

MSUD NEWS

Family Support Group in

Israel

Written by Tzvi Kaidanov

MSUD ISRAEL (IL) Association Meeting, November 7, 2014

On 11/07/2014 in sunny Israel 8 families from all over the country gathered to celebrate one thing, and one thing only – their kids! These happy and cheerful children have one of the world's most rare diseases, MSUD - maple syrup urine disease.

This meeting has been the first step to reviving an active MSUD IL Association. This group was founded in order to unite all MSUD families regardless of race or political point of view in order to achieve a high quality of medical support for our children. We are an eclectic group including Jews and Muslims. This is what makes our group so special! At the reunion we witnessed a really eclectic group gathered by the same cause and by the same troubling inaction of governmental institutions. In a society like Israel it was really amazing to see the unity in such a group around the concern for the welfare of our children.



The names of the kids in the photo are: Sari 18 years old, Rotem 18 years old, Noa 16 years old, Aviel 15 years old, Noy 12 years old, Shada 12 years old, Roni 4 years old, Tamar 1.5 years old. All of them have Classic MSUD.

The meeting took place at the National Park of Israel at the Tel-Aviv area over picnic baskets filled with adjusted foods without or almost without any protein. The variety of the choices would've left the healthy person filled with envy in a good way. There were vine leaves, patties, cakes, pasta, sweet pastry and salads. The most valuable thing for parents of the MSUD kids is to be able to feed them with much taste and without any protein.

The meeting has given us the chance to get to know each other, create a connection in person and to share our personal experiences - the situation we've been through with different clinics, the different symptoms kids have and dealing with them, the

Inside This Issue:

(Israel cont. on page 2)



cover, 2 Group in Israel

- Jeff Fredericks
- Noy's Bat Mitzvah
- From The Editor
- First Bites
- 5 Emory Camp
- Welcome Sawyer
- Lobby Capital Hill

- 8 Conner's Story
- 9 A Night at the Races
- 10 My Story is Like All Other
- 11 Advocacy
- 12 Published Research
- 14 Diet Wise

back Contacts



The information contained herein does not neccessarily 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

(Israel cont. from page 1)

recipes of multiple cousins and products adjustable to MSUD limitations. It was fascinating to feel the immediate connection among the group kids and parents as one.

At the meeting, after a very large quantity of very tasty food we went through the goals of the MSUD IL Association which included:

- Mapping the patients in Israel and organizing them through the Association. We have already located 15 families in Israel.
- Mapping the physicians to route new patients towards the Association upon diagnosis.
- Providing support network among the members.
- Promoting legislation for the recognition of MSUD patients as entitled for disability upon discovery of the illness.
- Promoting subsidies of metabolic products such as Anamix, Maxamaid, Valine and Iso-Leucine in the public healthcare system.
- Raising funds and starting research towards a cure for the MSUD.
- Raising public awareness of this orphan disease through personal presentations.

Our hope is that the MSUD IL Association will give us the power and influence to really make a difference in Israel and maybe worldwide. §

A Personal Story



Jeff Fredericks

By Anne Fredericks, Mom

On the last Sunday in October, Jeff complained of severe pain that ended up being a cecal volvulus, which is very rare. It is a serious medical issue involving the intestines where the cecum, the first portion of the large intestine, loops around itself and creates an obstruction. Ater 2 hours in the local emergency room trying to find a service to take him to Lancaster General, we had to drive him ourselves (about a 2 hour drive) We were praying the whole time that we didn't lose him before he could have life-saving surgery. The surgeon here and in Lancaster both agreed that Jeff had hours not days to get the operation. While we were driving him, I knew he was still alive because he was snoring. He had part of his ileum removed, plus the appendix and gallstones taken out and he battled pneumonia while in the hospital and at home. He now has a large scar up his belly. He has healed very nicely and is back to normal - working and volunteering. We are so thankful to Dr. Morton, Dr. Strauss, and Donna from the Clinic for Special Children for their amazing medical work as well as the very dedicated nurses on the Pediatric floor at Lancaster General. It was funny to have Jeff, who turns 40 on Feb. 17 to be on that floor. He tried to take some of the nurses home. I know we tried our best but we just weren't as pretty or as nice as the ones on the floor. §

Metabolics

www.medicalfood.com

Order your Low Protein Pasta online at MedicalFood.com

Save \$\$ when you buy by the case.



