As I sit here in my home office – social distancing myself with the outside world – I try to remain calm during these troubling times. As a parent of a child with an organic acidemia – we all worry about germs – but this is one huge colossal germ and doesn’t seem to mind its manners! I am praying that all of you are taking all the precautions possible during this time and hopefully we will all weather the storm!

Unfortunately, we have made the painful decision to cancel this year’s family conference. We understand the disappointment, but feel that traveling in July might still be difficult.

We are hoping to set up a virtual session with our professionals to discuss a variety of topics. Please connect to our private Facebook page to keep up-to-date on these events.

We will host a conference in the summer of 2021 - and plans are underway -- stay tuned!!

Thanks to all who have shared their stories in this issue. Our next newsletter will be in the fall – please let me know if you would like to share your story – perhaps how you weathered the COVID-19 pandemic?!

Here’s a great website with information on the COVID-19 pandemic:

| Dr. Olaf Bodamer FACMG  
Boston Children's Hospital  
Hunnewell 539, 300 Longwood Ave.  
Boston, MA 02215 | Elaina Jurecki, MS, RD  
BioMarin Pharmaceutical Inc.  
105 Digital Drive  
Novato, CA 94949 | Mendel Tuchman, MD  
Professor of Pediatrics,  
Biochemistry & Molecular Biology  
Children's National Medical Center  
111 Michigan Avenue, NW  
Washington, DC 20010-2370 |
|---|---|---|
| Stephen Cederbaum, MD  
Mental Retardation Research Ctr./NPI 635  
Charles E. Young Dr. South Room 347  
Los Angeles, CA 90095-7332 | Stephen G. Kahler, MD  
Univ. of Arkansas for Medical Sciences  
Clinical Genetics Division Slot 512-22  
Arkansas Children's Hospital  
800 Marshall St.  
Little Rock, AR 72202-3591 | Keiko Ueda, MPH, RD, LDN  
Clinical Dietitian Specialist  
Biochemical Diseases (Metabolism) Program  
British Columbia Children's Hospital  
4480 Oak Street, K3-211  
Vancouver, BC V6H 3V4 Canada |
| Kimberly A. Chapman, MD, PhD, FACMG  
Assistant Professor of Pediatrics  
Section of Genetics and Metabolism  
Children’s National Medical Center  
111 Michigan Avenue, N.W.  
Washington, D.C. 20010 | Mark Korson, MD  
VMP Genetics, LLC  
Director of Physician Support  
Director of Education  
5579 Chamblee Dunwoody Road  
Suite 110  
Atlanta, GA 30338 | Charles P. Venditti MD, PhD  
Genetic Disease Research Branch  
National Human Genome Research Institute  
National Institutes of Health Bldg 49,  
Room 4A56A  
Bethesda, MD 20892-4472 |
| Carla Cuthbert, PhD, FACMG, FCCMG  
Chief, Newborn Screening and Molecular Biology Branch  
The Newborn Screening Quality Assurance Program, Division of Laboratory Sciences, NCEH, Centers for Disease Control and Prevention  
4770 Buford Highway, MS-F43  
Atlanta, GA 30341 | Piero Rinaldo, MD, PhD  
Biochemical Genetics Laboratory  
Department of Laboratory Medicine  
Mayo Clinic  
200 First Street SW  
Rochester, MN 55905 | Jerry Vockley, MD, PhD  
Professor of Human Genetics & Pediatrics  
Chief of Medical Genetics  
Children's Hospital of Pittsburgh  
3705 Fifth Avenue  
Pittsburgh, PA 15213 |

2020 OAA CALENDAR

www.createphotocaldendars.com/shop/organicacidemiaassociation

Thanks to Raymonde DeGrace for creating our fabulous calendar!

Other items are still available at our CafePress shop

www.cafepress.com/organicacidemiaassociation
I’m Holly, I’m 54 years old and was diagnosed with CMAMMA in 2017. It is combined malonic and methylmalonic aciduria with high levels of malonic acid and methylmalonic acid. This form of MMA has higher levels of methylmalonic acid than malonic acid in the urine. I was experiencing very scary headaches while I happened to be doing the Keto diet, a connection I didn’t put together until much later at the NIH.

The headaches would usually come on in the evenings shooting up the side of my head then I would feel a tingly sensation and became very foggy brained. I was afraid to fall asleep, worried I was having a cerebral hemorrhage like my grandmother, and I have children and not prepared to have a serious health crisis. This went on for a couple of weeks, not every day but enough to tell me something was really wrong.

