From the Editor

Our 2016 FOD/OAA International Metabolic Conference in Westminster, Colo. on July 8 – 9, 2016 was a huge success. We had over 300 attendees for our day and a half conference. Many also made the week a family vacation in the beautiful Rocky Mountains. Thank you to my co-organizer Kathy Stagni, OAA executive director, for being such a fantastic teammate.

Thank you to The Metabolic Clinic at Children's Hospital Colorado and the University of Colorado School of Medicine for being our Premier Sponsors. And thank you to all of our sponsors. We could never have offered this phenomenal opportunity without their financial assistance.

All of our speakers did a wonderful job and graciously spent several hours answering questions from our attendees that came to not only learn, but to network with others living with a similar disorder and challenges. Check out their presentations. We’re going to take a break for awhile, but once 2017 arrives Kathy and I will be back planning for another fantastic family conference.

Always remember—whether you’re a family member or a professional, we are all striving to create awareness, education, screening and diagnosis, long-term clinical treatment, and research—by sharing your story or your expertise...

‘We are All in This Together’

Take care... Deb Lee Gould, MEd, Director
Editorial

Welcome to **FOD Awareness Month** around the world! Share your Family Stories with family, friends, co-workers, professionals and everyone else that is willing to listen. Please also share our banner on your social media sites and purchase some of our Awareness items and wear them with Pride! You can use our **FOD AmazonSmile link** when you shop online—we benefit from all of your purchases all year round by earning a certain percentage of your total purchase! Donations to the FOD Group are tax-deductible and help us as we plan for our future services & conferences. *Please keep us in mind* if you are able to donate throughout 2016 and beyond!

The mission of our group is to connect, share experiences, and provide support through our newsletters and online groups. However, over the last few issues, we have been struggling to provide new content for our newsletters. I often post in the groups asking for newsletter contributions, and members will agree to write something—but then I often don’t receive it. So if you’d like to **submit** something, *please do!* Our next **deadline** will be **Dec. 15th**, for the Jan 2017 issue.

What could you contribute? Families: We welcome *all* new or updated Family Stories and pictures, and we especially encourage families dealing with the less common FODs such as HMG, GA2, Carnitine Uptake Defect, TFP, and CPT 1&2 to share their experiences. We’re also always looking for more low-fat recipes, poems, ‘Silver Linings,’ pictures, and ‘Reach for the Stars’ accomplishments of our kids, adults, and families.

Professionals: We need to hear from you too! Articles about new medical research, nutritional information, or counseling and coping are always appreciated.

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Learn more at [www.fodsupport.org](http://www.fodsupport.org)
Invisible Disabilities

ISABELLE SHARON STAHRFISHER, AGE 18, MITO/FOD
FORT WORTH, TX • ORIGAMI OWL CONSULTANT

Growing up, I always saw FOD like how I see my hair: frustrating, changes from day to day, and in the heat of the summer, downright unbearable. However, it is a part of me that I wouldn’t trade because when I put my mind to it (and with help from my mom) I always could see the blessings it brought. I learned how to advocate for myself, listen to my body, and trust myself when it came to certain things I knew to be true. I would love to tell parents and doctors that FOD never restricted me, but that wouldn’t be true.

This last year has been particularly difficult on my body as I finished my senior year of high school. I ended up crying at the Endocrine’s office in the middle of the school year when my doctor told me that I wouldn’t be able to work and be able go to school at the same time; something I knew but didn’t want to hear.

Then my Endocrine said something to me that I hope I never forget. He went over my medical history and explained how incredible it was that I am even alive, let alone graduating high school. He told me that I should be proud of my work. He acknowledged that my journey had been extremely hard and that I had survived so many battles and what I face now are just pains from the scars catching up with me.

There are many things that are hard when it comes to having a disability, especially an invisible disability, yet I think sometimes we are hardest on ourselves. I know my family goes from one extreme or the other: We either focus on the disability or the invisibleness of it. I think part of it comes down to the comparison of pain: “I may not be able to work in college but at least I can go to college.” While other times we don’t want others to pity us or a desire to achieve normal: “I’m just like anyone else. I’m normal.” These mindsets are detrimental physically, emotionally, and mentally to children, teens, adults, families, and the common bystander. By comparing pain or difficulty, we are devaluing the truth in our journey and others’ journeys because life just hurts everyone in a different way.

It has taken me many years and, actually, I have only recently come to this understanding. I’m not a disabled writer, disabled speaker, disabled activist, or a disabled woman. I am a writer, speaker, activist, and woman who has a disability and a journey that has its ups and downs. Our world will never understand what it is to have an invisible disability. They will never have compassion or sympathy in their words or actions until we speak in earnest. My disability doesn’t define my life but my story wouldn’t be mine if I didn’t have Mitochondrial Disease.
What a wonderful conference. I feel so blessed to be part of this group. It was a weekend of meeting new families and reconnecting with old friends who understand the day-to-day challenges of managing this disorder. I left the conference feeling a little more hopeful that better treatments are on the horizon and that I am not so alone in my corner of the world. Thank you so much Deb Lee Gould for bringing us all together.