Our Daughter Noy Celebrating Bat Mitzvah

By Widezki Family



Hi everyone, we are the Widezki Family from Israel and we are proud to introduce you all to our daughter Noy who celebrated her BAT MITZVA on February 13, 2015.

All of you know that children's birth is an exciting event.

All children land on their parents happily even if those moments involved concerns and excitement. But Noy came with a big drama, and we were young parents, without realizing that we would be forced to make difficult decisions.



Noy born on February 9th, 2003 and was diagnosed as MSUD classic in 14 days.

After 4 days in PICU we were told that Noy has MSUD and she must have Hemo-Dialysis as all her body was already toxic with leucine levels of 2,340mg!!!!

Today, we all know that we have chosen this gamble right for us and for Noy.

We chose to raise this special girl, as a normal child, of course with food restrictions however we never prevented her from experiencing flavors. I

remember strongly when we participated in our first symposium in Atlanta

2004 and we asked some families "tell us what is the daily menu of your children?", Most of them answered: "Potato chips and all forms of potatos".

Without press and cameras we ran this marathon race without breaks, and some falls when we went to the hospital, but we always get up and keep running. Noy has grown to be a girl called wise and determined that nothing stands in her way. She knew from a young age always to get up and to move on.

Life is not easy for her but absolutely possible.

Our mission to all of the MSUD families is to show that MSUD can be managed. §



FROM THE EDITOR

You may have noticed that this Winter 15 issue of our newsletter is arriving later than usual this year. I was unexpectedly taken ill, and lost about a month of time. I feel fortunate to be almost back to normal and ready to get this issue rolling! Meanwhile,



it's the end of March and I'm still waiting for the first flowers to bloom. Instead, what do I see outside of my window??? Snowflakes! I take heart in knowing that by the time you are reading this the warm weather will be here.

My daughter Hannah (classic) is about to turn 21! How did this happen? This community has been a part of my life for 21 years, and I don't know where I'd be without it.

I'm grateful to those who were willing to share their personal stories with us. For me, those pieces are the most gripping and meaningful. It gives us all the opportunity to learn how others are managing MSUD, where ever they live.

In this issue you will be introduced to our new Advocacy chairperson, Jordann Coleman, and also hear about the efforts of the Jones' family and their success in raising funds to help meet the needs of our members. I hope these articles will inspire you to step up and participate in any way you can.

MSUD continues to be a focus of research. In this issue I review 3 papers published over the past few months. One tells us the status of MSUD in Brazil, another informs us of the results of an experiment with carnitine supplementation, and the third reviews the case of a successful liver transplant with mom as donor.

We no longer have a "Diet Wise" editor providing recipes using lo protein foods, but Dana Angelo White has provided a couple of recipes using healthful foods naturally low in protein and also shares with us information about her newly published cookbook. More recipes can be found online through the NBS Connect website: www.nbsconnect.org

Finally, we are grateful for the continued support we receive from Nutricia and Vitaflow.

All my best,

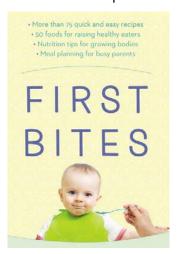
Karen Dolins

Mom to Hannah, Classic MSUD, age 20

NUTRITION BOOK BY MSUD MOM DANA ANGELO WHITE

FIRST BITES is the quick and easy reference guide that all parents can keep on hand to whip up tasty and nutritious meals for their babies and toddlers in no time. Recipes are

designed to help to foster healthy eating habits and create a diet filled with 50 fresh, minimally processed superfoods that are just as delicious as they are healthy. In this book, fruit and veggies take center stage in new and exciting ways,



yet parents will also learn to create healthy spins on classic kid favorites like mac and cheese, pizza, chicken fingers and cupcakes.