I’m not an anxious person but this was giving me anxiety. When I was able to see my doctor, Dr. Nicole Sudduth, my internist, she performed a neuro exam and thankfully there weren’t any issues there. We talked through everything again and she decided to run some blood tests. One of them happened to be the MMA test and Homocysteine. She really wasn’t expecting it would produce anything and we were both surprised it did.

When the results came back we had no idea what it even meant. The range for MMA was (87-318) I was at 7,180, homocysteine was 13.8. I know now these numbers aren’t as high as others with an MMA diagnosis but it was very scary for me especially since there was zero information online at that time on adults with elevated MMA. My doctor didn’t know what it meant for an adult especially at my age, she could only find infant cases.

My childhood didn’t have a lot of health challenges, tonsillectomy at 3, a lot of ear aches, and strep throat several times in my teens which seemed like an annual event, but nothing metabolic. My doctor referred me to Stanford’s Children’s Genetics Department. I saw Dr. Enns and Laurel Calderwood. They went through everything, ran my genetic testing and all my labs again. They were able to confirm ACSF3 is where the genetic defect is.

The only thing they recommended was a reduced protein diet and B12 injections. The good news is CMAMMA was a more benign form of MMA, although they know very little about it. What I did learn is it causes hypoglycemia, adult onset usually comes with a decline in thinking ability and memory loss.

I do have these, I’ve always struggled with blood sugar dips causing shaking hands and sweating so I’ve always eaten protein to combat this issue which was then causing an MMA build up. I had no idea what was helping one problem, was causing another. The memory loss has started, which is scary, I am the one in our group that has all of the childhood stories and those are slipping away slowly or I really have to dig them out of the recesses of my brain. I always knew bands names and people’s names, but now with those I’m starting to draw blanks. I wish I knew how to slow this down.

They didn’t test for CMAMMA in the US at birth, however Canada had started a study at infancy and they have followed those diagnosed for the past 20 years. I was told when I was first diagnosed that I was somewhere around the 23rd person diagnosed. I understand the numbers to be higher now but that was scary to hear, with so few how do they really know what the long term health is for someone living with CMAMMA?

My other health challenge is Hashimoto disease and was diagnosed at 16 years old by a doctor at Stanford. It’s an autoimmune disease where my body has destroyed my thyroid. So I have CMAMMA as my body’s baseline, and a destroyed thyroid on top of it, now menopause. I learned that my body doesn’t process 5 amino acids through the Krebs cycle into the mitochondria so I don’t get the energy my body needs and a destroyed thyroid also causing energy issues. I have always had to force myself to do things, my comfort zone is resting and reading so I have issues with weight that started in my 30s. I’ve been trying to find the right diet for me, but it’s something I’m still struggling with. I have always been a meat eater, but I wonder if we do better on a plant based diet?
I’ve always had a strong work ethic which leaves me spent most days and then I get a second wind around 9 pm, when what I really need is sleep, I end up awake late most nights. I joined the MMA/OAA group on Facebook and met a woman Carrie who also has CMAMMA and she was so helpful. She called me and talked me through her health issues which are so different than mine which puzzled me more. She was headed to the NIH and gave me all of the contact information. I was quickly signed up to go in January of 2019.

Meeting Dr. Venditti and his team was amazing and they taught me a lot. They tested everything, it is exhausting but so worth it. They were looking for yellow spots on my retina, lesions on the brain, heart muscle issues, muscle weakness and many other things.

I spoke with a dietician and with Jen Sloan a geneticist who helped explain that all meat has the same 23 amino acids, which include the 5 we don’t process. So there wasn’t a way to avoid the amino acids that build up. Jen also learned from the blood work that my genetic tests show a new variant to ACSF3 she hasn’t seen before and had no idea what that means. She was going to flag it to see if it pops up in another patient. I thankfully didn’t have any of the other conditions that have been found in other patients.

I know as this comes up for people as adults it can be very scary and confusing and I don’t know if my story will help give anyone comfort to know they don’t think it’s life threatening. My memory issues and processing isn’t what it used to be, and I pray this doesn’t mean I will slowly lose my ability to process information.

Dr. Venditti instructed me to never do the Keto diet which is how I put the two together as a trigger for my symptoms, he also said not to fast ever! I did the B12 injections for a few months. It helped a lot in the beginning but then I didn’t seem to notice a difference, it was expensive because the insurance doesn’t cover it. I also had a very high B12 blood test so I am not confident my body was using what I was giving it. My levels were up to 16,746 so I caution anyone to carefully monitor your blood work while doing injections.

