



ADVOCACY AND FUNDRAISING

ADVOCACY

By Karen Dolins



As our legislators headed home for their August break, Rare Disease Legislative Advocates got busy. They contacted everyone on their contact list and asked them to participate in In-District Lobby Days. I simply registered on their website and notified them of my availability so that they could schedule appointments

for me with my Senator and Congressman.

I visited Senator Kirsten Gillibrand's office as a representative of our group, and was joined by others lobbying for their respective rare diseases. We met with Senator Gillibrand's senior advisor, who spent over half an hour with us listening to our stories and our "asks." I highlighted the need for sponsorship for the Medical Equity Act, which would mandate coverage of metabolic formulas and low protein foods.

When I met with Congressman Engel, it was me alone with him and his Chief of Staff! We shared family stories, talked a bit about politics in general, and then got down to my specific concerns. Congressman Engel is a member of the Rare Disease Congressional Caucus, so I knew I had a supporter sitting in front of me. He asked me to tell him about MSUD, which I did in great detail. I then told him about this specific bill and asked him to consider co-sponsoring the legislation. Of course he said he needs to read the bill first, but did assure me that this was a piece of legislation he was likely to support. I also emphasized the need to fully fund the FDA and NIH, which he agreed was vital to the health of our nation. Unfortunately I forgot to ask for a picture!

Advocating with my elected officials was easy to do and, truthfully, fun! When people hear our stories, they want to help. I urge every one of you to try it! \$

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"I WANT TO HELP OUT, BUT I DON'T KNOW HOW"

By Jordann Coleman, Advocacy Chair



Have you ever wanted to help out the MSUD Family Support Group but were unsure about how to contribute? The MSUD Family Support Group is actively looking for volunteers to assist with advocacy and fundraising efforts.

Volunteering doesn't have to be a large commitment. Here are some tips I received from a seasoned rare disease advocate about how you can become an MSUD & Rare Disease Advocacy Champion:

1. Learn who your elected officials are and follow their voting and policies for rare diseases. Calls, tweets, emails, and visits to your officials can go a long way. Be sure to share your personal story!
 - a. If you want to make more of an impact - volunteer for the campaigns of the elected officials in your area. This will enable you to get to know their staff so they'll be familiar with you when you show up with a specific ask (request for support).
2. Get involved with or follow other organizations that are committed to rare disease advocacy such as Newborn Screening Regional Collaboratives (www.nccrcg.org/), NORD (www.rarediseases.org/), Global Genes (www.globalgenes.org/), Everylife Foundation (www.everylifefoundation.org/), or other metabolic disorder organizations (PKU or other allied disorders). Some of these larger organizations are able to train advocates and may even pay for attendance at conferences. A great way to learn how to advocate is by hitching

yourself to an additional cause.

3. Write human interest articles/blog posts on people within the MSUD community who are doing interesting and amazing things. Focus the article on what is interesting about them but include a 2-3 sentence description of MSUD. This will allow the reader to become engaged in the topic and inspire them to learn more about the disease. Make the articles positive & uplifting as well as educational and timely. Some suggested article ideas are:
 - a. MSUD Patient/Parent Profile
 - b. Submit an article to themighty.org
 - c. Find a parallel publication of interest and tie in your MSUD experience. For example, those who ran in the Denim Dash, could write a post for *Runner's World* about why they ran.
4. Set Google Alerts for news about diet trends, protein, etc. worldwide. Different alerts could lead into new conversations and opportunities to talk about MSUD.
5. If friends & family ask how they can help - encourage them to advocate for MSUD. The more voices we have talking about MSUD, the more impact we can have on our lawmakers.

It can seem daunting and intimidating to get involved with advocacy if you have no experience. The MSUD Family Support Group will give you all the support and guidance you need to get more involved. A session on Advocacy Basics will be presented at next year's symposium, and we are in process of creating a webinar with tips on getting active. Rare Disease Legislative Advocates (RDLA) is a great resource for staying informed and getting involved with rare disease issues. Some of our members went to meetings with members of Congress during the past summer recess. RDLA scheduled all of the meetings as well as helped provide information to the advocates in the meetings.

Making lives better for those with MSUD and their families depends on creating awareness and advocating for our cause. If everyone chips in a little, our impact can be substantial. §

MSUD ADVOCACY UPDATE

By Jordann Coleman, Advocacy Chair



Healthcare and issues facing the rare disease community have been at the forefront of national conversations over the past 6 months. As an organization, we joined the National Organization of Rare Diseases (NORD) and the

American Academy of Pediatrics in opposing the proposed House and Senate health care replacement bills. The position of both of these organizations is that these bills, if enacted, would be detrimental to those with MSUD and other rare diseases as they proposed to cut hundreds of billions of dollars from Medicaid, roll back key pre-existing conditions protections, and cause a rapid loss of insurance access. At the time of this article, efforts to repeal the Affordable Care Act have not been successful, but bipartisan efforts are needed to ensure adequate support to strengthen it. At the time of this writing it is unclear whether the current administration will continue subsidies which help insurers cover the costs of lower income Americans who cannot afford deductibles and copays. Another concern is that the administration is reducing efforts to promote enrollment. **It is vital that you contact your Representatives and Senators to advise them of your position on health care legislation.**

We urge our membership to call their Members of Congress to ask for their support of the following legislations:

- The Medical Nutrition Equity Act of 2017 was introduced to the U.S. Senate by Senators Grassley (R-Iowa) and Casey (D-Pennsylvania). This bill

requires coverage for medically-necessary foods through Medicaid, Medicare, the Federal Employee Health Benefit Program, and private insurance.