FIRST BITES offers all the tools parents need to turn the naturally healthy foods they have on hand into delectable breakfasts, lunches, dinners and snacks designed to encourage youngsters to become strong and healthy eaters for a lifetime.

About the Author



Dana Angelo White, MS, RD, ATC is a registered dietitian, certified athletic trainer, nutrition and fitness consultant, and mother to a 3-year old (Charlie, Classic

MSUD, transplanted) and a 5 year old. She specializes in culinary nutrition for children and adults, recipe development and sports nutrition. §



21st Annual Metabolic Camp at Emory University





June 22-27, 2015 Atlanta, GA

Join us June 22-27, 2015 for the 21st 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.

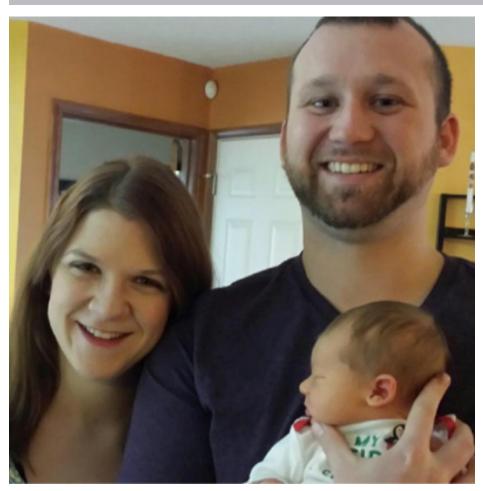


To learn more about the Metabolic Camp and to register:

Visit http://metcamp.net

or

Contact **Rosalynn Blair** (Camp Coordinator) atrborlaz@emory.edu or (404) 778-8521







Welcome Sawyer Michael Richards!

By Brittany Fuller Richards

I was born on September 24, 1987 with classic MSUD to Tish and Mike Fuller. I had a liver transplant on February 3, 2006 in Pittsburgh. Through the nine years since being transplanted, my levels have remained in good standing without any problems with rejection.

I married Shawn Richards on September 1, 2012. On December 18th Shawn and I welcomed our first baby boy into the world. As I was hoping to get pregnant, I was referred to a high risk doctor. I was told that liver transplant patients are at risk for preeclampsia, liver rejection and preterm labor. Once I did become pregnant I was under constant observation throughout the pregnancy and we didn't run into any of those complications. In the beginning I was monitored every month and then towards the end every week. We got to see our little guy grow through the ultrasound at every appointment.

Sawyer was estimated to be due on December 28th but as this was a high risk pregnancy the doctors delivered him a week and a half early. On the night of Sawyer's arrival, my doctor was thinking I would have a C-section delivery. I was really hoping for a normal birth and was allowed to go into labor. After a total of 10 hours labor, we got to welcome Sawyer Michael into the world. It was more than what we thought when he was placed in my arms. I was overjoyed that our little boy was here and healthy. Both sides of the families were happy for his safe and healthy arrival. Sawyer was born 6:38pm in Columbus, Indiana. He weighed 6 pounds 13 ounces and measured 19.5 inches long. The day after his birth, the doctors ordered some blood work to be done to verify how my liver was doing. With luck on our side the liver numbers remained perfect. §

Join us in May as we lobby on Capitol Hill!





We are pleased to invite you to lobby with us on May 18 and 19, 2015 for the Medical Foods Equity Act (MFEA) in Washington, D.C.! The MFEA would require all federal programs to cover the cost of medical foods (both formula and food modified to be low in protein) for children and adults with PKU and other inborn errors of metabolism.