I try to maintain between 40-60 grams of protein daily. If I eat excessive protein the weird headaches come back but at least I know what’s causing it. I added more fruit and vegetables to keep my blood sugar stable. I just wish I understood exactly what the long term effects are. That question remains a mystery as no one knows the answer to that yet. I know there is another female in her 60s who is doing well, but I continue to research and ask questions.

I am also still in the care of Dr. Enns and go to Stanford just to check in, and I will return to the NIH in a few years. They asked if I would come back every 3 to 5 years, or if I have changes in my health. My heart goes out to families with children with the more serious conditions, I love how this community helps and supports each other.

For those of you who don’t know me, my name is Bryan and I am 33, with Propionic Acidemia, Cardiomyopathy, stage 3 Kidney failure and Lyme disease. In my first article I talked about how I pride myself on my independence. I live on my own without much help. I pay my own bills, make my own phone calls and make it to most of my appointments. These efforts recently had to be doubled due to my parents recently getting divorced.

They are under enough stress so I had to take action. I now take the LANtaVan to work on most days. Although I work at a food store, going shopping after has always been hard for me. That’s why I started online shopping. It’s a bit pricey, but you have to do what you have to. If I need to get out or want to do something not work related I’ll use Uber since the LANtaVan is only for work and appointments.

Last July 4th I suffered a Metabolic Acidosis but it was my own fault. Had a little too much fun. Lucky for me I made full recovery. I still exercise daily. Yoga and walking are my favorites but I also run and do light lifting. Meditation is also something I’m huge into. It helps me keep my mind at bay. Overall my I believe my health is better than ever. I fully intend to live life to its fullest.

If you would like to reach out to me.
E-mail - Bryank186@hotmail.com
Or check out my blog
www.whenlifegivesyouachance.com/
The Organic Acidemia Association and MitoAction will be co-hosting the 2020 International Metabolic Conference, July 24th-July 26th at the Wyndham University Center Hotel in Pittsburgh, PA. Organic Acidemia Association and MitoAction have partnered with Dr. Jerry Vockley and the International Network for Fatty Oxidation Research and Management (INFORM) to bring you series of presentations by leading experts in the field of organic acidemias and fatty acid oxidation diseases.

The conference is free of charge for patients, parents, family members and friends. Please use the following link to register for the conference, each individual must be registered separately. The last date to register is July 15, 2020.

https://give.mitoaction.org/event/international-metabolic-conference-2020-registration/e266702

There is a group rate for the Wyndham University Center Hotel of $145.00 plus tax per night. To secure hotel accommodations either use the link on the conference registration page or call (412)682-6200, use group code INFORM or 07246841FG. Last date to book hotel is July 3, 2020.

Friday, July 24th, there will be a casual evening reception. Saturday July 25th and Sunday July 26th there will be presentations by leading experts in the organic acidemia and fatty acid oxidation diseases. The conference will conclude the afternoon of Sunday July 26th.

OAA and MitoAction are gathering recipes for a cookbook that patients and families can download and share. If you have a recipe you would like to share, use the following link https://www.mitoaction.org/internationalmetabolicconference/submit-your-recipe?fbclid=IwAR3Z7lMz2zLBEChIAg5YwYIThe3T9OAL-HERRVzMoegayzqrOssao

To stay up to date on the International Metabolic Conference agenda, speakers and activities, follow us on Facebook @ InternationalMetabolicConference. Information will also be posted on the OAA Facebook page. We will need volunteers to assist at the Conference. If you are interested in volunteering please contact Erin MacLean, OAA conference coordinator at charlieerinwill2@msn.com. We look forward to seeing all of you in Pittsburgh!

POSTPONED

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POSTPONED

more information to follow...
In Memoriam

Andrew

Methylmalonic Acidemia Mut 0
April 11, 2001 - December 4, 2018

Andrew lived a full, happy and joyful life for 17 years. He entered and exited this world with strength, spunk and determination. Andrew’s early years were spent mostly inpatient due to instability and infections. After receiving a combined liver and kidney transplant at 5 years old. After transplant, Andrew started gaining energy, eating more and growing. He joined the local Challenger Club sports; baseball, basketball, soccer and karate. Andrew discovered his love and talent for baseball. He was finally able to attend school, ride the bus and play out at recess. Andrew remained relatively stable for a few years, but still had inpatient stays and many doctors visits and an ever-increasing medications list. Andrew spent most of his doctors visits ignoring the doctors and preferred to sit and color or play with his iPad than engage in all the medical talk.

