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MSUD NEWSLETTER

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UPCOMING EVENTS

19TH BIENNIAL MSUD SYMPOSIUM

I can't believe that almost two years have passed and it is time for another MSUD Symposium! I am especially excited about this conference because I've built in extra time for social interaction. You'll have an opportunity to renew old friendships, and meet new families while learning about groundbreaking topics from speakers who are experts in their fields.

Check the MSUD website at www.msud-support.org for informational updates.

Registration: Register for the symposium on the [MSUD website](http://www.msud-support.org) by May 31, 2018.

Date: June 28-30, 2018

Location: DoubleTree by Hilton Hotel Pittsburgh – Green Tree (the hotel is located 20 minutes from Pittsburgh International Airport (PIT) and 3 miles from downtown Pittsburgh).

500 Mansfield Avenue, Pittsburgh, PA 15205
Phone 412-922-8400 Fax 412-922-8981

Cost: The cost for the weekend conference is \$25 per attendee with a maximum of \$75 per family. This is a change from prior conferences in order to help defray the cost of food.

Hotel Rate and Accommodations: Room rate is

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The information contained herein does not necessarily represent the opinions of the MSUD Board, Medical or Nutritional Advisors, or all of our members. Before applying any of the information contained in this newsletter, you must consult a MSUD specialist.

\$109 per night which includes breakfast for up to 4 people. (\$12 per person for additional guests) Rooms have 1 king bed or 2 queen beds. Handicap rooms are available. The hotel has 3 restaurants. Other amenities include an indoor pool, outdoor pool, refrigerator in each room, fitness center, business center, and free parking. There is also complimentary shuttle service to and from the airport.

Hotel reservations: Reservations can be made by calling the hotel directly at 412-922-8400. *State that you are attending the MSUD Family Support Group Symposium to receive the discounted rate.* If you prefer to make your reservation online, you can do so through the MSUD website. The special room rate will be available until June 7th, 2018 or until the group block is sold out, whichever comes first.

Meals: Complimentary drinks and light meal will be provided for all attendees on Thursday evening 6-28. Breakfast Buffet is included in the cost of the room rate for all those staying at the DoubleTree by Hilton Hotel on Friday 6/29 and Saturday 6/30. Those not staying at the DoubleTree will need to provide their own breakfast on those mornings. Lunch on Friday 6/29 and Saturday 6/30 will be provided to all attendees with low protein food options available during these times also. Dinner will be provided on Friday 6/29 for MSUD families on the Gateway Clipper (see below).

Hotel check-in is 3:00PM and check- out is 12:00PM.

Attire: Comfortable, casual attire is appropriate for the entire symposium

Child Care Activity Room: There will be a room available with activities/entertainment for children and there will be several volunteers providing assistance. However, there will be no babysitting services. Please keep this in mind as you plan your trip. Consider bringing a grandparent, teenager, or sibling to babysit your younger children. Older children, teens, and young adults are encouraged to attend the general sessions.

Shuttle Service: Please call the hotel (412-922-8400) once you get off the plane as the shuttle service is on-demand and the hotel is 20 minutes away. Meet the

shuttle through Baggage Claim at Door 8.

Gateway Clipper: Children's Hospital of Pittsburgh of UPMC is sponsoring a social event Friday evening June 29th. Join other MSUD families on a riverboat cruise in downtown Pittsburgh. Check out the MSUD website for more information. Indicate how many from your family will be attending and the number needing low protein food on the registration form.

NBS MSUD Connect patient registry: If you have not completed a profile on the NBS MSUD Connect patient registry, you will be able to do so at the symposium. Staff will be available to assist you. If possible, please bring information including the affected MSUD individual's leucine level at diagnosis, recent leucine levels, genetic mutation and/or enzyme testing, and a current list of medications and supplements with you to the symposium. You may need to contact your metabolic team to obtain some of the information. Those that have been transplanted are encouraged to participate in the registry also.