The lobbying will take place on both Monday, May 18 and Tuesday, May 19. Volunteers will be paired with seasoned advocates for the lobbying appointments. If you can't make it to D.C. in May, you can still help us by securing appointments for the NPKUA with your member of Congress. If you are interested in joining our efforts in D.C. or making an appointment for the NPKUA volunteers, please contact Amy Oliver at amy@goipad.org for more information and materials.

Information is also available on the NPKUA website at http://www.npkua.org/TakeAction/MedicalFoodsEquity-Act.aspx. Thank you for your help in advocating for the MFEA! Together we can make our voices heard!

Thank you,
The National PKU Alliance



Conner's Story

By Jessica Godfrey, Mom

Ten years ago... a normal Thursday in Georgia. Jody & I were awaiting the birth of our son. We felt a bit experienced since our daughter Katelyn was born less than 18 months prior. Conner Glaze Godfrey came into this world beautifully. However, I remember having a continual feeling in my gut - something was "off" with my boy. We were discharged from Northside hospital in a suburb of Atlanta on Sunday. I made an appointment with our pediatrician the next morning, because Conner didn't have much of an appetite and he slept constantly. The doctor dismissed my concerns saying "This is normal, babies can be lethargic at first."

Conner had been given a newborn screening test at birth. The doctor did a follow up test and sent us home, telling us the results should be in by the end of the week. Our phone rang later that night around 6:30 PM. Mayo Clinic called stating that our son's newborn screening came back with an abnormal reading for a rare disease, but that we didn't need to worry, just follow up with our pediatrician in the AM. When my husband told me of the call, I asked him to call back and ask about the symptoms of the disease. Conner matched every symptom - highpitched cry, struggled to eat and hours upon hours of sleeping. Mayo Clinic immediately arranged for us to go to Egelston Children's Hospital. Around 9:00PM we were headed to the hospital and the doctors were expecting us. They immediately stopped feeding Conner and they started IV fluids just to be safe in case that he did have a metabolic disorder. At 5 days old, treatment with formula had started. We met with geneticists and dietitian, Dr. Rani Singh. We were told about MSUD. Our world was turned upside down. The next few days are a blur... learning to make formula, learning about the risk of illness and metabolic crisis... it was overwhelming. I was grateful for my husband, who has strong faith and an awesome sense of humor... he gave Conner the nickname pancake because he smelled just like Aunt Jemima Syrup and we wanted



Conner Glaze Godfrey, Classic MSUD, Age 10

to eat pancakes when we held him!

Dr. Rani Singh has been Conner's dietitian since that time and she has been an indescribable gift to our family. She advised us to be homebound the first year of his life in order to avoid illness. We followed the protocol. The Godfrey family is very social so this was extremely hard, but we made it work. We found a new normal. As a mom, I struggled those first years with fear of Conner's future. I still have days where I struggle with the thoughts of the unknown future, yet for the most part – our new normal is good.

Conner was hospitalized for the first time due to metabolic crisis around 18 months of age. Then hospitalized around the age of 3 when he had his first seizure. This was the scariest moment of my life.

After experiencing 5 seizures, we decided to put him on seizure medicine for two years. We then weaned him off the meds. It has been 5 years since his last seizure and I pray it was his last. We have had other hospitalizations due to illnesses, but all have been quickly treated and his metabolic levels stabilized.

Conner's personality is passionate. He enjoys life,

(Conner cont. from page 8)



The Godfrey Family: Caleb (8), Jessica, Jody, Katelyn (11), Conner (10).

mostly sports and being with friends and family. His dream is to play football, however, his doctors advise against it. He plays basketball, baseball and lacrosse. He has some great friends. His close friends know about MSUD since they see him drinking "Conner's Juice" and know that he cannot eat everything they eat. But most of the kids around him don't even know about it. We have a supportive administration, school nurse and teachers in his school who know about MSUD and the signs to look for. They all know to call me the moment he shows signs of lethargy or dehydration. Classmates are often envious of his lunch, which includes goldfish, sugar-coated strawberries, Little Debbie's and Fruit Snacks. Conner doesn't allow the disease to define him. He believes that it makes him "unique" and "special".