Marilyn, adult SCAD, Victoria, Canada

Grateful to meet so many dedicated parents and caregivers as well as affected children and adults at the conference! It was nice to see how we are similar, see how we are different (even in the same disease group) and work toward supporting one another. That’s the goal, right?

If you weren’t able to attend, please feel free to ask any questions! I’m sure there are so many attendees who would be happy to share knowledge, opinions or info. Till 2018! Thank you Deb Lee Gould for all your dedication and hard work. You have crafted an avenue for healing, compassion, information and education. Quite a miracle really. Much gratitude! I’m sure I speak for many.

Stacie, partial CPT 2 mom, MI

Conference Comments

2016 Conference Extras
Please check out the Conference Agenda and Ending ceremony video
Sorry we couldn't make it to the second day of the conference, but we loved the first day! Fantastic speakers and great information. As we were going through the lunch buffet line yesterday we heard adults and kids talking about how many fat grams were in the foods and it hit me we are not the only ones doing this! Sometimes it feels that way. It was nice to be in a group that truly understands. Thank you! See you in 2018!

Jessica, LCHAD mom, CO

I just hope people will recognize how important these conferences are!! We can talk face to face with these professionals! We can ask our questions and get immediate responses. Most importantly we can talk about our fears and little joys and triumphs and cry and laugh with each other. I always leave these conferences feeling so much more connected to those of us going through this together.

Gwen, GA 2 mom, MA

The FOD conference is an experience that is hard to describe. For me It is like a family reunion with people who speak your language, have shared experiences, and understanding that I NEVER find in our daily life. In a short time I feel as though I have attended medical school, had peer emotional counseling, and have participated in LCHAD Mom Therapy. It seems like those lonely early years were so long ago. These kiddos are amazing and the medical professionals who have invested their careers for them are superheroes in disguise.

Lynne, LCHAD mom, TX
Articles of interest

• Clinical relevance of short-chain acyl-CoA dehydrogenase (SCAD) deficiency: Article from sciencedirect.com

• Potentially Harmful Drugs for Mitochondrial Patients: Article from mitopatients.org

• Table of Reported Drugs with Mitochondrial Toxicity: Table from mitoaction.org


• Nord Physician Guide to Mitochondrial Myopathies: nordphysicianguides.org (Free)

• Mitochondrial Global Networks: www.google.com/maps

• Social Security help for loved ones with GAII: www.disability-benefits-help.org
Fundraisers

My name’s Nicole Lackenby, I’m 25 years old from England. I decided to run the Edinburgh Marathon on 29th May 2016. I had never ran a marathon before but it’s something I’d always wanted to do so I decided to run for a cause that is close to my family’s heart.

My parents are both carriers of the gene for a Neonatal Glutaric Aciduria type-II (Neonatal GA2).

Twenty two years ago, I had another sister called Chloe who had Neonatal GA2 and sadly only lived for 1 week. I sought out the FOD Support Group as I wanted to support them to raise funds for the training of new FOD Professionals, for future FOD Research and also to provide grief support for families who have lost children to FODs such as Neonatal GA2.

I have nearly finished collecting in my sponsorship money so will keep you posted once it’s all in and counted and ready to transfer to this amazing charity!

Thank you for taking the time to read my family’s story and also sharing your own.

Nicole x
‘Max the Monkey has MCADD’

Nearly a year ago, we were very stressed out and struggling to get our 2-year-old with MCADD to eat much of anything. Every meal was a challenge, nearly all of our plates were hurled off our dining room table and broken—it was just awful! It went beyond simple 2-year-old pickiness for us because we knew how important regular meals were to managing our son’s MCADD.

I tried reading lots of children’s books I found at the library about why our bodies need good food, but was really longing for something that started a conversation with him about why his body is special and really needs food.

I approached Laurie Weiss Bernstein and Joanna Helm, just two of the many amazing staff members in the metabolic clinic at Children’s Hospital Colorado, about writing a children’s book about MCADD to help my family and others like us. They loved the idea and last spring/summer, we wrote Max the Monkey has MCADD.

We started reading an early draft, printed out at home and stapled together, with our son last summer just after he had turned 3, and it instantly made a difference. He now has words that help him understand MCADD on his level and he seems to have a much better understanding of why he needs to eat often in order to have enough energy, just like Max does in the book.

Our five-year old son (unaffected) has also really benefited from the book. We no longer have the argument at bedtime about why his little brother gets a snack and he doesn’t. He knows that his brother needs it because he has MCADD. Now he helps us make his brother’s snack and encourages him to eat, right along with my husband and me!

