Successful Joint FOD/OAA Conference!

We ALL had a ‘Peach of a Time’ at our 2010 FOD/OAA National Metabolic Conference in Atlanta, Georgia on July 30-31! With the help of Carol Barton, Executive Dir of OAA and Kathy Stagni, OAA Administrative Director, Dr Rani Singh and Rosalynn Borlaza of Emory University School of Medicine, the Emory Conference Center Hotel, and many parent volunteers, we were able to offer a terrific experience for almost 200 Families and Professionals. Yet, we wouldn’t have been able to even have another Conference if it wasn’t for the generosity of Vitaflo as our Premier Sponsor and all of our other generous Conference Sponsors and Vendors (posted on our website). The FOD Group was also blessed by an ‘Angel on Earth’ who gave an extremely generous donation that assisted 20 of our Families in defraying registration, travel and hotel costs. FOD Families traveled all the way from Iceland and Australia because of this ‘Angel.’ This donation not only benefitted Families for THIS Conference, but will also help for our next one in 2012 ~ wherever that may be!

We will post some pictures and all the Speaker Presentations as soon as we can so everyone can learn what we had the pleasure of learning face-to-face with our FOD/OAA experts. Friday was a full day of presentations and networking for each specific Group topped off with a fantastic Reception at Wisteria Lanes for great food and bowling! On Saturday we joined together in a large conference room to hear Speakers discuss topics that related to both our Groups. I would like to thank everyone for participating this year ~ especially in such a rough economy ~ we made it work and no one regretted coming!

If anyone has suggestions for where our 2012 Conference should be please share with me ~ since we have been mainly in the Midwest and south for almost all of our Conferences, we are EXPLORING sites possibly out west ~ we won’t make any decisions quickly because there are alot of factors involved; the biggest one being whether we can find a committed Host and Premier Sponsor with funding!

Now that we are ‘relaxing’ a bit before starting to plan for that 2012 Conference, Families continue share great ideas for raising not only Awareness of FODs and expanded NBS but also for raising as many funds as possible ~ some of the Family Fundraisers are posted in this issue. Also please share our ‘2010 FOD Letter of Giving’ on our homepage with your Families, Friends and Medical Professionals. Other ways of fundraising are posted on the right sidebar of our homepage — they include our awareness bracelets, window ribbons, others, poems, others.

Several times this year we displayed our poster board and brochures. Carol Barton and her husband, Frank, represented both OAA and FOD at the Society for Inherited Metabolic Disorders (SIMD) Conference on March 28-31st, in Albuquerque, NM. And Shantel Matthews, an OAA mom also familiar with FODs, displayed at our joint booth for the 2010 GMDI (Genetic Metabolic Dieticians International) Meeting titled ‘Navigating Changes in Nutrition — Management of Genetic Disorders’ on April 15-17 in Baltimore, MD. I also attended a Newborn Screening meeting in Atlanta on Feb 19. Emory University and several other organizations have partnered to develop an interactive clinician-supported patient registry. That is a developing activity so I will report more in a future issue.

We welcome ALL new or updated Family Stories and pictures and we encourage Families dealing with the less common FODs (i.e. HMG, Carnitine Uptake Defect, TFP, CPT 1&2 etc.) to share their experiences. We’re also always looking for more low fat recipes, poems, ‘Silver Linings,’ and pictures.

Professionals ~ we need to hear from you too! New Medical, Research, Nutritional, Counseling/Coping, etc articles are always appreciated. Whether you’re a Family 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...  DLG
I had an amazing time at this year’s FOD/OAA National Metabolic Conference! I must start by thanking the wonderful Kathy Stagni (OAA) for inviting me to attend! The FOD & OAA did a fantastic job providing families dealing with Fatty Oxidation Disorders (FODs) or Organic Acidemias (OAs) with resources, information from an array of speakers from parents to professionals, and what may be most important of all, a chance to meet other families dealing with the same rare disorders.

I was privileged to speak with many of these families and meet their children. I met families from all over the United States, as well as Canada. An indelible impression was made on everyone by an amazing couple from Australia, who had met other families dealing with their son’s disorder for the first time (our hearts & love are with you— you are never alone). I learned a great deal both as an advocate and as a parent of children with a rare disease.