Conner has asked over the years to meet some people in the MSUD community. We were able to attend a symposium years ago when Conner was a baby. We hope to attend the next one in 2016. Conner is hoping to make some connections and meet some friends, so if you see us, please introduce yourself! We are grateful that Facebook helps our MSUD community connect.

Conner is currently in the middle of the Buphenyl trial with Dr. Brendan Lee. We look forward to seeing how his body responds to this medicine.

Although I hate that my son has to deal with this nasty disease, Conner's passion and bravery has taught us to treasure each day and live life boldly. §



A NIGHT AT THE RACES

By The Jones Family Dean, Amy, Derek (Classic MSUD age 12), Adam

We have had a Night at the Races to raise money for MSUD research for the past 7 years.

We live in a small community in NE Ohio, and over these 7 years we have been able to raise nearly \$40,000 for the MSUD Family Support Group to use wherever it is needed. We usually sell about 250 tickets to this event, and we have many prizes and baskets donated for raffles. It is a catered event and we sell 100 horses for \$10 each that the buyer can name and own for a race. Tickets to enter the event are usually \$15 each, and this includes entry, dinner, and drinks. It is always a fantastic time and is the talk of the town when it comes around annually. In 2015, our annual Night at the Races will be held on October 10. We always advertise it in our local newspaper and social media has been a huge help in getting the word out. Friends and family have come in from out of town for this event, not only for Derek, which is obviously the main reason, but also because it is such a great time.

Dave and Sandy Bulcher have made the trip within the past few years and in 2014 we were joined by Jordan Bulcher as well! It's always awesome for our community to see and meet other people that are affected by this disease and also that we as the MSUD community appreciate their support.

If anyone is ever interested in joining us, our doors are always open to you at our annual MSUD Night at the Races!!!! §

My Story Is Like All Other

By Catarina Costa

My story is like all the others, I'm just another young woman in the world but rare.

My name is Catarina Costa and I live in Portugal. For 20 years I have lived with an inseparable "friend" MSUD.

When I was born in 1994 there was no way to detect my disease in my country. Everything was fine until I refused the breast of my mother with an annoyed cry. This was taken as normal, and my mother thought I might not have been hungry. Over the next few days I started making repetitive movements with the legs like riding a bicycle, but I could not control them.

My parents took me to the doctor and he thought the problem was that I was not eating. He gave me a bottle with regular baby formula. After a few hours I was in a coma. Exams hither and thither and the diagnosis was not arrived at until after 13 days of life. I was given dialysis to lower my BCAA levels quickly.

In Portugal at that time only the MSUD formula was available, not special food without protein, so I ate only fruit, vegetables and corn flour. I was very small and skinny for my age. Low protein foods became available when I was 4 years old, and my parents paid for them.

We moved to the country when I was five years old. I was in a small group at school to reduce the risk of infection. I had walking difficulties because I put the feet aside and could not climb stairs. In two years I learned to walk and climb stairs, thanks to river stones in the mountain and to a lady who looked after me, who became like a second mother to me. My food was controlled with diet and the formula with valine and isoleucine supplements.

My childhood was good without metabolic crises or infections. I had no problems at school. I had lunch at home and when there were parties the mothers of my

friends made vegetarian gelatin for me to eat. By this time special food without protein was available and was paid for by the Portuguese government.

Adolescence was complicated because I started to become aware of the disease and its day to day



Catarina Costa, Classic MSUD, Age 20

difficulties. I wanted to be normal thousand times... I had problems in my relationships with others for fear of what they thought of the disease.

I did my schooling with good grades. I had some difficulties in physical education, drawing and mathematics and needed to make an extra effort.

At this moment I have a slightly more liberal diet with potatoes, rice and yogurt, along with my formula and low protein food. I have been eating this way for three years. This has brought me a great joy as I can have dinner with friends without carrying the food with me, and have gained some weight so I am not so skinny.