Travel Assistance: Again we received a generous donation from the United Service Foundation to assist with travel expenses. If you would like to attend the symposium and need financial assistance, you may apply through the MSUD website or contact Sarah Dworcan at sarahlipskar@yahoo.com, phone # 718-496-7185

Don't forget to complete your registration form and make your hotel reservation!

If you have any questions, feel free to call me at 740-972-5619 or email at sandybulcher@gmail.com. ■



See you in Pittsburgh!

SYMPOSIUM AGENDA

Thursday June 28th

7:00-9:00 PM Registration/Reception - Salon C, D, E (light meal and drinks provided)

Friday June 29th

6:30-8:00 AM Breakfast Buffet - Salon A (hotel guests only)

8:00-8:15 AM *Sandy Bulcher MSUD Symposium Coordinator*
General Session - Salon C, D, E Welcome

8:15-9:15 AM *Nicholas Ah Mew MD, Children's National Health System*
Medical Management of MSUD

9:15-9:45 AM *Rani Singh PhD, RD, Emory University*
NBS MSUD Connect Patient Registry

9:45-10:15 AM Break

10:15-10:45 AM *William Andrews MD, FACP, Acer Therapeutics*
Drug Development

10:45-11:00 AM Introduction of families attending the symposium for the first time

11:00-11:30 AM *Brian Wamhoff PhD, HemoShear Therapeutics*
Novel Treatments for MSUD

11:30 AM-12:00 PM doyourshare.com video
Group photo of MSUD children and adults, location to be announced

12:00-1:00 PM Lunch - Salon A (all attendees)

1:00-4:00 PM General Session - Salon C, D, E
Liver Transplant breakout - Salon B

1:00-1:45 PM *Stephen Strom PhD, Karolinska Institutet*
Amniotic Epithelial Stem Cell Transplant

1:45-2:00 PM MSUD Board update

2:00-2:45 PM *Arvind Ramanathan PhD, Buck Institute*
Metformin Research Update

2:45-3:15 PM Break

3:15-4:00 PM *MSUD Teen/Adult Panel*

5:30 PM Bus transportation to the Gateway Clipper social event
All MSUD families welcome

6:00-9:00 PM Social gathering for MSUD Families/ UPMC staff - Gateway Clipper downtown Pittsburgh (dinner included)

Saturday June 30th

6:30-8:30 AM Breakfast Buffet - Salon A (hotel guests only)

8:30- 9:15 AM General Session - Salon C, D, E
Kendra Bjoraker PhD, LP, 3:1 Neuropsychology Consultants
Living with a Chronic Condition

9:15-10:00 AM *Rani Singh PhD, RD, Emory University*
Nutrition Management of MSUD

10:00-10:30 AM Break

10:30-11:30 AM *Professional Panel with Dr Ah Mew, Dr Singh, Dr Bjoraker*
Question and Answer

11:30 AM-1:00 PM Lunch - Salon A (all attendees)

1:00-1:30 PM *Ed Fischler and Herb Foster*
Fundraising

1:30-2:00 PM *Karen Dolins and Chad Farquharson*
Advocacy

2:00 - 3:00 PM *Chef Neil, VitaFlo International*
Low Pro Cooking

Dismiss Video of past symposiums

See you at MSUD Symposium 2020!

HALF-DAY TRANSPLANT WORKSHOP

1 TO 4 P.M., FRIDAY, JUNE 29, 2018

HILLMAN CENTER FOR PEDIATRIC TRANSPLANTATION AT CHILDREN'S HOSPITAL OF PITTSBURGH OF UPMC

Advances in Liver Transplantation: Is Liver Transplant Right for You?