The importance of continued research and education for newborn screening was a hot topic. There were several parents who lost babies due to the absence of proper newborn screening in their areas. They did not die in vain: many parents had babies saved because of detections in the newborn screening process, available thanks to these brave families who shared their stories & advocated for the next generation. To learn more about newborn screening, visit [www.cdc.gov/newbornscreening/](http://www.cdc.gov/newbornscreening/).

The Coriell Institute for Medical Research attended to inform patients of their cell repository.

From genetic counselor Tara Schmidlen:

“We collect blood samples and clinical data from individuals with rare genetic diseases and chromosomal abnormalities and make cell lines and DNA, which are banked and made available for distribution to researchers around the world. Scientists use these well characterized samples for a variety of purposes, including: the discovery of disease genes and their function, further study of known genes and gene expression, development of new genetic testing and development of potential therapeutics.”

Further information can be found on our web site [www.dare-to-hope.org](http://www.dare-to-hope.org) or contact Tara directly at tschmidl@coriell.org

An obvious favorite for the children with FOD was the pudding samples. Pudding samples? Yes! Samples of MCT Procal were made into chocolate and vanilla pudding, so I couldn’t resist giving it a try! It was delicious! MCT Procal is made for patients with fat malabsorption, long chain fatty acid oxidation disorders, type 1 Hyperlipidemia, malnutrition and chylothorax. More information can be found on [www.VitafloUSA.com](http://www.VitafloUSA.com) to bring to your doctor for advice.

Another notable sample was the So Delicious Coconut Milk, which surprisingly enough I had never tried before. It really did taste more like cow’s milk than coconut! So Delicious products are dairy and lactose free, rich in medium chain fatty acids, and frozen sweet treats are sweetened with agave. Visit [www.sodeliciousdairyfree.com](http://www.sodeliciousdairyfree.com) for more information about their wide array of products. Always consult with your doctor if you or your child has food allergies or a metabolic disorder before trying a new food.

Thank you so much to the FOD/OAA! The parents and professionals involved were incredibly open and welcoming!

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**About Gina:**

Ainsley Paige Higgins’ Dare To Hope Foundation Co-Founder, Gina Gareau-Clark, is mother to 5 year old identical twin girls, Julia & Maya, who were born with a rare disorder called twin-to-twin transfusion syndrome, and have been diagnosed with mitochondrial encephalomyopathy & autism spectrum disorder. She has been a parent support & resource advocate for 4 years, is a contributing author for the Children’s Rare Disease Network, founded the volunteer group F.A.N.S. of Autism Speaks of Georgia which provides local resources and support for families dealing with autism, and volunteered with the Make A Wish Foundation for the 4 years prior to her daughters’ birth.

She holds the firm belief that no parent should walk alone.
‘Peach of a Time in Atlanta’
FOD/OAA Family Support Groups
National Metabolic Conference
Atlanta, Georgia
July 30 & 31, 2010

[more pictures will be on our site’s Gallery Photos page soon]

Dr Rani Singh, Kathy Stagni (OAA) and Deb after our terrific Conference!

Out on the town in Atlanta with our new Aussie friends!
Dr Stephen Kahler, Brenda G, Lynda G and Glen M (Australia GA2), Gwen A, and Deb

Kathy Stagni and Carol Barton of the Organic Acidemia Association

The power of connecting and networking ~ HUGS!

FOD Parents and Grandparents saying ‘see you later’ after the Ending Ceremony ~ hoping to see each other again in 2012!

FOD and OAA Families having a great time bowling and playing pool, after eating lots of terrific food at Wisteria Lanes!
Rebecca’s Story ~ MCAD

Rebecca’s story begins when she came into this world on December 4th, 2005. Her parents couldn’t believe their eyes. She was a beautiful baby girl weighing in at 6 lbs 10 oz, and 21 inches long. Rebecca’s mother Karin had a normal delivery with no complications. She checked to see if her precious baby girl had 10 fingers and 10 toes, and that her Apgar scores come back in the normal range, as all Parents do. They left the hospital after 2 days and brought their baby home to start a new chapter in their lives.

Rebecca’s parents received “the” phone call alerting them that something came back as abnormal on her expanded newborn screen. MCAD deficiency was mentioned, and they were told they needed to get her to the pediatrician as soon as possible. They went to the pediatrician, not knowing what to expect next.