I'm in the last year of the University where I study Portuguese and Spanish to one day be a teacher. My real dream is to help in a community that needs me. I have friends and have lost the fear to show who I really am. I have a boyfriend too and he told me "you are normal like me only you eat vegetables but one day I know you will be able to eat everything you want." I wrote a poetry book in 2012 and I hope to write histories for children and a book about my life.

I want to go to the international meeting for MSUD one day to finally meet those I wrote to and helped over 6 years every night on Facebook. One day I would like to have a liver transplant.

MSUD is not a prison. I live well with it and I think that it has given me a special sensitivity to others. I answer questions, explain in a thousand ways what I have, and even I laugh about it. I am happy living like that. Next year I plan to go to Spain as part of my education to be a teacher. I hope to be accepted to a program in Madrid or Barcelona. §

By Jordann Coleman, Mom to Carter, Age 2, Classic MSUD

The MSUD Family Support group recently created an advocacy committee to help steer collective efforts in issues that are important to those with MSUD and their loved ones, and I have been appointed Chair. Although the position is in its infancy, the advocacy efforts of our members are not. In the coming months, we will continue to identify advocacy opportunities for our group. This may also include issues that are not specific to MSUD but to others with metabolic disorders or the general population. Our goal is to help enhance the lives of those living with MSUD.

At the end of 2014, the MSUD Family Support Group was added as an official member organization of the National Organization of Rare Diseases (NORD). With

our NORD membership, the MSUD Family Support Group will become part of a larger voice for the rare disease community and have the backing of an organization with an aggressive public policy agenda. Many of you may remember the Newborn Screening Reauthorization Act that was stalled in Congress this past fall. NORD was a key group that garnered support from the public to help push the passing of this bill.

In 2015 and beyond we will look to extend our reach to the genetics regional collaboratives across the country as well as attend industry conferences and Hill Days to spread awareness of MSUD.

We had a really nice showing from the members on Facebook for Rare Disease Day this year. We saw so many of the beautiful faces who have this disease and their loved ones. It was inspiring to hear everyone's stories. We have some exciting ideas on how to expand our presence for Rare Disease Day next year. Stay tuned.

If you have any issues that you feel are important to the MSUD or Rare Disease communities, please bring them to our attention. Issues can local, national, or international. No issue it too small.

If you would like to be a part of this exciting committee, we'd love to have you!

You can contact me at coleman.jordann@gmail.com or find me on Facebook (Jordann Bass Coleman). §



News From the Research Journals

NEWLY PUBLISHED RESEARCH



By Karen Dolins, Editor

Heterozygote to homozygote related living donor liver transplantation in maple syrup urine disease: A case report

Liver transplantation has become more widely practiced but livers are scarce. This paper reports on a successful liver transplantation using the mother of a 2 year old child with MSUD as a donor. According to the authors, this is only the second successful case reported where a patient with MSUD received a liver from a live donor who is a heterozygous carrier (has a defective gene) for the disease. After transplant BCAA levels normalized and remained so on an unrestricted protein diet. The authors note that longer term follow-up is necessary to ensure that the child remains healthy.

Patel N et al Pediatr Transplant. 2015 Feb 10. doi: 10.1111/petr.12439. [Epub ahead of print]

Maple Syrup Urine Disease in Brazil: a panorama of the last two decades

Brazil instituted a newborn screening program in 2001, but MSUD is not one of the diseases screened for. Laboratory testing and the metabolic formula are not provided by the government health service. The authors of this study reviewed all patients diagnosed between the years of 1992 and 2011 in an attempt to inform public policy.

The researchers identified 83 patients who met the criteria for a diagnosis of MSUD. Only 48 were alive at the time of the study. The age at diagnosis ranged from 7 days to 10 years. Only 12 patients were diagnosed early, defined by the researchers as by the 15th day of life. Almost half of these patients had a family history of the disease. All of those with MSUD exhibited neurological damage, including those who were diagnosed early. The authors note that this is due to the difficulties in obtaining the metabolic formula. Those who have received formula often accomplished this through legal action.