- The Orphan Product Extension Now, Accelerating Cures and Treatments (OPEN ACT) could bring hundreds of safe, effective, and affordable medicines to rare disease patients within the next several years by incentivizing drug makers to repurpose therapies for the treatment of life-threatening rare diseases. EveryLife Foundation, NORD, Global Genes, and Genetic Alliance are among the more than 220 patient organizations supporting this bipartisan legislation.

In addition to asking for the support of the above legislations, we also urge our U.S. membership to ask their Members of Congress to join the Rare Disease Congressional Caucus. The Caucus is a forum for Members of Congress to voice constituent concerns, collaborate on ideas, facilitate conversations between the medical and patient community and build support for legislation that will improve the lives of people with rare diseases. If your Members of Congress have already joined the Caucus, we encourage you to thank them!

Subscribe to the MSUD Family Support Group Mailing list (<http://msud-support.org/> home page) for advocacy alert email blasts. We also encourage you to subscribe and follow NORD, Global Genes, and Rare Disease Legislative Advocates (RDLA) to keep up with the advocacy issues that face the rare disease communities.

Lastly, we want to give big congratulations to the participants of the Global Genes Denim Dash MSUD Road Warriors team. The team ran/walked 5ks throughout the month of April to raise money for both Global Genes and the MSUD Family Support Group. The team raised over \$10,000 for the Denim Dash as a whole with \$5,314.56 being donated directly to the MSUD Family Support Group. Special thank you to: Ashley Bricker, Dana Chambers, Jordann Coleman, Tracy Clouser, Karen Dolins, Michelle Flanagan, Susan Mays, Chassidy Turner-Williams, and Sarah Wagner. You are all rock stars! §

FUNDRAISING

By Ed Fischler, Board Member, MSUD Family Support Group



In the 2016 survey of the membership of the MSUD Family Support Group, research for improved treatments and potential cure was rated "most important" by 90% of the responding members. As a result, the MSUD Family Support Group Board has adopted a goal to promote and support research that may result in better treatments and a cure for MSUD. Over the next two years, the board wants to accomplish the following:

- Implement a patient registry for MSUD patients and increase enrollment in the patient registry to the majority of the family support group membership.
- Promote use of the patient registry to MSUD researchers.
- Facilitate new MSUD research projects.

For the past decade, Mr. Herb Foster and a few others have raised substantial donations providing some "seed money" to get this effort started. To sustain momentum and fund the registry and new research projects, we will need to take on the responsibility to raise additional funding. Later this year the board will initiate a number of fundraising activities to support the research objectives, which may include:

- An annual fundraising appeal explaining current MSUD research, recent accomplishments, and a request for donations to continue the work.
- One or more on-line or silent auctions of donations such as sports memorabilia, art, services, vacation packages, etc.
- Other activities, such as "bowl-a-thons, walk-a-thons and other kinds of "thons", golf tournaments, and participation in other fund-raising activities championed by MSUD families across the country.

To support these goals, we need as many of our members as possible to participate in these efforts! Over the next several weeks, we will be reaching out to you to communicate how you can volunteer and help to achieve these accomplishments. Expect to receive a call for volunteers in the near future! §

20TH ANNUAL WHITE HORSE BEACH CHARITY GOLF TOURNAMENT

By Herb Foster, Board Member, MSUD Family Support Group



On July 29, 2017 Charlie O'Rourke and his committee held the 20th Annual White Horse Beach Charity Golf Tournament. This year there were 92 golfers in attendance, and for the first time in the history of this event we had a bit of inclement weather. The golfers were treated to a dinner and raffles after golfing.

The tournament raised \$5,600.00 for the Scott C. Foster Metabolic Research Fund which is administered by the MSUD Family Support Group.

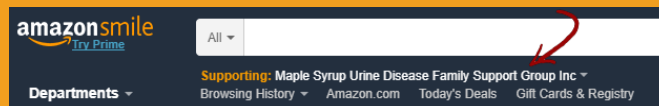
I can't remember how many years now that Charlie has been raising money for the fund but it is safe to say he has raised over \$50,000 in memory of my son. Thanks to Charlie and his committee for another successful year. §

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MSUD AWARENESS DAY

By Susan Needleman, 27 year old Classic MSUD

Now more than ever before we are hearing about National Awareness Days which are set by organizations or the government to bring attention to issues of importance. In the case of disease days, information about the disease may be posted on social media, along with other forms of communication, to spread awareness of it.



Soon you will hear about MSUD Awareness Day! I am working on having June 16th set as MSUD Awareness Day. This date was selected as it is the birthday of Cindy Blau, the first person with Classic MSUD known to the Maple Syrup Urine Disease Family Support Group to have survived.

For the past few months I have been working on the legal paperwork to make MSUD Awareness Day an official day. I am now working on getting two U.S. Senators, one from each party, to co-sponsor it. Once they agree to it, it will be official and hopefully by Jun 16, 2018, you will be hearing "Happy MSUD Awareness Day!" §

