acidemia (PA) and helping families affected by this disease, there were around 500 articles published on PA since records began. This year, we are on track to exceed a cumulative sum of 1,000 articles, if you include the American and British spelling of PA. This growth is encouraging, but compared to other conditions, PA is still poorly understood. For comparison, "cystic fibrosis" triggers over 62,000 hits, whereas COVID-19, which has only been around for a few years, will soon have 400,000 articles written about it. Discoveries take time but also require team effort across the world, so it is important to involve as many scientists as possible. Although we like to think that research is planned and always in control, many discoveries happen by chance. My mentors always told me that the best way to make a breakthrough is to work hard, because only then do the odds start working for you.

In relation to PA, our lab has two aims. Find better treatments for PA. Engage the wider scientific community in PA research. The first aim is obvious because it is our service in return for donations and funding. The second aim is necessary to bring the best scientists to think collectively about PA, and it relates to the serendipity of discovery. This objective is best achieved by disseminating our findings on PA to a wide community of scientists to raise awareness. Most people I meet in my department have never heard of PA, but a five-minute chat is enough to engage them in the topic. Our most recent publication on PA has now been accepted in the prestigious journal Nature Cardiovascular Research, which has a wide reach, well beyond people embeded in organic acidemia research. The article can be found on PubMed, or by following the link: https://doi.org/10.1038/s44161-023-00365-0. In it, we describe how the chemicals that build-up in PA cause changes to gene expression by chemically modifying the scaffolds (called histones) around which DNA is wound. This is an important finding because modifications to histones can turn genes on or off. For example, we showed that in PA, a gene called Pde9a is switched on. This gene has been linked to heart disease, and we think that blocking this pathway could improve patient outcomes. To that end, we found that these modifications can be reduced by increasing the availability of a substance called beta-alanine. This unusual amino acid is necessary for making carnosine and other substances in the heart that confer protection from metabolic oxidative stress, the process that makes hearts weaker. Our next aim is to test if a diet enriched in beta-alanine can improve PA in mice. We think that our finding can be implemented in PA (and MMA) diets for our patients because beta-alanine is not propiogenic, and specialized diets for athletes already use this supplement safely. Understanding the disease mechanisms is important because we need to know what causes the problems in PA, and how this can be alleviated. Although we know of markers of PA, such as 2-methylcitrate/citrate ratio, it is important to ensure that treatments are not simply aimed at correcting a number but rather the disease. Merely reducing 2-methylcitrate/citrate ratio may not fully reverse PA, especially if gene expression had changed. A useful analogy is infection and fever. We can take over-the-counter drugs to reduce our body temperature, but this doesn't get rid of the infection, although a marker of infection is being "cured".