Given the fact that Rebecca’s pediatrician had no experience with MCAD, he told her parents that he had looked it up online and that all they needed to do was to feed her frequently. He directed them to a website for information, and informed them he would be referring Rebecca to a genetic specialist. In addition, another heel prick was done for a second newborn screening.

Karin and her husband looked at the website the pediatrician had suggested, and read things like “brain damage” and “death.” Needless to say, this was devastating for them. Karin collapsed on the floor crying, and her husband tried to console her and told her that everything was going to be alright. Unfortunately their appointment with the genetic specialist wasn’t until one week later which seemed like forever because they wanted answers to their many questions.

In the meantime, Karin knew she still had this precious little girl to take care of, and she nursed her around the clock every 1.5 to 2.5 hours. This, along with all of the emotional stress, took its toll on both Karin and her husband. However, their daughter was thriving, and so they endured.

Within a week, the family received word that the second screen did come back positive for MCAD. They met with a genetic specialist, who took the time to answer all of their questions and provide them with detailed information on what needed to be done to properly care for their daughter. They were also told that Rebecca’s octanoylcarnitine concentration was 28.6 micromol/L. Though they didn’t fully understand what that meant, the specialist told them that the highest she’d ever seen was a 30.0. The word “impressive” was used, and not in a good way. They were also told “when”, not “if,” Rebecca gets a fever or is not eating, to call her right away.

That day came on Labor Day in 2006 when Rebecca was 9 months old. She caught a virus, had a fever of 104, was vomiting and was unable to keep any food down. She was also shaking uncontrollably (they believe now that this is due to both hypoglycemia and muscle breakdown). Her parents called the specialist, who called ahead to the ER to let them know they were on their way. Rebecca spent the next 5 days in the hospital on IV D10. She was poked so many times because the IV lines kept blowing, that they ran out of spots on her arms and hands for IV placement sites, and had to place the IV in her feet. Seeing Rebecca in this state was devastating to her parents. They now have come to know what needs to be done in order to keep Rebecca alive and well. The IV is her lifeline when she is not well. Once the fever subsided and Rebecca was able to consistently eat and drink on her own, she was discharged from the hospital.

It helps tremendously for Karin to realize that she’s not alone in this. She often thinks of the other moms with children with these types of disorders and what they are going through.

Rebecca had another hospital stay shortly thereafter due to a UTI and, as a result, received a diagnosis of Stage III Vesicoureteral Reflux. She was put on a daily maintenance dose of antibiotics, which she is still currently taking. She is due to see her Urologist this summer and hopefully this condition will have reversed itself. The family is crossing their fingers! If not, then Rebecca will need corrective surgery. Her family will deal with that if and when the time comes.

Rebecca has had a few more hospitalizations since then, all usually resulting in a 2- or 3-day hospital stay. Karin is always prepared to run out the door when Rebecca is ill. She always makes sure to have bags packed and glucose gel on hand in case of hypoglycemia en route to the ER. Karin also has a very thick binder where she keeps all of Rebecca’s medical information, including copies of her emergency protocol letter, to hand out to the ER staff. Rebecca is even flagged on the hospital computer system so she gets ahead of the queue when they arrive.

Through all of this, Karin and her husband have developed an amazing support system, ranging from Rebecca’s pediatrician and genetic/metabolic specialists, to caring friends and family members. It is a great comfort for them to know that these people in their lives ‘get it’ and are right there for them when needed, no matter what time of day or night. Karin also met some wonderful moms through the FOD Family Support Group. Through this, she continues to form a very close-knit group of friends. Karin loves the opportunity to be able to bounce ideas off other families, and even share some laughs!
Rebecca ... cont’d

Rebecca is currently 4 years old and a joy. She knows she needs to take her daily dose of Carnitine for her MCAD plus the antibiotics. She knows she needs to ‘not eat too many fats’ and that she has to eat frequent meals. Rebecca absolutely loves all fruits and vegetables. She is not a picky eater, and will try anything once. The family has a ‘house rule’ and that is that if you try it, and you don’t like it, then you don’t have to eat it. This has been working out very well, as mostly everything she tries she likes!