FAMILY NEWS

ADJUSTING PROTEIN IN AN ADULT WITH MSUD

By Anne Fredericks

Mom to Jeff, Variant MSUD, age 41

A little over a year ago, in January, Jeff was just not himself. He had limited energy, was not eating well, and often appeared slightly agitated. We thought that it was SAD (seasonal affected disorder) so we got out the light bar and made sure he put all the lights on when in a room. But this was not the cause. His condition got worse so we took him to see Dr. Morton, even though Jeff yelled at us for "kidnapping" him from his job at McDonald's. His blood leucine levels were slightly elevated and the ratio of isoleucine and valine was not normal. Also his tryptophan levels were very low. This enzyme helps regulate mood. We increased his Zoloft, gave him Melatonin, and 5-hydroxytryptophan (for a brief period). He also went on a sick day regime. Dr. Morton helped us understand that because Jeff is 41, his metabolism has slowed and he needs less protein. Jeff has a variant form of MSUD so he has always been able to handle more daily natural protein. We had to look at his diet and start limiting some of his snacks, many of which had 1 gm of protein. The 2 toughest changes were French fries and orange juice. A small serving of McDonald's French fries has 3 gm of protein so he now has 2 hash browns at lunch plus a salad. Orange juice is high also so he now drinks an orange/pineapple drink. We have been using some gluten free products. After these changes, we had his blood levels checked and his leucine level was within normal range, much lower than it used to be. Jeff is back to the fun guy he has always been. He sleeps better due to the melatonin. We hope that when he is in his 50's this will not start again. We also hope, as do all of the MSUD patients, that there will be a cure by then or at least a drug that allows them to consume more daily natural protein. §

GALEN CARRINGTON

Classic MSUD age 27

By Jody Carrington, Mom



Galen Carrington is a 27 year old Indiana resident who has classic MSUD. He underwent liver transplantation 5 years ago at Children's Hospital UPMC by Dr. Kyle Soltys as a treatment option for MSUD. Since surgery, Galen's health has been excellent! He graduated from Wilmington College with a Bachelor's degree in Psychology and is currently employed by the Carl Linder YMCA and Cincinnati Recreation Commission as a swim instructor and lifeguard. He has enjoyed swimming in 2 consecutive Transplant Games of America which were held in Houston and Cleveland-he brought home a total of 8 Gold Medals in all his events which included butterfly, breaststroke and freestyle!

This summer, Galen had the privilege of representing the USA at the World Transplant Games in Malaga, Spain! With over 30 countries in attendance and a strong competitor facing Great Britain, he managed to bring home 1 Gold and 4 Silver Medals! What's more important than the medals is the global support for the success of transplantations and the need to increase awareness of organ donations.

Galen emphasizes how important it is to be a part of the MSUD Family Support Group as well as the Donate Life campaign in order to successfully manage his disorder and belong to a community of others who can relate to his condition. Galen continues to strive in his swimming career in honor of his donor family. Please look for him to represent Indiana in the next Transplant Games to be held in Salt Lake City, Utah August 2018! §

MY TRIP TO ISRAEL

By Hannah Dolins, Classic Age 23

I met Avi, Dikla, and Tamar Starr last year at the MSUD Symposium in Raleigh, NC. Tamar, classic MSUD, was 2 ½ at the time, and they invited me to come to Israel and stay with them for a year. I laughed it off, thinking they were just joking, but I gave them my number so we could keep in touch. Avi messaged me on WhatsApp a few times, sending me pictures and telling me how they were doing. One day in early June, he called (at a time when the time difference wasn't so bad) and asked me when I was coming to Israel to stay with them. I was surprised, I hadn't expected him to really mean it, but he said I should come for 2, 2 ½ months and that I could stay at their house with them. I gave the phone to my mother because I didn't know what to do, I had never considered the possibility that I could agree to a vacation like this without seriously planning it in advance and figuring out logistics like what I would do if I got sick, or how I would get my formula there. My mother got off the phone with him and it was immediately decided that I would go to Israel for 6 weeks. I was blown over. It was quite a whirlwind, I have to say, to be able to agree to something like that so quickly.

I had to go soon since my school started August 28th. So within the next two weeks we got a ticket for me to fly to Israel on July 6 arriving the next day, and coming home on August 15th. My doctor Melissa Wasserstein, MD was supportive of my trip. She called the metabolic doctor that Tamar uses, Dr. Stanley Korman in Jerusalem, to let him know I was coming in case something happened, and between her and my parents, I figured out how to get enough formula in advance so I could leave the country with close to two months' supply.

Unfortunately I ended up getting sick on the fourth of July, and my levels were too high to travel so I had to push my flight to Israel back a few days. My levels came down quickly, and I was cleared to go by my doctor.

I was all kinds of nervous on my way to the airport.



Avi Starr, Tamar Starr (3.5 Classic) on his lap, Noy Widezki (14, Classic), Krish Gheravada (4 months, Classic) on her lap, Hannah Dolins (23, Classic), Eli Dworcan (2 Classic) on her lap, Yona Paretzky age 7.

It wasn't flying by myself that scared me, I'd done that plenty of times before. What if they didn't like me? What if I couldn't communicate with them? I only knew a few words in Hebrew, and they had 3 kids other than Tamar, who by now was 3 1/2, none of whom knew English. What if I got there, and was there for a week or two, and they realized they made a mistake and didn't want me there? But everyone was all smiles when I got there and I soon found out how to communicate (more than I first could) with their older kids, Noa and Maor, who don't have MSUD, and Tamar, for the most part. I was able to talk to Noa (9 years old) with the help of Google Translate, and Tamar using the few Hebrew words I knew. Most of the time I could figure out what they were saying and some of the time I had to ask Avi or Dikla. Their youngest, Roi, was easiest because he was only 2 months old. I learned a few words every day (or almost every day) while I was there.

The part that sent me panicking, for a bit, was the food. Avi and Dikla count protein for Tamar, while I count leucine. They don't have a book that tells them what is what, they just go by the food labels

on wrappers. While I sort of do that, too, the food was a bit different in Israel and I got very confused, very fast, with how I was supposed to eat. With time I became more comfortable.