As Andrew reached adolescence, his MMA levels started to rise causing increasing injuries to his brain and his transplanted kidney began slowly declining. Andrew’s warrior spirit, relentlessness and determination came across in each setback he would push through. Andrew very rarely viewed himself as different, as he would say “I’m just Andrew” or “everyone should have a pump”.

In spring of 2018 Andrew had three metabolic strokes a few days apart. His health started was starting to decline quickly. After 3 months of decline and with the help of his palliative care Child life therapist, Andrew voiced his request to go on Hospice. Andrew knew his body and what he was capable of overcoming.

Our last months together at home were filled with cherished memories.

Andrew had an amazing sense of humor, sharp wit, loved music, baseball, arts & crafts, movies, karate and video games. He could quote any movie he had watched once. His favorite superhero was Captain America. He was always fashionable, would wear bold colors and look great in them.

Andrew enjoyed traveling, he was able to go on many family vacations; Disney, Universal, Hole in the Wall Gang Camp, New York City, New Hampshire, Virginia and the Bahamas. Andrew’s favorite person in the world is his big brother Will. Andrew always wanted to be by Will’s side, participating in everything Will did. Andrew admired and adored his brother.

Andrew gained his angel wings December 4, 2018 at home with his family.

Andrew is forever in our hearts and we know he is at peace.

We love you Andrew to the moon and back!

Our family appreciates all the love and support from fellow OAA families over the years. We are grateful to all of Andrew’s physicians, nutritionists and nurses for all of their years of dedication and compassion to our family.
When I was three years old, I was diagnosed with a genetic disorder called Isovaleric Acidemia (IVA). Having IVA means that I have to keep track of my daily protein consumption. The enzymes in my body do not break down protein the same as people without the disorder. If I do not achieve the amount of protein I need (75 grams), then like anyone else, I am not getting enough protein to be healthy. However, if I consume too much, my enzymes will break down the protein it can, but the excess will build up as waste in my body. If enough waste builds up, my immune system can shut down, making me more susceptible to deadly diseases. Twice a day I take Carnitine and Glycine to stabilize my levels.

Despite being diagnosed with the disorder at three, I have had IVA since birth. Both of my parents are carriers of the disorder, but they were unaware until the day I was diagnosed. The first three years of my life tormented my parents because no matter what they did to take care of me, I was irritable and sick, and they had no idea why. Eventually, my protein consumption became so inconsistent that my whole body shut down. I fell into a coma for approximately 36 hours. With a 50/50 chance of survival, there was an even lesser chance of surviving with a functioning brain. Luckily the wonderful people at St. Louis Children’s Hospital saved my life.

After being diagnosed with the disorder, my parents tried to learn as much about the rare disease as possible. In addition to that, they began lobbying for Expanded Newborn Screening, allowing parents to screen their newborns for diseases as soon as they’re born. In 2005, my family had the opportunity of meeting Governor Roy Blunt Jr. as he signed off on Expanded Newborn Screening for Missouri. While it is pretty cool having a piece of state legislature be based on my story, I am happier that current and future parents don’t have to worry about being blindsided by their children’s sicknesses or worse. It also allows for doctors to treat children with disorders sooner, ensuring the best possible result.

In July of 2010, I was granted a wish by the Missouri Make a Wish Foundation. Since I idolize the most recent Hall of Fame inductee, Derek Jeter, my wish was to meet him at Yankee Stadium. Spending a whole week in New York, my family and I went to the Empire State Building, the Statue of Liberty, downtown Manhattan, and, of course, Yankee Stadium. We had dinner at the ballpark, a tour of the stadium, and I got to go down to the clubhouse where I met Derek Jeter in addition to over a dozen other Yankees. Sitting five rows behind Rudy Giuliani, who I did not know at the time because I was eleven, we watched the Yankees beat the Tampa Bay Rays 5-4 on a walk-off single by Nick Swisher. I refer to that week as the high point of my life, and I have my parents, the Make a Wish Foundation, and even my disorder to thank.