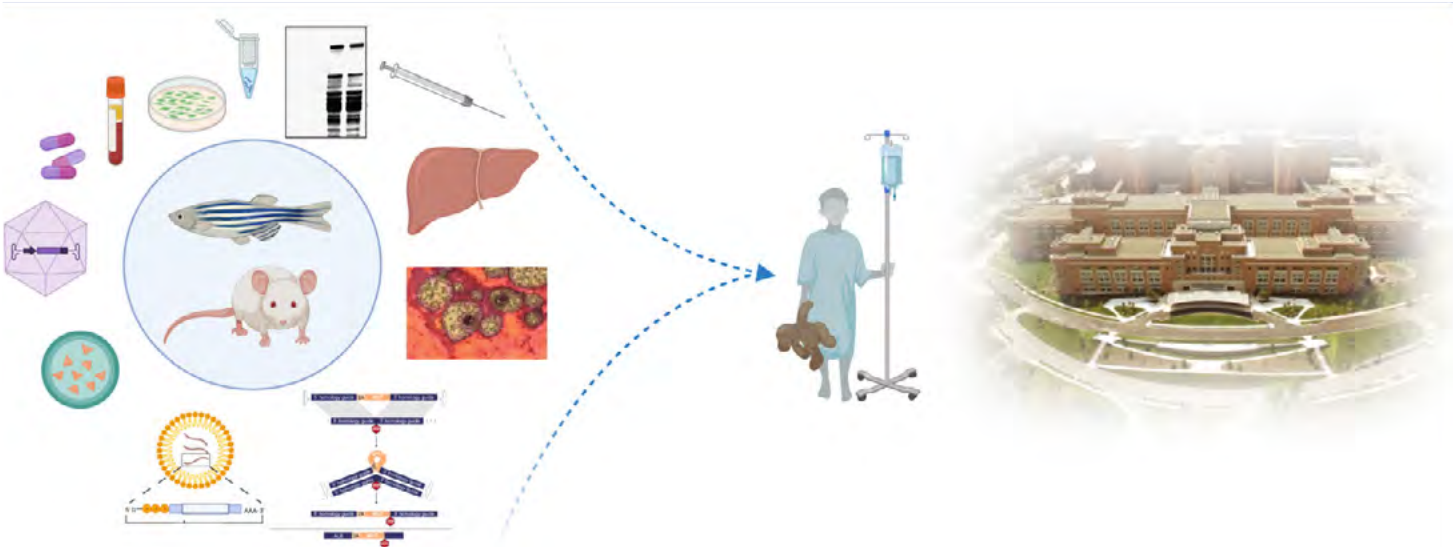
Our Nature-branded publication has global reach, and will be accompanied by a briefing from the news team at Nature. This is not a PR exercise to boost our ego, but an effort to get the new generation of scientists interested in organic acidemia because without them, the field won't grow. This is why I want to reach out to potential donors and consider funding PhD programmes at Oxford aim at organic acidemias. Please get in touch to learn about development opportunities at various levels of funding. Your funding could ensure that organic acidemia research has an established place at one of the world's top university that attracts the best talent globally and has the best labs to do the research.

Our work was initially supported by a research fellowship from the British Heart Foundation, and then two project grants from the Propionic Acidemia Foundation. Last year, we received a donation from OAA for which we are very grateful, and helped us through a very difficult year because of the steep rise in the cost of research. You will be aware of inflation eating into your salaries; the same applies to research costs, if not more. Typically, we spend around $1000-1500 per month to maintain a colony of animals. Assays may cost $10,000 per set. Special animal diets are priced at $3,000+ per year. We must also pay researchers a decent stipend to retain them, which is increasingly difficult because of competition from BigPharma who have a different funding model that tends to de-prioritize rare diseases. The advantage of the research system in the UK, where I am based, is that the PI's salary is supported by the university, not the funder, which improves the value-per-dollar of your donations. Thank you.

Pawel Swietach
Oxford
pawel.swietach@dpag.ox.ac.uk

Post Covid Update from the National Human Genome Research Institute at the National Institutes of Health

Approaching 20 years of clinical and basic research on MMA, PA, and Cobalamin Disorders



On behalf of the Organic Acidemia Research Section team at the NHGRI, NIH, I wanted to provide a brief update on our clinical and laboratory research programs. 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 protocols 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. 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 lenguage y culturales y permitir que más pacientes hispanohablantes tengan la oportunidad de participar en nuestros estudios. ....SE HABLA ESPANOL !!"

In 2024, we will be celebrating the 20-year anniversary of our flagship protocol "Clinical and Basic Investigations of Methylmalonic Acidemia and Related Disorders" (ClinicalTrials.gov Identifier: NCT00078078) and look forward to achieving a similar milestone for our protocol "Natural History, Physiology, Microbiome and Biochemistry Studies of Propionic Acidemia" (ClinicalTrials.gov Identifier: NCT02890342). Since the inception of our natural history study for MMA and cobalamin disorders (2004-current) and PA (2016-current), we have enrolled >730 participants, including 336 affected individuals, 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, and currently support many active projects including: defining the neurocognitive outcomes and autism in PA; analyzing the cardiac phenotypes in cblC and PA; describing the expanded outcomes of MMA post solid organ transplantation;

overviewing the natural history of MMAA- and MMAB-related MMA and ACSF3- related CMAMMA; delineating the natural history of chronic kidney disease and ophthalmological phenotypes in patients with isolated MMA, cblC, and PA; characterizing the obstetric, gynecological, and reproductive/endocrine phenotypes in MMA and PA patients; analyzing the effects of hydroxocobalamin dose escalation and newborn screening on the neurological, visual and cognitive outcomes of cblC, and describing immune syndromes in patients with MMA and PA. Of special note, we are continuing to investigate dosing of hydroxocobalamin in the treatment of cobalamin disorders, especially cblC deficiency.