Their house was very nice in Ashdod, just a couple blocks away from the beach on the Mediterranean Sea. Ashdod is a big city, and I'm sure I never even saw half of it. It was also very, very hot.

The first weekend I was there, we went to Jerusalem where we saw Sarah and Yossi Dworcan from Florida, who were in Jerusalem with their son, Eli (2, Classic). Other Israeli MSUD families came, too. It was us (me, Tamar, Noa, Maor, Roi, Avi, and Dikla Starr), Eli, Sarah, and Yossi, Shiri and Miki Widezki and their daughter (Noy, 14, Classic) and two sons, an Indian couple named Hetal and Jet Gheravada with their son (Krish, 4 months, Classic), and Faigy Paretzky and her son (Yona, 7, Classic). It was a lot of fun and wonderful as always to meet up with MSUD families!!

The Starrs also drove me into the Negev (desert) an hour away to Kibbutz Dvirah where Naftali and Eden

Zer, and their daughter Rotem (16 months, Classic MSUD) live. I loved being able to visit them, and soon I went back by train so I could spend a few days with them. I also took the train to Haifa to spend a day with my visiting cousins, and from Haifa I went to Tzfat to stay with Yuval (22, Classic) and her older brother and mother at their house. Avi had told everybody I was in Israel from the minute I landed, and gave me her mom's number so I could get in touch with her and figure out travel arrangements.

My mom wanted to take me to Israel but wasn't able to because of work. Instead, she came on August 4th, about two weeks before I was going to leave. We stayed in Ashdod for a couple days and had a wonderful Shabbat dinner with the Starr family. Then we went down to the Kibbutz because Eden wanted to meet and talk to my mother. We have cousins who live in Metulla, up north on the border of Lebanon, whom we haven't seen in a while and we traveled there to visit them. Our cousin Yael told us all about how the family moved to Metulla in the late 1800s and cultivated the land to grow the beautiful olive trees, peach trees, fig trees, and apple trees that are there. We went to Haifa and did the Bahai'i Gardens tour (forgetting to bring water bottles!), and I showed Mom a restaurant there I had been to and liked (the hummus was awesome!).

Next we went to Jerusalem. A family friend lives there, and he was really wonderful to us, driving us places, and letting us use his apartment so I could make my formula using the blender Avi and Dikla had let me take on the road with us. He also picked up the Gheravada family and brought them to his apartment for tea. It was wonderful getting to talk to them and know them better and understand more of what was going on with them. Noa Peleg (17, Classic) and her family traveled to Jerusalem to see us and treated us to a wonderful dinner in a restaurant overlooking the Old City. In Tel Aviv, where we stayed next, Miki Widezki arranged for us to stay in a hotel, and the entire family came to spend an afternoon with us there. And then, sadly, my trip came to an end.

It was wonderful to see how well connected these families were, to spend time with them, and talk about how we were all doing. I can't wait to go back! §

SWEET ODYSSEY

By Idario Santos



Artur Santos was born on January 18, 2002, the second son of Soraya and Idario Santos. They never imagined how their lives were about to change as the second baby arrived.

It was clear from the early days that something was wrong. Artur stopped eating, became lethargic, and began having spasms.

Initially Artur was diagnosed with Leukodystrophy, but his father did not believe this was the correct diagnosis. He then insisted on obtaining other professional opinions and finally his son was properly diagnosed with Maple Syrup Urine Disease – MSUD – at the age of 31 days. Many were the challenges that they faced. They went financially broke in a very short period of time. Literally, their lives turned upside down. “Sweet Odyssey” tells the story of this family’s journey.

As Dr. Kevin Strauss director of the Clinic for Special Children says on his book-forward message “Sweet Odyssey tells a similar tale when compared to the legendary King Arthur. The only exception is that Sweet Odyssey is a true story and the main protagonists young “King Artur Santos” and his father Idario Santos are real-life heroes made of flesh and blood. In Sweet Odyssey, you will learn that the challenges faced by the mythical King Arthur pale in comparison to those overcome by one courageous young boy and his family...”

The Santos family traveled all over Brazil looking for better treatment for their newcomer. Their luck started to change when the MSUD Family Support Group invited them to the 2004 bi-annual symposium in Atlanta, GA. A little over one year later, Artur Santos became the first Brazilian to receive a liver transplant and was freed from MSUD. Since then, the Santos family advocates for those in need.

Sweet Odyssey co-author Vinicius Santos, Artur's brother, states, “In Brazil, only a few diseases are tested for

through the newborn screening program and diseases like my brother's are not detected. Even worse, some other countries do not even have a newborn screening program..."That's why his father wrote a law entitled "Artur Bucar Santos Law" which was presented to the Brazilian House of Representatives. The law is in the evaluation process and is protocolled as PL7674.

Dr. Harry Hannon, former Chief of the newborn screening branch at the Centers for Disease Control and Prevention says, "The reader of Sweet Odyssey learns that life's struggles require an enormous amount of faith and perseverance to perhaps achieve success -- no guarantee, but certainly one gains greater strength for future challenges. I strongly recommend this book to all parents, grandparents, newborn screeners, and healthcare professionals as a must read!!

"The fight is not over," Says the co-author Vinicius. Children suffering from genetic disorders still need our help. 50% of proceeds from Sweet Odyssey will be donated to the Clinic for Special Children.

Short Biography



Born in Prata – PB, Northeast of Brazil, Idario received his college degree in 1993.

He works as an agronomist in a vibrant city of Petrolina – PE. Early in his career Idario Santos was awarded a Certificate of Excellence by the

Brazilian Board of Agronomy, known as CREA due to his important work as a consultant to fruit exporters of the São Francisco River Valley.