A workshop for pre- and post-transplant patients and their families

Time	Minutes	Topics	Presenter(s)
1-1:20 PM	20 Min	It Takes a Village: A Team-based Protocol to Managing MSUD	Deanna Steele, MCG, LCGC
1:20-1:40 PM	20 Min	Transplant vs. Medical Management of MSUD: A Clinician's Perspective	Jim Squires, MD
1:40-1:45 PM	5 Min	Q & A with Dr. Squires and Deanna Steele	Moderator: Chris Divens, RN, MSN, CPN
MAKING TRANSPLANT SUCCESSFUL:			
1:45-2:10 PM	25 Min	Improving the Odds: Techniques and Outcomes in Liver Transplantation and Living-Donor Liver Transplants	Kyle Soltys, MD Swaytha Ganesh, MD
2:10-2:25 PM	15 Min	Improving the Odds: Immunological Monitoring and Outcomes	Rakesh Sindhi, MD
2:25-2:35 PM	10 Min	Q & A with Drs. Ganesh, Sindhi, and Soltys	Moderators: Jim Squires, MD and Chris Divens, RN, MSN, CPN
2:35-2:45 PM	10 Min	BREAK	
2:45-3:10 PM	25 Min	Developmental and Cognitive Impact Before and After Transplantation	Diana Shellmer, PhD
3:10-4:00 PM	50 Min	Panel Discussion, including: <ul style="list-style-type: none"> • Deanna Steele, MCG, LCGC, Genetic Counselor • Jim Squires, MD, Pediatric Gastroenterologist • Kyle Soltys, MD, Transplant Surgeon • Rakesh Sindhi, MD, Transplant Surgeon • Swaytha Ganesh, MD, Medical Director of UPMC's Living Donor Program • Diana Shellmer, PhD, Psychologist • Jonathan Szolna, MSW, LSW, Social Worker • Meghan Rice, Dietician • MSUD domino and recipient family • MSUD transplant recipient 	Moderators: Chris Divens, RN, MSN, CPN Jonathan Szolna, MSW, LSW

THE MSUD FAMILY SUPPORT GROUP IS EXCITED TO ANNOUNCE THEIR PARTICIPATION IN THE MILLION DOLLAR BIKE RIDE



The MSUD Family Support Group is excited to announce their participation in The Million Dollar Bike Ride, a fundraiser organized by The Penn Medicine Orphan Disease Center. The Million Dollar Bike Ride (MDBR) will be held on Sunday, May 20th, bringing together hundreds of

cyclists and volunteers to Philadelphia's Highland Park in support of rare diseases. In four years of this event, 25+ teams have raised over \$6.4 Million to fund research projects for the diseases they represent.

WHY IS THIS IMPORTANT?

A recent survey of our members indicated that the vast majority want to see further treatments and potential cures developed for MSUD. 100% of the funds raised by our team during the MDBR will be used towards MSUD-specific research projects. Also, all funds raised by our team are matched by The Penn Medicine Orphan Disease Center to use towards research grants. Upon reaching a goal of \$25,000 in donations, matching funds will increase the total amount to be used for research projects of our choice to \$50,000!

THE MSUD FAMILY SUPPORT GROUP NEEDS YOUR HELP IN REACHING OUR \$25,000 GOAL!

There will be a team of cyclists in Philadelphia to participate in the race on May 20th, but you don't need to be a cyclist, nor be in Philadelphia to be a part of our team. Here is how to participate:

1. Join our team of riders in Philadelphia - Our MSUD community will have a handful of riders participating in various lengths of the MDBR. The cost to register is \$25 (note, you must raise at least \$250 before the event). Fundraising cyclists will

receive an official 2018 Million Dollar Bike Ride cycling jersey and a T-shirt. You must register by March 12th (date approximate) to receive a jersey at the event. All fundraising cyclists who register after March 12th will receive their jerseys in the mail.