The authors make the following recommendations:

- MSUD should be included in the public newborn screening program
- 2. Metabolic formulas should be available to all patients
- A national center specializing in liver transplantation for metabolic disorders should be established
- A network of multidisciplinary teams specializing in MSUD management should be established

Herber S Jornal de Pediatria 2014. http://dx.doi.org/10.1016/j.jped.2014.08.010

Urinary biomarkers of oxidative damage in Maple syrup urine disease: The l-carnitine role

It is known that high levels of leucine in the blood as well as high levels of the metabolic product alpha keto acid are responsible for the neurological damage observed in MSUD. Oxidative stress, caused by an increase in free radicals, is also thought to play a role. The body has a natural antioxidant defense system which neutralizes free radicals. Carnitine, a substance found in cells,

(Research cont. from page 12)

functions as part of this system and has been studied for its potential to block some of the damage caused by free radicals.

In this study conducted in Brazil, 7 young MSUD patients who were diagnosed late were given L-Carnitine or placebo and markers of oxidative stress in their urine were observed. The researchers found that some of the children were deficient in carnitine prior to supplementation and observed a lowering of oxidative markers in the urine after 2 months of supplementation.

It is important to note that only 7 children were in the study, and all were diagnosed late as Brazil does not screen for MSUD. The researchers do not specify the time of diagnosis. Dietary compliance was not discussed, nor was their intake of food sources of antioxidants (fruits and vegetables). From the above article, we know that many do not have access to the metabolic formula. It is uncertain how this information can be applied to individuals who are diagnosed shortly after birth and who are compliant with diet. However, MSUD patients should be monitored to make sure they are not deficient in carnitine.

Guerreiro G et al International Journal of Developmental Neuroscience 2015 Feb 10. pii: S0736-5748(15)00011-8. doi: 10.1016/j. ijdevneu.2015.02.003. [Epub ahead of print]

Visit our website at

www.msud-support.org

to find recent and past
newsletters and more.

Also, join the growing
group over at Facebook:
www.facebook.com/
groups/2220742408/

SAVE THE DATE

MSUD SYMPOSIUM
2016

Raleigh, North Carolina

Embassy Suites Raleigh-Durham
Airport/Brier Creek

Thursday June 23rd to
Saturday June 25th

Look forward to seeing you!



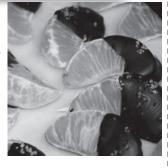
Many thanks to *Dana Angelo White* and *Chad Farquharson* for submitting recipes!

Our readers appreciate sharing in any tasty recipes you have found or developed, so please send them in!

Clementine Dippers

- 6 clementines, peeled and separated
- 4 ounces dark chocolate, finely chopped

Line a baking sheet with parchment paper. Place chocolate in small bowl and melt over a double boiler



or in the microwave*. Dip each piece of clementine in chocolate (about halfway) and transfer to baking sheet. Place in the refrigerator for 10 to 12 minutes, until chocolate has hardened. Serve chilled or at room temperature.

- * If using the microwave, cook on high in 20 to 30 second increments, stirring well each time.
- Yield: about 36 pieces

Nutrition information per piece:

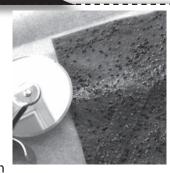
Protein:	0 g	Sodium:	0 mg
Leucine:	0.01 g	Cholesterol:	0 mg
Isoleucine:	0.02 g	Fiber:	0 g
Valine:	0.03 g	Vitamin D:	0 IU
Calories:	22	Calcium:	4 mg
Total Fat:	1 g	Iron:	0.1 mg
Carbohydrate:	3 g	Sugars:	3 g

Excerpted from First Bites: Superfoods for Babies and Toddlers by Dana Angelo White.