Author of the true story Sweet Odyssey, Idario Santos launched his book in Portuguese at the American Chamber of Commerce in São Paulo – Brazil. The book is now available in English via www.amazon.com or in bulk via www.sweetodyssey.net.

Idario Santos wrote this book in hopes that it will be used as an inspirational tool and that it will help children and their families suffering from MSUD and other genetic diseases. §

OUR STORY

By Sarah Dworcan

Mom of Eli, Classic MSUD Age 2

On April 23 2015, our precious firstborn son Eliyahu Tuvia was born in Jacksonville, FL. All seemed well and we took our bundle of joy home. At four days of age, we took him for his first doctor's visit and he was, thank God, gaining weight and doing well. The doctor cleared him for his Brit Milah - circumcision.



You can imagine our concern when over the next few days he stopped eating as well as he had been and we started noticing changes that didn't seem right. It was as if, without us realizing, a dark cloud was slowly closing in.

At 4 am Wednesday morning (the day before he was to have his Brit), while feeding him, I looked

down and my baby wasn't breathing. I can't begin to describe the intense overpowering feeling of fear. In those few moments I experienced the feeling no parent should ever experience. I shouted for my husband who was up in a moment and told me to lift the baby. As I did so, he projectile vomited out a significant amount of blood. In fear and panic, we called 911 and rushed our 6-day-old baby to the emergency room.

To our surprise, without performing a blood test the emergency room physician told us that this could sometimes happen, that our baby was fine and we could go home. We were confused and concerned to say the least. At a follow-up appointment with our pediatrician later that day, we expressed our concern and shared that we had been noticing different things that seemed strange to us. The doctor, without even walking over to look at Eli, kept telling us that our baby was fine. From sheer exhaustion and this underlying sixth sense that something was wrong, I broke down crying. I tried to explain that Eli was fighting not to eat and would cry and cry while doing "swimming motions". Without hesitation, he responded in no uncertain terms: "Mom if you're not going to be strong you're not going to be any good for your baby." Defeated, scared and confused we went back home.

That day our Eli refused to eat - he just slept. We didn't know it then but he was already drifting into an encephalopathic, comatose state. At 5 pm that afternoon we got an urgent call from the state laboratory telling us that our son's State Newborn Screen had come back irregular and we were to rush him back to the ER. This time when we entered the same pediatric ER we had visited at 4 am that morning, a very different scene met our eyes. It was a scene out of movie; a team of doctors and nurses were waiting for us, and everything we had been trying to express over the past 12 hours was now golden. Every piece of information mattered. They hooked our tiny Eli up with IV's and blood and transported us with lights and sirens in a mobile ICU to the closest metabolic center for the state, the Shands University of Florida children's hospital, two hours away in Gainesville.

It was there, in the P-ICU, that our precious Eli was diagnosed with MSUD.

Unbeknown to us, he was so sick that within only a matter of hours his body would have completely shut down due to overwhelming toxicity. Our Eli's life was spared by mere hours. It was only months later that we learned how miraculous it was that we received the screening results when we did. All Newborn Screening tests for the entire state of Florida are run in Jacksonville. Most tests take 8-10 days to receive results. We received them on day 6. Had we received them on day 7 or been living down south where we had moved from the year before, the extra night for shipping would have God forbid changed the ending of our miraculous story to an unimaginable one.

Life for Eli will never be the same as it is for a regular kid. Although he is thank God developing and growing normally, every day is a challenge and a journey. Today, at 26 months old he has endured 6 lengthy hospital stays, been in metabolic crisis twice and now has a gastric feeding tube (G-Tube) to help maintain his protein levels. He will never be able to eat most foods that other kids and adults enjoy. Any slight illness can cause his body to break down its own protein and cause a metabolic crisis with a potential for severe brain damage. We hope and pray that God will protect our special child and that very soon the cure for MSUD will be found.

Our Eli is a living miracle and a truly incredible little man. He has outshone anything we read in the literature. He is reaching beyond his milestones and we couldn't be more grateful to God.

We have since learned that many weren't as blessed and as fortunate as we thank God are. MSUD is so rare that often doctors aren't able to diagnose it based on the symptoms shown, and many babies don't survive. If they do, it is often with significant brain damage. We are blessed to live in a country where every child is given the Newborn Screen Test - unlike our country of birth, South Africa. It was thanks to that test that our Eli was saved.

However, this is something we should have

known about even before Eli was born. Like all religious Ashkenazic Jews, we underwent a genetic screening test called Dor Yeshorim before marriage and were told that we were genetically compatible. Little did we know that we were both carriers for an extremely rare, but already known, disease that was not yet included in this panel.

We have since started an organization, Jnetic - to create awareness and education on the importance of comprehensive testing for Jewish genetic diseases.

We encourage the following for our community and others:

- All known life-threatening diseases and mutations should be tested for. This includes Tay Sachs, ML4, cystic fibrosis, glycogen storage disease, and 35 additional diseases.
- As with any other personal medical information, results should be available and explained by a

genetic counselor upon request by the patient.

- The stigma and fear factor associated with carrier status should be broken. The answer to this is: Education, education, education. There is no shame in being a carrier; every person in the world is a carrier for at least 5 different mutations.
- When both parties are carriers, there are ways to have healthy children to the best of science's ability.
- MOST importantly: We all have the right and obligation to be informed and educated.

For more information please visit www.jnetic.org. Please feel free to reach out to us at info@jnetic.org.