- 2. Join our team as a "virtual rider"** - Can't make it to Philly? You can still participate in the bike ride by riding in your hometown. Gather a group of friends or ride on your own in support of MSUD. Any length ride is acceptable when you are a "virtual rider". You can ask your team members to contribute to the general MSUD fundraising page (see: <http://givingpages.upenn.edu/FamilySupportGroup>) or you can create your own individual page for contributions. There is no cost for doing either.
- 3. Join our team as a fundraiser** - Don't own a bike or nervous about riding 13+ miles? It's ok! You can still support our group by helping us fundraise. Fundraising is the most important part of this event and we want as many people to help as we can. We have created a general MSUD fundraising page for the MDBR. Fundraisers can create their own individual pages to help us reach our goal. You can customize your page with stories about you/your loved one's life with MSUD, pictures, and videos. We encourage the use of email and social media to spread the word about your fundraiser.
- 4. Make a donation** - Aren't interested or don't have the time to run a fundraiser? You can still support! You can either donate via the MDBR MSUD fundraising page or send a check to the MSUD Treasurer, with your contribution:

Dave Bulcher, MSUD Treasurer
9517 Big Bear Avenue
Powell, Ohio 43065

Are you ready to join our team?

Go to: www.milliondollarbikeride.org/2018-cyclist-registration/ to sign up. All members who join the team either as a rider or fundraiser will receive guidance and ideas on promoting their fundraiser, what to add to their pages, soliciting donations, etc. If you have questions about the MDBR, please visit www.milliondollarbikeride.org. If you have questions specific to the MSUD team, please contact [Ed Fischler](#). If you need help creating your own fundraising page, contact [Eddy Wang](#). ■

ADVOCACY

MSUD ADVOCACY REPORT

By Jordann Coleman, Advocacy Chairperson

Medical Nutrition Equity Act



The Medical Nutrition Equity Act (MNEA) would require all private insurance plans (state regulated or self-insured/self-funded) and federal health programs, including Children's Health Insurance Program, Tricare, Medicaid,

Medicare, and Federal Employee Health Benefit Plans, to provide coverage for formula and low-protein foods for all children and adults with MSUD. It is being sponsored by Representative John Delaney (D-MD) and Representative Jaime Herrera Beutler (R-WA) in the House (HR#2587) and by Senator Bob Casey (D-PA) and Senator Chuck Grassley (R-IA) in the Senate (S#1194). We urge our membership to contact their members of Congress and ask them to support this bipartisan bill.

The MSUD Family Support Group recently signed on with Patients & Providers for Medical Nutrition Equity, a coalition formed to build bipartisan support of this legislation. The coalition wrote a letter to the four Congressional co-sponsors in late February, detailing the needs of those with digestive or inherited metabolic conditions, the challenges they face in securing proper nutrition, and the dangers which occur when medical foods are not covered by insurance. The coalition will meet with the co-sponsors in late-March to further discuss the needs of those who require medical nutrition and the Act.

RARE Act

On February 28th, Rare Disease Day, Congressmen Andre Carson (D-IN) & Ryan Costello (R-PA) introduced the Rare Disease Advancement, Research, and Education (RARE) Act. This Act would address some of the commonalities seen by the Rare Disease

Community, aiming to improve rare disease treatment, research, and diagnostics. If enacted, this bill would provide for:

- 1. Rare Diseases Clinical Research Network/ Centers of Excellence** - The RARE Act would enhance an existing and successful program of the National Institutes of Health (NIH), the Rare Diseases Clinical Research Network (RDCRN). This unique Network is made up of 21 research 'centers of excellence' studying rare diseases in an interdisciplinary way, working with patients and others on clinical studies and other research. The RARE Act would increase and extend the RDCRN's funding authorization.
- 2. Surveillance of Rare Diseases** - The RARE Act would require the Centers for Disease Control (CDC) to create a National Rare Disease or Condition Surveillance System. Modelled off of similar systems for other conditions, this formalized infrastructure would fill critical gaps in tracking rare disease data, helping researchers to understand commonalities between diseases.
- 3. Health Professionals' Awareness of Rare Diseases** - The RARE Act would require the Agency for Healthcare Research and Quality (AHRQ) to expand and intensify its work to ensure that health professionals are aware of rare disease diagnoses and treatments.
- 4. Report** - The RARE Act would require the National Academies of Sciences, Engineering, and Medicine to update its 2010 report "Rare Diseases and Orphan Products: Accelerating Research and Development," to evaluate rare disease efforts and make further recommendations to policymakers. ■

END OF YEAR FUNDRAISING DRIVE

By Dave Bulcher, MSUD Family Support Group Treasurer

Thanks to all who sent letters to family and friends, or donated themselves. We raised a total of \$9,000 from this initiative, which has been credited to our research fund.