Strawberry-Kiwi Fruit Leather

- 1½ cups chopped fresh strawberries
- ½ cup chopped fresh kiwi
- 2 tablespoons sugar
- 2 tablespoons honey

Preheat oven to 170°F. Line a baking sheet with parchment paper or a Silpat mat and set aside. Place fruit, honey, and sugar in a medium



saucepan. Bring to a boil and cook for about 5 minutes, then puree using an immersion blender*. Continue to cook over medium-high heat for an additional 10 to 15 minutes or until thick and syrupy; the mixture should be thick enough to coat the back of a spoon. Pour the hot fruit mixture onto prepared baking sheet and spread evenly into approximately an 8×12 inch rectangle. Place in the oven and bake for 3 hours. After 3 hours have passed, turn off the oven and allow to sit overnight. Cut into strips with a pizza cutter; roll up in a clean piece of parchment paper. Store in an airtight container for up to 3 weeks.

- * If you do not have an immersion blender, puree in a food processor and then return mixture to saucepan.
- Yield: 12 strips

Nutrition information per 1 strip:

Protein:	0 g	Sugars:	4 g
Leucine:	0.01 g	Sodium:	1 mg
Isoleucine:	0.01 g	Cholesterol:	0 mg
Valine:	0.01 g	Fiber:	1 g
Calories:	21	Vitamin D:	0 IU
Total Fat:	0 g	Calcium:	6 mg
Carbohydrate:	5 g	Iron:	0.1 mg

Excerpted from First Bites: Superfoods for Babies and Toddlers by Dana Angelo White.

Cake Frosting

- 1/4 cup margarine
- 2 cups confectioners' sugar
- 1tsp vanilla
- 2 tbsp Vanilla International Coffee Creamer

In a mixing bowl, thoroughly cream margarine and sugar. Stir in vanilla and coffee creamer.

Per recipe total is 0.4g protein

Submitted by Chad Farguharson

Nutricia has a New Website!



- Request FREE formula samples online
- Learn more about managing a low protein diet
 - View delicious low protein recipes ■
- Buy your low protein food direct from Nutricia
- Share your Story and learn from other families

Visit us at www.MedicalFood.com

Resource Persons:

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

Sandy Bulcher, Director Powell, Ohio 740-972-5619 sandybulcher@gmail.com

Donations:

Dave Bulcher, Treasurer Powell, Ohio 740-972-5618 davebulcher@gmail.com

Legislative & Education issues:

Marcia Hubbard

Corresponding Secretary Cedar Hill, Missouri 314-277-8168 secretary@msud-support.org

Inquiries in Spanish:

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

Medical Advisors:

Holmes Morton, M.D.

Clinic for Special Children, Inc. P.O. Box 128 Strasburg, PA 17579 717-687-9407 Fax: 717-687-9237 www.clinicforspecialchildren.org

Melissa Wasserstein, M.D.

Director Program for Inherited Metabolic Diseases Associate Professor Department of Genetics and Genomic Sciences Mount Sinai School of Medicine New York, NY 10029 212-241-2478 Fax: 212-860-3316

Susan C. Winter, M.D.

Director medical Genetics/ Metabolism Valley Children's Hospital 9300 Valley Children's Place Madera, CA 93638 559-353-6400 Fax: 559-353-7213 winter2571@aol.com

Neil R. M. Buist, M.D.

Professor Emeritus Pediatrics and Medical Genertics Oregon Health & Science University buistnrm@aol.com

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

Advocacy:

Jordann Coleman

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



MSUD Family Support Group Board

Sandy Bulcher Ohio

Karen R. Dolins New York

Ivan Martin Pennsylvania

Dave Bulcher Ohio

Anne Fredericks Pennsylvania

Denise Pinskey Michigan

Amy Jones Ohio



This Newsletter does not attempt to provide medical advice for individuals. Consult your specialist before making any changes in treatment.