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INDIGO CHARLIE MAYS

Variant MSUD Age 4

By Susan Mays

Meet our girl Indigo Charlie Mays. After a smooth pregnancy and delivery, she was born on July 21st, 2013 in Seattle, WA. After spending just over 24 hours at the hospital, we headed home to start our life as a family of three. My husband Adrian and I couldn't have been happier! She was so perfect!



Indie took to breastfeeding well, and for the first two weeks of her life I fed her on demand. When she was two weeks old we took her in for a routine well child check-up. She was doing well, but our doctor mentioned that we would need to have her second newborn screening (NBS) completed which required the heel prick test. In Washington, I learned, there are always two NBS tests performed: one at 24 hours and one at two weeks. I remember asking my doctor if a second test was overkill since the first one had come back fine. She told us sometimes more mild cases are picked up but that it was very unlikely. We agreed to do it and for the next couple of days we didn't think any more about it. Indie was still doing so well.

Flash forward a few days and then we got a call – the call

– from our doctor asking odd questions about Indie and how she was doing. Our doctor asked if Indie was feeding okay, seeming lethargic, or otherwise seeming “off”. She then let us know that she had tested “presumably positive” for a very rare metabolic disorder called Maple Syrup Urine Disease. She went on to give us a little more information about the disease and some next steps, but kept it quite brief. To be honest the rest of the conversation was a total blur as we had no idea what to think and what this could possibly mean for our perfect little girl. The next thing I really remember was being told that our healthy, hungry, happy infant would need some further testing and that we needed to take her into Seattle Children's hospital right away. It was a Friday afternoon, so unfortunately we had to wait until Monday to get the results. That weekend was one of the hardest weekends, waiting, wondering, pondering what this diagnosis could mean. How could it be possible? What does this mean for her life?

Monday morning came and we got a call from the genetic counselor. Indie did in fact have MSUD. Even though we knew there was a chance she had it, it was still such a shock because she was showing no signs of it. So, Indie was officially diagnosed with a mild form of MSUD at 3 weeks old. While her levels at diagnosis were not incredibly high, they were outside the normal range for her age. Over the next year, we regularly met with her new metabolic team at the University of Washington and started her on a combination of formula and breastmilk and she has thrived. We were reassured that she will always be our perfect little love, she'd just need some extra care.

Fast forward a few years and she is now a rambunctious 4 year-old, goes to preschool a few days a week, is starting her first season of soccer, and enjoys playing dress up with her little brother. Indie loves her formula, for which we are so grateful. Her current protein allowance is around 12 grams of protein a day. She's a very healthy, happy girl. We have been so lucky that although we have had a couple of visits to the ER each year for hydration and to have her levels checked (due to gastrointestinal illnesses), she has never needed inpatient care.

We feel so incredibly blessed to live in a state where there are two NBS tests performed. It's the reason I'm so passionate about NBS, because without it, our life would look completely different. §

MSUD FAMILY SUPPORT GROUP NEWS

FROM THE CHAIRMAN'S DESK

By Ivan Martin



▲ NIH meeting in Bethesda, MD from left to right: Dave Bulcher (MSUD Treasurer), Sandy Bulcher (MSUD Vice President), Phoebe Saunders, Jennifer Saunders (MSUD board member), Tom Eggerman MD, PhD Program Director, Division of Diabetes, Endocrinology, and Metabolic Diseases, Mary Kathryn Martin, Ivan Martin (MSUD President), Herb Foster (MSUD board member), Ed Fischler (MSUD board member) and Karen Dolins (MSUD secretary)

On July the 21st the MSUD Board of Directors traveled to Bethesda, Maryland for our annual Board meeting. We stayed at the Hyatt Regency in Bethesda. The location and hotel was selected for two reasons: We would be meeting with a scientist from the National Institute of Health (NIH) and we wanted to check out the hotel as a possible future Symposium site.

On Friday afternoon we met with Tom Eggerman, MD PhD, Program Director of the Division of Diabetes, Endocrine, and Metabolic Disease at the NIH. Our goal was to be better informed about the workings of the NIH and the way in which they secure funding for research. He advised us that the best way to get financial support is through Congress. As an example he noted that funding for Type 1 diabetes research is mandated by Congress. He recommended that we take this approach, either by contacting our own congressperson or those who serve on a specific committee. With a mandate to fund research related to MSUD, the NIH could then put out a request for

proposals (RFP). He noted during our meeting that for the first time the FDA has approved gene therapy for leukemia. He noted that there is currently no research specific to MSUD in their rare disease portfolio. We were pleased and felt our time with him was well spent.

After our meeting with Dr. Eggerman we convened for our board meeting, which we continued the next day. Our first order of business was the election of officers. The following officers were elected:

- President: Ivan Martin
- Vice President: Sandy Bulcher
- Treasurer: Dave Bulcher
- Secretary: Karen Dolins

The remainder of the meeting focused primarily on two areas: finalizing a business plan and developing a patient registry.

A clearly conceived business plan is essential to moving our organization forward. Our business plan identifies 4 broad goals:

1. To connect with families and professionals
2. To promote research
3. To engage in advocacy
4. To develop a fundraising plan which will allow us to achieve our goals

Development of a patient registry is an important step in promoting research for MSUD. The board decided to partner with Emory University and their NBS Connect which has developed a registry. Sandy Bulcher and Karen Dolins will be meeting with Dr. Rani Singh who spearheads this effort at Emory to finalize the details. Please see the article on page 16 which further describes the Registry.