MSUD FAMILY SUPPORT GROUP NEWS**FROM THE
CHAIRMAN'S DESK**

By Ivan Martin, President MSUD Family Support Group

As I sit here reflecting on how much the care and treatment of MSUD has changed over the years, my mind goes back to 1978 when our son Keith was born. At that time very little was known about the care of a child with MSUD, especially during times of illnesses. I clearly remember on one of our many hurried trips to Children's Hospital in Philadelphia, Dr. Marc Yudcoff commented that maybe not in Mary K or my lifetime but surely in Keith's lifetime there would be a cure for MSUD.

Now, almost 40 years later, I believe we are on the brink of seeing a cure for MSUD. The medical field is moving rapidly, with more frequent articles in the medical journals describing gene therapy and other therapies with the potential to correct different disorders. I believe a cure for MSUD is not far behind.

As a Board, we are concentrating our efforts and resources on raising funds which will allow us to sponsor research projects looking for better treatment and ultimately a cure. Let's not lose hope but continue looking forward to the day when special diets will no longer be necessary. Just thinking about that is very exciting!

Along with fundraising, our aim to support research means we need more volunteer help. You will see more calls for volunteers to help out with these projects. A special thank you to Susan Needleman for agreeing to contact clinics and medical centers with the express purpose of looking for MSUD families who may not know about the MSUD Family Support Group.

Just a reminder: If you are planning to attend the symposium, don't forget to register. I hope to see many of you there. It's always good to reconnect with friends and create new acquaintances. I expect to hear much valuable information on a variety of potential therapies. See you in Pittsburgh on the 28th – 30th of June. ■

**EMORY METABOLIC
CAMP 2018
ANNOUNCEMENT**

Join us June 18-23, 2018 for the 24th Annual Metabolic Camp at Emory University in Atlanta, GA! This is a model, research-based camp for young women 12 years age and older with PKU and MSUD, which focuses on building social support through a variety of activities including nutrition education, cooking classes, discussion groups, and local field trips. The camp typically accepts 30 attendees on a first-come, first-served basis. Registered dietitians from across the nation and around the world volunteer their time to serve as camp counselors, and nutrition students provide support as assistant counselors. The cost of the camp is \$375.00 per person, which includes all sponsored meals, lodging, group activities, and field trips. Partial scholarships are available for certain financial circumstances. Check with your local RD and clinic to see if local sponsorship is available. To learn more and to register, contact Rosalynn Blair (Camp Coordinator) at rborlaz@emory.edu or visit <http://metcamp.net>.



Applications will be accepted beyond the deadline until all spots are filled. ■

FOOD AND NUTRITION

UPDATES TO NUTRITION MANAGEMENT GUIDELINES

By Dianne Frazier, PhD, MPH, RD



The Nutrition Management Guideline for MSUD was first published in 2014. Since that time, there have been reports of new research and experiences that have prompted updates of the guideline. The most significant update, which

is expected to be published before the end of the year, is the section on pregnancy in the woman with MSUD. In addition to these new recommendations for nutrition management in the guideline, there will be expansion of the toolkit to give practical examples of nutrition management throughout the stages of pregnancy and links to helpful resources. More details about the development of these new recommendations can be found at: <https://southeastgenetics.org/ngp/guidelines>

The recommendations for dietitians and other members of the metabolic team to follow when managing the care of women with MSUD before and during pregnancy and after delivery are:

1. Provide individualized pregnancy planning information to all women with MSUD of child-bearing age and update when pregnancy is confirmed.
2. Adjust dietary intake to allow blood LEU concentrations to be in the 100-300µM range and VAL and ILE in the upper range of normal (200-400µM) throughout pregnancy
3. Provide individualized dietary guidance so that nutrient intake meets the changing needs of each phase of pregnancy and the postpartum period.
4. Provide nutrient, clinical and biochemical

monitoring during all phases of pregnancy and the postpartum period.