Almost ten years later, I find myself as a junior at Southeast Missouri State University, majoring in English Education with a minor in Film and Literature. Keeping track of my diet can be difficult at times between being on my own for the first time and having to balance everything else that comes with being in college. However, with the strong supporting cast that I have, I am currently a proud member of the Sigma Chi Fraternity while carrying a 3.85 GPA.
My name is Brittany. I live with my husband, Robert, and three children in Colorado. My family’s journey into the rare disease community began suddenly and without warning almost nine years ago. We were living on the East Coast and had just given birth to our second child and first son.

Drew was born on a beautiful spring day, May 18th 2011. We welcomed him into our lives with all the love a child could possibly experience. To us he was perfect. However, as the days and weeks progressed, we began to grow concerned about certain things we noticed in his development. We frequently shared these concerns with our pediatrician only to be told that our concerns were invalid and that there was nothing wrong with our son.

Our whole world changed just a few days after his 2 month well child visit when Drew had his first life-threatening seizure. This episode caused him to stop breathing altogether due to the stress on his little body. I performed CPR on him in a desperate attempt to keep him alive until the ambulance could arrive. He was rushed to the emergency room of the local hospital, but once again, our concerns were dismissed and the doctors told us that he must have simply had acid reflux.

Less than a week after being discharged, Drew suffered another seizure again requiring CPR to stay alive until an ambulance could arrive. Unbelievably, and in spite of our adamant insistence to the contrary, doctors continued to believe that acid reflux was the cause. As a result, they kept him overnight only for observation but did not insert an IV, a choice that almost cost him his life. The following morning Drew experienced yet another seizure, but because he didn’t have an IV, there was no way for doctors to administer life-saving medication to quickly control his seizure. It took a team of doctors to resuscitate my son. Finally, the doctors began to listen to our concerns.

What ensued thereafter was three long weeks in the Pediatric ICU involving MRI’s, EEG’s, NG and G tubes, multiple spinal cord taps, countless blood draws and eventually having to be placed on a ventilator to stay alive. Despite all of these efforts, the stress on his little body became too much. Drew passed away on August 27th 2011 at the age of 3 ½ months. He had suffered severe brain atrophy caused by an undiagnosed ultra-rare metabolic disorder. His life lasted for 100 days...2,402 hours and then he was gone.

Nearly two full years after Drew’s death, and after multiple genetic tests and thousands of dollars in testing costs, we finally discovered that our son had been affected by a disorder known as Homocystinuria caused by a Cobalamin defect. However, we still had no way of knowing what sub-type of this disorder had taken his life.

It wasn’t until seven years later in March of 2019 that we were finally given a definitive diagnosis: Homocystinuria with a Cobalamin G defect. We received this knowledge because we gave birth to our fourth child and second son, Grayson, who suffers from the same disorder. As a result of thoughtful doctors who listened to our concerns during pregnancy and thanks to improved technology, immediately upon Grayson’s birth we were included in a research study at Children’s Hospital Colorado that shortened the genetic testing turnaround time from twelve weeks to three days and provided the results that we had sought for so long. Finally we were given answers that could explain why our son had died eight years earlier. These same answers provided a roadmap for how to treat Grayson so his outcome would be better than Drew’s. While we had previous knowledge of a genetic mutation for Cbl G that I was a recessive carrier for; we were told that the mutation that my husband carries is a novel mutation (which is why earlier testing did not detect it). Dr. Rosenblatt in Canada confirmed the diagnosis just a few months after Grayson was born.
Homocystinuria is a genetic metabolic disorder that causes toxic levels of the amino acid Homocysteine to build up in the blood and urine. When Homocystinuria is caused by a cobalamin defect, the body cannot properly metabolize cobalamin, more commonly known as vitamin b12, leading to elevated levels of Homocysteine and abnormally low levels of Methionine, both of which have serious health implications. Without early treatment, Homocystinuria can cause serious, life threatening issues. Even with treatment, individuals living with this disorder may experience vision problems, seizures, developmental delays, anemia, heart disease or blood clots as well as feeding and growth problems. Early detection and treatment are critical to success in treating this disorder.

Grayson is now 11 months old and he has endured a weeklong stay in the NICU, an MRI, EEG, regular visits to metabolic specialists, pediatric ophthalmologists and neurologists, weekly blood draws to check levels of amino acids, daily injections of a specialized form of B12, and three different medications and supplements taken at each meal. While the medication tastes terrible, gives him an upset stomach and causes bad acid reflux, we have had to be creative in how we administer it. We have currently discovered a miracle elixir. Sunny Delight. While the sugary drink has absolutely no nutritional value, it somehow masks the bitter, disgusting taste of the medication. For that we are grateful because it means no tears or meltdowns at meal times...for Grayson or me.