Now any family can buy a book that explains MCADD in kid-friendly terms, written in engaging verse and accompanied by beautiful illustrations and yummy recipes. Please consider ordering one for your family and maybe even order an extra copy to take along to your next metabolic appointment that can be passed on to a family just receiving an MCADD diagnosis with their infant.

You can follow this link to purchase Max the Monkey has MCADD. If purchasing the book is a financial hardship for anyone, please email me at KayLKelly@gmail.com and I will send you one myself.
Rare New England (RNE) was formed from the integration of Mito New England with advocates for other rare diseases and complex disorders. Over the last three years, advocates in New England realized rare disease patients and families could more successfully advocate for their needs, and educate others on their conditions, if the rare disease communities began coordinating their efforts. To this end, Rare New England was created to offer regional resource for all patients, families, and others touched by rare and complete medical disorders in the New England area.

Rare New England's mission is to bring together New England patients and families touched by rare and complex disorders to provide awareness of available resources and offer educational opportunities to improve patient quality of life.

RNE provides education about issues affecting rare and complex patients and their families to the medical community, the education system, regional legislators, workplaces, and others. We address topics such as complex care coordination, ADA and IEP accommodations, medical insurance problems and more.

RNE can be found online at: www.RareNewEngland.org, Julie Gortez RN, julie@rarenewengland.org

Chelsea Hamner

Some of you are already aware, but for those who are not, Chelsea passed away May 29th, 2016.

We shared much of our recent (past two years) struggles with her health, but she is now free. Thank you all for your many years of support.

—Sonia Whitman-Schemel, Mom to 23 year old Chelsea Hamner, LCHAD (Mom to 3 year old Grayson), Oklahoma

‘There is no grief like the grief that does not speak.’
—Henry Wordsworth
The FOD Group is excited to announce a partnership with Rare Patient Voice LLC!!!!

Rare Patient Voice, LLC was formed to provide patients and caregivers with rare diseases an opportunity to voice their opinions through surveys and interviews to improve medical products and services.

Join the community and earn a $5 gift card of your choice at www.rarepatientvoice.com/sign-up. Your information is totally confidential, and your name is never shared. You’ll be invited to participate in surveys from time to time, where you will earn cash rewards and provide your input to improve medical products and services.

Anywhere in the referral area indicate the FOD Group and we will also receive a $5 donation for each qualified applicant. Rare Patient Voice invites patients with a variety of medical conditions to join their panels, so share this information throughout your circle and have anyone (14 years of age or older) with a disease, disability, syndrome, disorder, etc. or caregivers sign up and list the FOD Group as the referrer and make donations from Rare Patient Voice LLC grow!!!

For more information about Rare Patient Voice contact:
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410-218-0527

EXPANDED NEWBORN SCREENING SAVES LIVES!

‘We are All in This Together’
FOD Group Finances

The 2015 FOD Group 990 tax return is on our Financial page.

The bulk of Expenses are for monthly phone, website fees, supplies, Conferences, and for our Grief Consultation office (rent, advertising, etc) to offer pro bono grief support to local Bereaved Parents & Families (and also via Skype/phone to FOD Families around the world). We also donate FOD funds from undesignated donations to various FOD related entities (ie., for NBS issues, outreach) to support their efforts.

All Undesignated and Grief Consult donations are deposited into the General Fund or Gen Trust Fund, as are Bracelet and Ribbon Sales, Cafepress.com, iGive, Goodsearch, and any donation that isn’t specifically designated for the other Funds. Once the Research and Clinical Funds reach a substantial amount ($50,000) we will be able to offer grants to clinicians and researchers in the US.

Additionally, we have 1yr & 3yr certificates and long-term stocks/bonds earning interest and dividends for future FOD endeavors and programs.

Thank You

Family Donations: Neva and Ned Asplundh, Jenine Grainer-Iverson, Caitlin Garrison, Terre Williams, Katherine Pearl, Vicki Bello, Howard Rhodabeck, Jr, Deb Bennett, Avesta Johnson, Don and Jane Starwser, Nori Pennisi, Becky Schultz, Mimi and Sean Hogan.

T-shirts, Bracelets, Ribbons, CafePress, GoodSearch browsing, MissionFish/eBay selling, or iGive.com, Bravelets.com and AmazonSmile.org shopping: Tiffany Gilchriest, Michelle Cotton, Diane Schroppe.

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‘Nothing is impossible, the word itself says ‘I’m possible!’
- Audrey Hepburn -

Disclaimer: The views expressed in the FOD Communication Network Newsletter do not necessarily represent the views of our Advisors or all of our members. Before trying anything new with your child or yourself in regard to treatment, please discuss matters with your doctor or specialist. Please read our Disclaimer on our website—it also applies for all communications.

www.fodsupport.org