5. For the woman with MSUD who wishes to breast feed, closely monitor her diet and laboratory markers in addition to her infant's growth and development.

The workgroup of dietitians who have been contributing to this effort include the following: Barbara Marriage, Courtney Allgeier, Beth Ogata, Julie McClure, Surekha Pendyal, Nikki Drilias and Dianne Frazier. A notice will be sent when the updates to the guideline and toolkit are finalized and published. ■

BANANA ICE CREAM

By Dana Angelo White, RDN

Here's a simple recipe to make a delicious and nutritious alternative to ice cream. All you need is a single medium ripe banana. Each banana will yield about ½ cup of ice cream.



1. Slice banana into large pieces.
2. Place banana pieces in a freezer-safe bag and place in the freezer for at least 4 hours (overnight is better).
3. Place frozen banana pieces in the bowl of a food processor fitted with a steel blade and process until they create a frosty, creamy puree.
4. Serve immediately or place in a bowl covered with a piece of parchment paper to harden.

Nutrition information

- 105 calories
- 3 grams fiber
- 1 gram protein
- 80 mg leucine

Want to turn it into a sundae? Add 1 crumbled oreo (0.6 g protein 37 mg leucine), 2 teaspoons chocolate syrup (0.6 g protein) and/or 2 teaspoons coconut flakes (0.08 g protein). ■

CAMBROOKE THERAPEUTICS

Cambrooke Therapeutics continues to expand

its line of delicious and nutritious low protein foods to help improve the lives of individuals with Inborn Errors of Metabolism such as MSUD. In recent months, we have launched a fan favorite from patient events; Lynn's Enchiladas,

a low protein Mexican favorite made with Cambrooke tortillas filled with a rich cheese sauce, peppers, onions and low protein rice topped with enchilada sauce. It is very easy to prepare by just heating and serving. In addition, our Creamy Hot Cereal, which can also be mixed in with your Vilactin AA Plus, is a perfect dish for morning or even right before bed time. For those who like to be creative with savory or sweet recipes, try our new Rendi-Dough, all-purpose yeast leavened dough sheets that provide a base for many baked goods. Then coming real soon to the Cambrooke low protein food family is our cream cheeses. Two types can be used in many recipes or eaten with many of our breads or crackers. Do not forget to try many of our recipes on line at <http://www.cambrooke.com/recipes> that pair well with Vilactin AA Plus. Request a sample at <http://www.samples.cambrookefoods.com>



See you this summer in Pittsburgh at the 2018 MSUD Symposium. Stop by our table to try our great tasting formula and low protein foods and learn more about Cambrooke. ■

NBS-MSUD CONNECT: YOUR ONE-STOP SHOP FOR MSUD RESOURCES

By Lauren Youngborg, MS, CGC
Genetic Counselor, NBS Connect
NBSCONNECT.ORG



NBS-MSUD Connect was launched as part of the Newborn Screening Connect patient registry (NBS Connect) in 2013 through a partnership between the Department of Human Genetics at Emory University, the Maple Syrup Urine Disease (MSUD) Family Support

Group and other key stakeholders. As a complement to the fantastic resources and services already provided by the MSUD Family Support Group, NBS-MSUD Connect is designed to connect patients and families while providing information and tools for living with MSUD. NBS-MSUD Connect also gives participants the opportunity to contribute to MSUD research by creating and maintaining a registry profile that collects data on a variety of key issues within the MSUD community, such as diagnosis, treatment, symptoms, outcomes, barriers to care, and quality of life.

To access the resources outlined below, please create an NBS-MSUD Connect registry account or login to your existing account today!