We count our blessings every day that Grayson continues to grow and develop. He currently has occupational therapy through the early intervention program to monitor his development. He loves to be outside on his little playground and play with his sisters. We are especially grateful to be living in Colorado where we have an excellent team of doctors that monitor his growth and development on a regular basis.

BRITTANY PARKER, COLORADO
PARKEBRITTANY85@GMAIL.COM

Xandinho America (cblC) and Captain Rare Bear America from Brazil are ready and protecting the world from Coronavirus and staying at home!
Since my last article in the newsletter, we welcomed our second child, Alhumdulillah on December 22, 2018. We were very worried whether our baby would have PA or not. In my early stages of pregnancy we couldn’t go for check up. So we waited for baby birth and tests. I had a C-section and my baby was not given to me after birth. They sent her to another hospital where test were possible. My son, Muhammad was left with his grandmother, who came from Pakistan to look after him, but he was not familiar with her at that time. My husband remain home at night because my son Muhammad always sleep with his baba (father).

The decision for second baby was not so easy but now my daughter is 1 years old and both brother and sister have great bounding. My little one has great love for his brother, but my son’s way of love is bit hard. (he shows his love by biting -- maybe he thought its love?). Actually my PA son Muhammad is also a special kid and victim of autism but still he accepts his sister presence. It is a beautiful sight when I saw them. If one is sleeps the other is curious that why he sleeps and want to wake each other.

Having two kids is totally and very tough when there is a hospitalization. We are all with Muhammad ---fighting this disease and other health issues. Muhammad is 5 now and has improved his walking and he also say mama. First time in 5 year! He is still using diapers. His muscle tone is weak and immune system too. We will try as parents and I know his little sister too wants her brother to play with her. Where ever my son goes my little one follow him. I wish good health for both.

ZAREEN | OMAN
ZAREENZAIGHAM416@GMAIL.COM
TEMPLE Booklets and Videos: for IVA, GA-1, and other conditions provide easy-to-understand education for family & friends

TEMPLE (Tools Enabling Metabolic Parents Learning) is an education series for inborn errors of metabolism, that includes Glutaric Aciduria Type 1 (GA-1) and Isovaleric Acidemia (IVA). These booklets and videos explain the condition and its management in easy-to-understand language and pictures. They are ideal for educating new parents and families after a positive newborn screening. TEMPLE booklets and videos can also be used to teach grandparents, relatives, and friends about the condition. TEMPLE was created by Nutricia.

Share TEMPLE with relatives and friends in your life to help them better understand the basics of your child’s or loved one’s condition. You can find TEMPLE booklets on Nutricia’s website (MedicalFood.com/learning-center) and TEMPLE videos on Nutricia’s YouTube channel (Youtube.com/LowProLiving) or Search “Nutricia Metabolics”.

Exciting news from Nutricia is that they recently added a TEMPLE video for Isovaleric Acidemia. It’s a simple 8-minute introduction to IVA. Plus, the GA-1 and IVA booklets are now available in Spanish and French! Pass along to those you know who may have Spanish- or French-speaking relatives or friends who would like to better understand the condition.

Learn more about Nutricia North America’s products and services at MedicalFood.com

THANKS HEMOSHEAR THERAPEUTICS TEAM!
Hemoshear stepped out in February for #RareDiseaseDay.
They ran/walked/biked 2500 miles to raise funds to help support the incredible work of Organic Acidemia Association. Together we can help advance new treatments! #rarediseases!
# Medical Food Access