Thank you for your continued support and don't forget to mark your calendars for the next Symposium in Pittsburg, Pa. on June 28th thru the 30th 2018. I hope to see you there! §

FROM THE EDITOR

Karen Dolins



Hello to my MSUD family! The power of this family hit home this summer, when Hannah (Classic MSUD age 23 years) and I visited Israel. The trip came about because Hannah was invited to stay with Avi and Dikla Starr, who attended our Symposium last year with their daughter Tamar (Classic MSUD age 3 ½ years). She spent 5 weeks with them and traveled throughout Israel to visit other MSUD families (see Hannah's article describing her trip on page 6). I joined her for the last 11 days. We received warm welcomes from everyone we met. Perhaps most poignant, we met a couple from India who were in the country when their son Krish (classic MSUD age 4 months) was born. Knowing that treatment in India is poor, they were able to extend

their visa and hope to get a liver transplant.

In addition to editing the newsletter, I also serve on the Board as Secretary and have been working to expand our advocacy efforts. Please read the articles describing these efforts and learn how you can help. Also included are research updates and plans for fundraising, which will enable us to support promising research projects.

Thank you to Susan Mays, Sarah Dworkan, Jody Carrington, Hannah Dolins, and Anne Fredericks for your family stories. Remember, we all enjoy hearing each other's stories and important events. Please don't hesitate to contact me at karen.dolins@yahoo.com if you'd like to tell us yours.

Finally, a big thank you to our advertisers Cambrooke Foods, Vitaflo, and Nutricia for their continued support. §

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MSUD SYMPOSIUM 2018

SAVE THE DATE!

WHEN: June 28-30, 2018

WHERE: Doubletree Greentree, 500 Mansfield Ave Pittsburgh, PA 15205 (located 3 miles from downtown Pittsburgh)

WHO: MSUD families, professionals, researchers, and vendors from the US and throughout the world

WHY: Increase knowledge of MSUD including medical and dietary management, transplant option, research updates, psychosocial issues, advocacy and more. In addition, it is an opportunity to meet new families and renew old friendships. Incorporate the symposium as part of a family vacation!

SPEAKERS: To be determined

HOTEL RESERVATIONS: You can make your hotel reservation now via the link on the MSUD website www.msud-support.org or call the hotel at 412-922-8400 and mention MSUD when you make your reservation. Room rate is \$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.

HOTEL AMENITIES: The hotel boasts complimentary shuttle service to and from the airport, free parking, 3 restaurants, refrigerators in each room, indoor and outdoor pool and fitness center.

WHAT'S NEW:

- Two full days of speakers/topics.
- Half day transplant symposium hosted by Pittsburgh transplant team.
- As in the past, attendance at the conference is free, but this year there will be a charge of \$25 per person or maximum of \$75 per family to help defray the cost of food. This will enable us to invest more on research projects.

MEALS: Low protein food will be available for those on diet.

TRAVEL ASSISTANCE: It is not yet known whether or not funds will be available to assist with travel expenses. More information to follow in early 2018.

QUESTIONS: Contact Sandy Bulcher, MSUD Symposium Coordinator, at 740-972-5619 or sandybulcher@gmail.com

SCHEDULE:

(times subject to change)

Thursday June 28th
7-9PM

Registration/reception

Friday June 29th
8AM-4:30PM
General session

Friday June 29th
7-9PM
Social event

Saturday June 30th
8AM-3PM
General session



RESEARCH

METFORMIN AS A POSSIBLE THERAPEUTIC AGENT IN THE TREATMENT OF MSUD

By Karen Dolins and Arvind Ramanathan



The MSUD Family Support Group has provided funds to Buck Institute for its preliminary studies investigating metformin, a drug commonly used to treat diabetes, and the impact it may have on the metabolism of branched-chain amino acids (BCAAs) including leucine.

They also plan to investigate the use of Triacetoacetin (TAA), a substance which provides molecules which are generated during normal metabolism and which are deficient in individuals with MSUD.

BCAAs play a critical role in the development of muscle tissue. Leucine is a key trigger for muscle protein synthesis and is also used as a fuel source by the muscle, particularly during high intensity exercise. Abnormalities have been observed in the muscle fibers of mice with intermediate MSUD (iMSUD), and have also been observed in critically ill children with classic MSUD.

As an initial step, the researchers have developed the tools they will use to demonstrate an effect of treatment on muscle fiber size and muscle strength. They have been able to observe that iMSUD mice have fewer Type 1 "slow twitch" muscle fibers which are used for endurance types of activity. In contrast, they found increased levels of Type 2 "fast twitch" muscle fibers which rely less on oxygen for their fuel and are used for quick bursts of activity.

But on the whole, the ability of the iMSUD mice to utilize glucose was diminished, suggesting an overall physiological defect in MSUD. They also found that the muscles of iMSUD mice were weaker than those of mice without MSUD. After treatment with metformin, iMSUD mice had lower levels of the keto acid which accumulates when leucine levels are high, but had similar levels of leucine. Very encouragingly, treatment with metformin reversed the loss of Type 1 fibers associated with the iMSUD mice. And in conjunction, metformin also restored muscle strength and glucose physiology of these mice. This suggests a promising therapeutic outcome for metformin in the future. The iMSUD mice are short lived with a survival of about 2-3 weeks. The team is now looking at the effect of metformin injections on the lifespan of iMSUD mice. Finally, as the skeletal muscle of iMSUD mice have insufficient biochemicals used in aerobic metabolism, the team will also test ways of supplementing these biochemicals by treatment with TAA as a precursor drug. §

NBS-MSUD CONNECT: ADVANCING MSUD RESEARCH AND MORE

By Lauren Youngborg, MS, CGC
Genetic Counselor, NBS Connect

NBSCONNECT.ORG



Rare disease registries have received attention in recent years because of the many ways in which they can benefit the rare disease community. Experts agree that registries are an important asset to professionals, patients and families, alike.