- **Ask an Expert:** Do you have questions about nutrition, clinical trials, genetic testing, family planning and more? The experts at NBS-MSUD Connect can help! Simply login at NBSCONNECT.ORG, fill out the online form on our "Ask an Expert" page, and connect with professionals who specialize in nutrition, genetics, research and other fields.
- **Kitchen Connection:** Spice up your diet with a new recipe! Kitchen Connection is a growing collection of low protein recipes developed or

adapted by registered dietitians. Each recipe includes a nutritional analysis complete with calories, protein and leucine content to make diet management as easy as possible. Visit our “Kitchen Connection” page and find your favorite recipe today.

- **Clinical Trials:** Advance MSUD research through participation in a clinical trial or research study. NBS-MSUD Connect aims to connect families who are interested in participating in clinical trials with researchers who are recruiting patients. Check out the “Clinical Trials” page for general information about understanding clinical trials, and register to view current research studies, including recruitment status and results outcomes.
- **Explore NBS-MSUD Connect Data:** After completing the surveys within your registry profile, see how your responses compare to other participants. Visit our “View Data” page to access aggregated data submitted by registrants with MSUD. YOUR RESPONSES REMAIN ANONYMOUS. INDIVIDUALS WHO PARTICIPATE IN THE REGISTRY ARE NOT IDENTIFIED IN ANY PUBLISHED DATA.

- **Additional Internet Resources:** For your convenience, NBS-MSUD Connect has gathered a variety of online resources that may be useful to those living with MSUD. This includes the Genetic Metabolic Dieticians International’s guide on “Leucine and Protein Content of Foods Appropriate for Individuals on a Leucine-Restricted Diet;” the USDA’s guide for “Accommodating Children with Special Dietary Needs in School Nutrition Programs;” search engines for locating a genetic counselor, geneticist, or metabolic dietitian; and much more.

Please contact the registry team if you have any questions about NBS-MSUD Connect. We are also available to provide assistance in creating or updating an account.

Email: coordinator@nbsconnect.org;
Phone: 404-778-0553.

Register at www.nbsconnect.org today!

*HRSA Supported Partnership — Principal Investigator:
Rani Singh, PhD, RD, LD; Grant #UH7MC30772 ■*

VitaFlo has the **formuLa4success™**

formuLa4success is a personalized support program created to help you save time and ease the process for getting the VitaFlo MSUD medical foods you need.

Single Dose AMINO ACIDS

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PERSONAL STORIES

MELVIN CARRUTH

By MaryJo Blount

This letter is a tribute to my brother Melvin Carruth! We believe he is one of the oldest living African Americans with Maple Syrup Urine Disease. Melvin was born July 31, 1965 to Margrett Tim and Eunice Carruth. In addition to MSUD, Melvin was born blind, deaf and with a club foot. The first couple weeks of his life were filled with constant crying and intermittent body spasms. Eunice took him to Grady Hospital and he was eventually referred to Bellevue Hospital in New York. This is where Melvin was diagnosed with MSUD. He underwent several surgeries and had to wear casts and braces for several years. (Oh, did I tell you the Doctors advised my parents not to get too attached to Melvin because they didn't think he would live past 6 months). Melvin continued to develop and get better. Amazingly, his sight and hearing recovered. He eventually attended high school and received his high school diploma. Today Melvin is 52 years old and is doing well. He lives with our 84 year old mother and attends the adult day care at Frazer Center in Atlanta, Georgia. Our dad died in 1985 of pancreatic cancer. He is treated at Emory University School of Medicine.

Melvin had a younger brother, Kenneth Carruth, who was born June 7, 1969 and who was also diagnosed with MSUD. Kenneth grew up and did well also. He was married and worked several jobs at Kroger and different restaurants. Kenneth would occasionally have seizures and have to be hospitalized. Of course,



once he left home his diet was not well controlled. Kenneth passed away on May 21, 2013. An autopsy was performed because he died suddenly and because of his young age. The autopsy couldn't find anything remarkable. He had a seizure earlier that day and laid down and passed away.