## Emergency Fact Sheet

<table>
<thead>
<tr>
<th>Medical Food Manufacturers</th>
<th>Contact Information</th>
<th>Updated</th>
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<tbody>
<tr>
<td>Abbott</td>
<td>Website: <a href="https://abbottnutrition.com/therapeutic#metabolic">https://abbottnutrition.com/therapeutic#metabolic</a></td>
<td>March 2020</td>
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|                          | Consumer Relations: 1-800-227-5767  
Mon-Fri, 8:30 AM—5:00 PM EST |         |
| Ajinomoto Cambrooke       | Website: [https://www.cambrooke.com/](https://www.cambrooke.com/) (Under “Products” tab dropdown menu, select “Metabolic”) | March 2020 |
|                          | General Customer Care & Medical Food Product Support: 866-456-9776 (Option 2)  
Mon-Fri, 8:30 AM—5:30 PM EST |         |
|                          | Direct Contact: Ashley Park  
Phone: 267-382-6416  
Email: ashley.park@galen-pharma.com |         |
|                          | Patient Care Customer Services: 1-800-BABY-123 (1-800-2229-123)  
Mon-Fri, 7:00 AM—7:00 PM CST/CDT; Sat: 8:00 AM—4:30 PM CST/CDT  
Email: [www.enfamil.com](http://www.enfamil.com) |         |
| Medica Nutrition          | Website: [https://medica-nutrition.com/products/](https://medica-nutrition.com/products/) | March 2020 |
|                          | Phone (USA): 877-850-0985  
Phone (Canada): 888-606-6676  
Email: orders@medica-nutrition.com |         |
|                          | Nutricia Customer Service Department: 1-800-605-0410  
Mon-Fri, 8:30 AM—5:00 PM EST  
After Hours: 1-800-365-7354  
Mon-Fri, 5:00-PM—7:00 PM EDT |         |
| Vitaflo USA, LLC          | Website: [https://www.nestlehealthscience.us/vitaflo-usa/products](https://www.nestlehealthscience.us/vitaflo-usa/products) | March 2020 |
|                          | Customer Service: 1-888-VITAFLO (1-888-848-2356)  
Mon-Fri, 9:00—5:00 PM EST |         |

For additional information, please visit [www.mnt4p.org](http://www.mnt4p.org) and [southeastgenetics.org](http://southeastgenetics.org).

Sponsored by the Georgia Department of Public Health—Award #38206 and Southeast Regional Genetics Network—a HRSA Supported Partnership—Grant #UH7MC30772.
## Low Protein Modified Food Manufacturers

<table>
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<tr>
<th>Company</th>
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<tr>
<td>Ajinomoto Cambrooke</td>
<td>Website: <a href="https://www.cambrooke.com/">https://www.cambrooke.com/</a> (Under “Products” tab drop-down menu, select “Specialty Food—Low Protein”) General Customer Care &amp; Medical Food Product Support: 866-456-9776, Option 2 Mon-Fri, 8:30 AM—5:30 PM EST</td>
<td>March 2020</td>
</tr>
<tr>
<td>Dr. Schär’s/Mevalia</td>
<td>Website: <a href="https://www.mevalia.com/en">https://www.mevalia.com/en</a> Customer Service: 0800-988-2488 Email: <a href="mailto:info@mevalia.com">info@mevalia.com</a></td>
<td>March 2020</td>
</tr>
<tr>
<td>Ener-G Foods</td>
<td>Website: <a href="https://www.ener-g.com/">https://www.ener-g.com/</a> Customer Service: 1-800-331-5222 Mon-Fri, 8:00 AM—5:00 PM (PT) Email: <a href="mailto:customerservice@ener-g.com">customerservice@ener-g.com</a></td>
<td>March 2020</td>
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<tr>
<td>Nutricia North America</td>
<td>Website: <a href="https://shop.medicalfood.com/category/12/pku-products">https://shop.medicalfood.com/category/12/pku-products</a> Nutricia Customer Service Department: 1-800-605-0410 Mon-Fri, 8:30 AM—5:00 PM EST</td>
<td>March 2020</td>
</tr>
<tr>
<td>PKU Perspectives</td>
<td>Website: <a href="https://www.pkuperspectives.com/">https://www.pkuperspectives.com/</a> Customer Service: 866-758-3663 Mon-Thurs, 10:00AM—5:30 PM MST</td>
<td>March 2020</td>
</tr>
<tr>
<td>National Food Distribution</td>
<td>Website: <a href="https://nfdc.info/home.php">https://nfdc.info/home.php</a> National Food Distribution Centre: 1-888-606-6676, ext. 221 Email: <a href="mailto:info@nfdc.info">info@nfdc.info</a> Order: <a href="mailto:order@nfdc.info">order@nfdc.info</a></td>
<td>March 2020</td>
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<tr>
<td>Centre for the Treatment of</td>
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<tr>
<td>Hereditary Metabolic Diseases</td>
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<tr>
<td>(NFDC)</td>
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<tr>
<td>Taste Connections, LLC</td>
<td>Website: <a href="https://tasteconnections.com/index.php/en/">https://tasteconnections.com/index.php/en/</a> Direct Contact: Malathy Ramanujam Phone: 310-413-6499</td>
<td>March 2020</td>
</tr>
</tbody>
</table>

For additional information, please visit [mnt4p.org](http://www.mnt4p.org) and [southeastgenetics.org](http://www.southeastgenetics.org).