Our laboratory investigations have also continued with full effort as we work to develop gene therapy for MMUT-MMA, both forms of PA (PCCA, PCCB), MMAB-MMA and cblC deficiency using mouse models. 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; reviews that overview mouse models of MMA and gene therapy for organic acidemias; and an article on biomarkers.

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 MMA, PA, and cobalamin disorders. If any readers are interested in learning about our clinical and/or laboratory research, please write me an email to start the conversation.

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Bethesda, MD 20892-4472
Office: 301-496-6213
FAX: 301-402-4929
venditti@mail.nih.gov
genome.gov/27529399

Selected Recent Publications

1. Head PE, Myung S, Chen Y, Schneller JL, Wang C, Duncan N, Hoffman P, Chang D, Gebremariam A, Gucek M, Manoli I, Venditti CP. (2022) Aberrant methylmalonylation underlies methylmalonic acidemia and is attenuated by an engineered sirtuin. Sci Transl Med. 14(646):eabn4772. PMCID: PMC9872049.
2. Venturoni LE, Chandler RJ, Liao J, Hoffmann V, Ramesh N, Gordo S, Chau N, Venditti CP. (2022) Growth advantage of corrected hepatocytes in a juvenile model of methylmalonic acidemia following liver directed adeno-associated viral mediated nuclease-free genome editing. Mol Genet Metab. 137(1-2):1-8. PMCID: PMC9872049
3. Chandler RJ, Di Pasquale G, Sloan JL, McCoy S, Hubbard BT, Kilts T, Manoli I, Chiorini JA, Venditti CP. (2022) Systemic Gene Therapy for Methylmalonic Acidemia Using the Novel Adeno-associated Viral Vector 44.9, Mol Ther Methods Clin Dev, 27: 61-72. PMCID: PMC9490190
4. 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 AAV44.9 vector rescues a neonatal lethal mouse model of propionic acidemia. Mol Ther Methods Clin Dev, 30: 181-190. PMID: 37746248 PMCID: PMC10512014
5. Venturoni LE, Venditti CP. Treatment of metabolic disorders using genomic technologies: Lessons from methylmalonic acidemia. (2022) J Inherit Metab Dis. 45(5):872-888 PMID: 35766386
6. Manoli I, Sloan JL, Venditti CP. (2022) Isolated Methylmalonic Acidemia. 2005 Aug 16 [Updated 2022 Sep 8]. In: Adam MP, Everman DB, Mirzaa GM, et al., editors. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2022. PMID: 20301409
7. 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.
8. Head PE, Meier JL, Venditti CP. New insights into the pathophysiology of methylmalonic acidemia. J Inherit Metab Dis. 2023 May;46(3):436-449. PMID: 37078237. PMCID: PMC10181862
9. Manoli I, Gebremariam A, McCoy S, Pass AR, Gagné J, Hall C, Ferry S, Van Ryzin C, Sloan JL, Sacchetti E, Catesini G, Rizzo C, Martinelli D, Spada M, Dionisi-Vici C, Venditti CP. Biomarkers to predict disease progression and therapeutic response in isolated methylmalonic acidemia. J Inherit Metab Dis. 2023 May 27. PMID: 37243446 PMC: 10330948
10. Chandler RJ and Venditti CP. Gene therapy for organic acidemias: Lessons learned from methylmalonic and propionic acidemia. J Inherit Metab Dis. 2023 Aug 2. doi: 10.1002/jimd.12665. Epub ahead of print. PMID: 37530705

PKU News is now flok. Providing Support and Resources for All Disorders of Protein Metabolism

Say hello to flok—the evolution of PKU News. This reimagined organization is deeply committed to uniting the inherited metabolic disorder community. Our aim is to continually elevate the standard of care and accelerate scientific research for our entire community. One of flok's first new offerings is a brand-new mobile app, also named flok, designed for those with HCU, MSUD, PKU, Tyrosinemia, Organic Acidemias and Urea Cycle Disorders.