I was born on October 2, 1966 (between them) and was a perfectly healthy baby. In 1990, I was diagnosed with Multiple Sclerosis. I am married with 3 daughters and live with my husband in Stockbridge, Georgia. I code medical records for a living. Now I am doing this work at home. ■





Supporting you to live life to the fullest



Formula Coverage

One-on-one support to obtain formula coverage at no cost to you!



Education

Easy to understand disorder and product specific education



Life Stage Support

Ongoing support to help meet developmental, nutritional and diet goals



Social Communities

Inspirational stories and informational videos



Nutrition Specialists

Experts to answer your medical formula questions



Recipes

Low protein foods and recipes to help achieve diet goals



Low Pro Living Blog

Helpful tips, recipes and disorder resources



Email

Delivers our library of tools right to your inbox



Formula

Trusted products to help you manage and thrive



Diet-for-Life

Diet-for-Life Care Coordinator helps individuals with PKU return to diet

Visit [MedicalFood.com/Connect](https://www.MedicalFood.com/Connect) to learn more

Call **1-800-605-0410**
Monday – Friday 8:30 AM – 5:00 PM EST



Resource Persons:

Organizational information, printed material or addition to our mailing list:

Sandy Bulcher

Vice President
Powell, Ohio
740-972-5619
sandybulcher@gmail.com

Donations:**Dave Bulcher**

Treasurer
9517 Big Bear Ave
Powell, OH 43065
740-972-5618
davebulcher@gmail.com

Legislative & Education:**Marcia Hubbard**

Corresponding Secretary
Cedar Hill, Missouri
314-277-8168
marciathubbard68@gmail.com

Inquiries in Spanish:**Adriana Carbajal** (MSUD parent)

Mesa, Arizona
480-278-4713
adrianamc2014@yahoo.com

Vanessa Funes (MSUD adult)

Boston, Massachusetts
508-596-0672
mamilindafunes@live.com

Newsletter Editor:**Karen R. Dolins, Ed.D, R.D.**

Newsletter Editor
Scarsdale, New York
914-723-5458
karen.dolins@yahoo.com

Advocacy:**Jordann Coleman**

Advocacy Chair
Concord, CA
925-349-4601
coleman.jordann@gmail.com

Medical Advisors:**Holmes Morton, M.D.**

Founding Pediatrician
Central Pennsylvania Clinic,
A Medical Home for Special
Children & Adults
PO Box 5806
4527 East Main Street
Suite E
Belleville, PA 17004

Melissa Wasserstein, M.D.

Chief, Division of Pediatric Genetic
Medicine
Children's Hospital at
Montefiore
Associate Professor
Albert Einstein College of Medicine
Bronx, NY
718-741-2318

Harvey Levy, M.D.

Senior Physician in Medicine and
Genetics
Division of Genetics and Genomics
Boston Children's Hospital
Professor of Pediatrics
Harvard Medical School
Boston, MA
617-355-6394

Can Ficicioglu, M.D., Ph.D.

Associate Professor of Pediatrics
Perelman School of Medicine at the
University of Pennsylvania
The Children's Hospital of
Philadelphia
Division of Human Genetics/
Metabolism
Director, Newborn Screening
Program
Director, Lysosomal Storage
Disorders Program
Philadelphia, PA
215-590-3376

Jessica Scott Schwoerer, M.D.

Assistant Professor Dept of
Pediatrics, Division of Genetics and
Metabolism
University of Wisconsin Hospital
and Clinics/ Waisman Center
1500 Highland Ave Rm 341
Madison, WI 53705-2280
608-263-5497

Nutritional Advisors:**Rani Singh, Ph.D., R.D.**

Emory University
Division of Medical Genetics
2040 Ridgewood Dr.
Atlanta, GA 30322
404-778-8519
Fax: 404-778-8562
rsingh@genetics.emory.edu

Sandy van Calcar, Ph.D., R.D., C.D.

Child Development &
Rehabilitation
Oregon Health and Science
University
3181 SW Sam Jackson Rd
Portland, OR 97239
503-494-5500
vancalca@ohsu.edu

MSUD Family Support Group Board**President**

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