Sponsored by the Georgia Department of Public Health—Award #38206 and Southeast Regional Genetics Network—a HRSA Supported Partnership—Grant #UH7MC30772.
## Medical Food Access Emergency Fact Sheet

### Patient Organizations

<table>
<thead>
<tr>
<th>Company</th>
<th>Contact Information</th>
<th>Updated</th>
</tr>
</thead>
</table>
| Association for Creatine Deficiencies                       | Website: https://creatineinfo.org/  
Facebook Support Group: https://www.facebook.com/creatineinfo  
Email: info@creatineinfo.org                                                                 | March 2020 |
| Connecting Families Urea Cycle Disorders (UCD) Foundation    | Website: https://ucdfamily.org/  
Facebook Support Group: https://www.facebook.com/ucdfamilies/  
Phone: 918-490-3055                                                                                             | March 2020 |
| Fatty Acid Oxidation (FOD) Disorders Family Support Group   | Website: https://fodsupport.org/  
Facebook Support Group: https://www.facebook.com/groups/59945507904/  
Direct Contact: Deb Lee Gould, MEd, Director (Family Support Group Parent)  
Phone: 517-381-5206                                                                                             | March 2020 |
| Homocystinuria Network (HCU) America                        | Website: https://hcunetworkamerica.org/  
Facebook Support Group: https://www.facebook.com/HCUNetworkAmerica/  
Phone: 630-360-2087  
Email: info@hcunetworkamerica.org                                                                                        | March 2020 |
| Maple Syrup Urine Disease (MSUD) Family Support Group       | Website: https://www.msud-support.org/  
Facebook Support Group: https://www.facebook.com/msudfamilysupportgroup/  
Direct Contact: Jordan Coleman (Advocacy Chair)  
Phone: 925-349-4601  
Email: coleman.jorann@gmail.com  
Direct Contact (Espanol): Adriana Carbajel (MSUD Parent)  
Phone: 480-278-4713  
Email: adrianamc2014@yahoo.com                                                                                     | March 2020 |
| National Phenylketonuria (PKU) Alliance                     | Website: https://www.npkua.org/  
Find a Clinic: https://www.npkua.org/Resources/Find-a-Clinic                                                                                             | March 2020 |

For additional information, please visit [www.mnt4p.org](http://www.mnt4p.org) and [southeastgenetics.org](http://www.southeastgenetics.org).

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<table>
<thead>
<tr>
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<th>Contact Information</th>
<th>Updated</th>
</tr>
</thead>
</table>
| National Organization for Rare Disorders (NORD) Emergency Relief Program | Website: https://rarediseases.org/  
Patient Services: 1-800-999-6673 (Espanol: 844-259-7178)  
Mon-Thurs, 8:30 AM—7:00 PM EST  
Fri, 8:30 AM—6:00 PM EST | March 2020 |
| Organic Acidemia Association | Website: https://www.oaanews.org/  
Facebook Support Group: https://www.facebook.com/groups/33534928222/  
Direct Contact: Kathy Stagni, Executive Director (Propionic Acidemia Parent)  
Email: mkstagni@gmail.com  
Phone: 763-559-1797 (CT)  
Direct Contact: Menta Pitre, Director (MMA Cbl C Parent)  
Phone: 985-856-5631 (CT) | March 2020 |

Please contact us at semgenetics@emory.edu for any feedback and updates.

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**GET PAID for your opinion & benefit OAA at the same time.**

Patients (14 and older) and Caregivers (family, friends) of any disability, disorder, syndrome, disease or condition are provided an opportunity to voice their opinions through surveys and interviews to improve medical products and services.

Join the community on-line and earn a Dunkin Donuts, Starbucks or CVS gift card. We receive $5 for each qualified sign up. Refer others and we will benefit each time. Your information is confidential, and your email/name is never shared. You may be invited to participate in surveys from time to time, where you will earn cash.

Use this link and join today!  
rarepatientvoice.com/for-patients/patient-and-caregiver-sign-up/
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 a volunteer 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 & 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.

Organic Acidemia Association
9040 Duluth Street
Golden Valley, MN 55427
oaanews.org

OAA Google Group
OAA’s main mission is to empower families with knowledge about organic acidemias. If you would like to connect with other families who share the same or similar diagnoses, please join our private OAA Group. Visit the OAA News web site to sign up.