We all understand that living with a metabolic disorder goes beyond managing diet. That's where flok comes in. The app helps you understand how you eat, feel, move, and play, and how all of this affects your health. The tools it offers can enhance communication with your clinicians and foster a sense of community among users.

But that's not all. The flok app—which will be free to download and use when it launches in early 2024—facilitates a community-driven approach to research. By incorporating your lived experiences, we'll be able to prioritize areas of research that matter the most to you.

Interested in being one of the first in the Organic Acidemia community to test the flok app?
Sign up to be a beta tester at flok.org.

Community is Vital to flok

We're thrilled to announce that we're hosting in-person **flok Family Camps** on the West and East Coasts in 2024. All individuals in the flok and their family members and friends are welcome to join us for fun, education, connection, and a full weekend of delicious low-protein meals.
We invite everyone in the OAA community to join us!

Scan to sign up for info on all flok programs!

IRB Approved - Study 00024964

OHSU MOLECULAR AND MEDICAL GENETICS

Has the national formula supply shortage impacted you or your family?

Laura Sliwoski is a Metabolic Dietitian with Oregon Health & Science University in Portland, Oregon. She is studying how the national formula shortage impacted patients with inborn errors of metabolism (IEM) and their families.

Your input can help identify measures to minimize or prevent the risk of future shortages.

You are invited to take part in an online survey where you will answer questions about your experience during the formula shortage. This includes questions about nutrition, stress levels because of the shortage, and the difficulty of switching to a different formula.

Who is eligible?

- Parents/caregivers of a child less than 18 years of age with an IEM
- Parent/caregiver of an adult with an IEM who is decisionally impaired

This survey will take about 15 minutes to complete. As a thank you for your time and participation, you have the option to be entered in a raffle to win a $100 Visa gift card.

To learn more about this study, scan the QR code below or visit https://redcap.link/6od39e6q. For questions, or to speak with the study team, please call 503-494-3137.

We appreciate your interest in our study!

OHSU

Organic Acidemia Association
9040 Duluth Street
Golden Valley, MN 55427

oaanews.org

ANNUAL DONATION / CHANGE OF ADDRESS

Please accept $_____ as our annual tax deductible donation to the Organic Acidemia Association.

Suggested membership donation is $25 (US) and $35 (international). Extra funds are welcome and can be designated for research, OAA operating expenses, or to help others attend conferences.

Remember the newsletter does not get forwarded when you move!

Name: _____

Address: _____

City State Zip:_____

Email: _____

Mail to: OAA
9040 Duluth Street
Golden Valley MN 55427

Organic Acidemia Association

(OAA) provides information and support to parents and professionals dealing with a set of inborn errors of metabolism collectively called organic acidemias. The OAA is an organization registered with the IRS as a 501(c)(3) non-profit corporation. Donations to the OAA are tax deductible. OAA publishes a newsletter three times a year, hosts a Google Group for information exchange and maintains a website and Facebook page. Services are funded by corporate and individual donations. Annual membership donation of $25 (US) and $35 (international) plus $5 for the family roster is requested, but not required. Our 501(c)(3) non-profit status qualifies OAA for United Way donations through their write-in option. If there is a write-in option, just write "Organic Acidemia Association" in the blank line on your pledge card.

Donations can also be made at OAA's website through the "PayPal" and the "Network for Good" option.

- The information contained herein does not necessarily represent the opinions of our Board of Medical Advisors or Board of Directors
- Letters and photographs sent to OAA become the property of OAA and may be used or edited at the discretion of the OAA staff.
- Names or information will be kept confidential only if specifically requested in writing
- This newsletter does not provide medical advice. You should notify your health care provider before making treatment changes.