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. NBS Connect is a web-based, self-report patient registry for people affected by certain disorders included in the newborn screening panel.



NBS-MSUD Connect will help those with MSUD by:

- **Improving quality of care:** By collecting data on diagnosis, treatment, symptoms, outcomes, barriers to care, and quality of life, NBS-MSUD Connect aims to eliminate gaps in service and improve access to care while establishing best standards of practice for clinical management of MSUD.
- **Contributing to research:** Rare disease research and drug development can be difficult, expensive, and time consuming. Well-organized registries attract the attention of the research community by reducing or eliminating some of these barriers. For example, registries can expedite the identification of patients who may be interested and/or eligible for participation in clinical trials so that effective drugs can be studied more efficiently. Natural history data collected through registries can contribute to the scientific platform upon which drug development and other research can be built. By creating and maintaining an NBS-MSUD Connect profile, registrants support the development of genotype-phenotype studies, research cohorts, protocols for clinical studies and much more.
- **Prioritizing the patient/family perspective:** When participants in NBS-MSUD Connect share their experiences, they help research funding agencies, pharmaceutical companies, regulatory agencies, and patient organizations learn how to best serve the MSUD community and focus on the issues that are important to patients and families.

NBS Connect is also designed to serve as an internet-based support group that connects patients and provides information and tools for living with and managing NBS diagnosed conditions. NBS-MSUD

Connect can help registrants:

- **Become empowered to make more informed healthcare decisions:** NBS-MSUD Connect registrants have access to a variety of resources including education materials, information on the latest research/clinical trials, recipes, interactive health tracking systems, "Ask an Expert" tools, and more.
- **Connect:** NBS-MSUD Connect registrants can get to know other patients and families who are living with MSUD via our active social media platforms (Facebook and Twitter). This allows participants to collaborate, share, and learn from one another.
- **Learn about exciting, new initiatives:** The NBS Connect registry team is constantly searching for ways to better serve the patients and families participating in the registry. Most recently, NBS Connect is exploring avenues to offer quick, accurate and affordable genetic testing to all NBS Connect participants. This testing is essential to further research of MSUD as it can help advance understanding of disease progression and allow for the development of treatments that target an underlying genetic cause. Stay tuned for more information on this and other exciting new projects!

To ensure that the MSUD community experiences all the potential benefits that rare disease registries can offer, NBS-MSUD Connect must continue to grow with complete and up-to-date information. To this end, we encourage all adult patients and parents/guardians of individuals affected with MSUD to visit the website at nbsconnect.org and register or update their participant profiles.

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:
Dr. Rani Singh, PhD, RD, LD; Grant #UH7MC30772 \$*

IN THE PROFESSIONAL JOURNALS

Summarized by Karen Dolins

A Patient with MSUD: Acute Management with Sodium Phenylacetate/Sodium Benzoate and Sodium Phenylbutyrate

Köse, Melis, et al *Case reports in pediatrics* 2017 (2017).

This paper documents the experiences of doctors in Turkey treating a 19 month old boy with classic MSUD in a metabolic crisis. The boy was initially treated with formula through naso-gastric (NG) tube feeds. His level of consciousness decreased and he was placed on hemodialysis. While his leucine level decreased significantly with this treatment, he developed a fever and his levels rose again. The hemodialysis was discontinued due to a likely infection and a clogged catheter, and he was given sodium phenylbutyrate intravenously. After 24 hours of treatment with sodium phenylbutyrate, he developed full consciousness. Treatment continued via NG tube and blood leucine levels normalized. He continued to do well at follow up 1 year later.

Twenty novel mutations in BCKDHA, BCKDHB and DBT genes in a cohort of 52 Saudi Arabian patients with maple syrup urine disease

Imtiazi, Faiqa, et al. *Molecular Genetics and Metabolism Reports* 11 (2017): 17-23.

MSUD affects all ethnic groups with an estimated frequency of 1/185,000. The incidence in the Mennonite population is much higher (approximately 1/180). A higher than typical incidence is also reported in Ashkenazi Jews and in Portuguese gypsies. According to the authors, the estimated incidence of MSUD in Saudi Arabia based on newborn screening results is approximately 1/21,490 live births. This study reports on genetic testing done on 52 individuals with MSUD born to consanguineous parents (closely related). A total of 25 different mutations were observed in 3 genes coding for the enzyme complex involved in MSUD, only 5 of which had been previously identified.

Letter to the Editor: First Domino Liver Transplant in Saudi Arabia.

Mohammed Saad Al Qahtani et al *Experimental and Clinical Transplantation* (2016) 6: 691-692

This letter describes a domino transplant in which a 13 year old boy with MSUD received a liver from a boy who died of a head injury. His liver was then donated to a 55 year old woman with cirrhosis. Branched-chain amino acid levels were normal by 20 days. The boy did experience some post-operative complications which were resolved. Long term follow up was not described. §

IN PHOTOS



▲ Benefit auction in Shiloh, Ohio from left to right; Timothy Martin Classic MSUD age 15, Quinton Martin Classic MSUD age 5, Dr Kevin Strauss of Clinic for Special Children, and Jordan Bulcher Classic MSUD age 27



Celebrating Cindy Blau's birthday with a picnic at a park in Columbus, Ohio: Cindy Blau, Classic MSUD age 58, Jordan Bulcher Classic MSUD age 27 and Tia Vaidya Classic MSUD age 3.

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