Looking back at the time when Rebecca’s parents first learned of the diagnosis, Karin can’t deny that it was very hard on her and her husband, both emotionally and physically. She wouldn’t want to have to go back and relive it. They felt they were in a state of mourning, not having the ‘normal’ child that they had expected. The ‘new mommy excitedness’ was ripped out from under Karin. Those were dark days. But seeing Rebecca now, thriving and meeting all of her milestones, Karin would have to say it was all worth it. She wouldn’t change a thing. They love her just the way she is; to her parents she is perfect!

Karin Cleary
Massachusetts
Karincleary@aol.com

Family Stories

Douglas Schulte was diagnosed with LCHAD at age 6 months in early months of 1996. He had been suffering with episodes of severe vomiting, seizures, non-responsive lethargy and bouts of severe constipation. Combined with his mother’s HELPP Syndrome during Doug’s delivery, doctors at Yale Children’s Hospital headed by Dr Rinaldo were able to diagnose Douglas.

Since I am a high school wrestling and track coach the thought of my son not being able to participate in sports was icing on the cake of despair I felt over my sweet boy’s diagnosis.

As his life went on Douglas’ mother, Karen, and I decided to allow him to do the activities he chose. She was fine…I was a wreck. I always worried that playing sports at a high level would certainly cause an episode or worse.

I am happy and proud to report that Douglas just wrapped up his 9th grade year in June as a successful student-athlete at Centerville Junior High in Utah. Along with his academic achievements, Doug was the starting fullback and outside linebacker on his Viewmont football team which won the Ute Conference Championship. Over last Thanksgiving weekend Douglas and his teammates captured the National Youth Football Championships in Las Vegas, NV.

As a wrestler this year, Doug finished 4th in the junior high state tournament and second in the district tournament at 150 pound weight class.

Perhaps this comes across as boasting, but I send this out as a message of hope. When Douglas was diagnosed I felt such hopelessness. And while athletics are a small part of the lives of our children, Douglas’ achievements are proof that our children with FODs are not stricken to a life of inactivity.

When Doug is in-season we take certain steps to help keep him healthy. First, Doug eats more protein to help with the increase in physical activities. He also stays extremely hydrated when at and away from his training sessions. In addition, Doug is diligent to looking for warning signs that he may be heading down the road to an episode. When he gets sick, it is important Doug takes a few days off from training rather than gutting it through as he would prefer. He also watches the color of his urine in case there is an upcoming problem with his kidneys, etc…

We also educate his coaches to the best of our ability. We print off information about LCHAD and FOD and review it with his coaches and team trainers. In addition we keep more information in the team’s medical kit in an envelope. This is in case there is an emergency, whether related to LCHAD or not, so if he is taken to the hospital or is being dealt with by paramedics they have information about LCHAD. Education again is the key. We temper this education with the realistic knowledge that the chances of Doug having a life-threatening event suddenly at practice or a game are slim.

As Douglas took the mat during many matches we often spoke of him carrying the banner for anyone who has been given grim news of a horrible illness. We have no idea what his future holds, but Douglas is excited to enter 10th grade where he will participate in high school and wrestling.

Scott Schulte
Schulte_scott@yahoo.com

Douglas’ Story – Teen LCHAD
Team Ella Announces
2011 REGIONAL FAOD MEETING
with Margretta Seashore, MD and the YALE GENETICS TEAM

~ Ella ~

Keynote speaker Cary Harding, MD
Oregon Health and Science University

DATE: April 13, 2011 8:30 AM - 3:00 PM

PLACE: North Haven Holiday Inn, North Haven, CONNECTICUT
Meet the Speakers Reception April 12, 2011 6:00 - 8:00 PM

MORE INFORMATION: Email GoTeamElla@AOL.Com

FOD Awareness Displays

Shantel Matthews representing both OAA and the FOD Group at
the 2010 GMDI (Genetic Metabolic Dieticians International) Meeting
in Baltimore, MD

Deb at the MI Newborn Screening Followup Day in Lansing, MI

Carol Barton(OAA) and Frank Owens representing both OAA and the FOD Group in Albuquerque, NM at the Society for Inherited Metabolic Disorders (SIMD) Conference
Hello everyone! It’s been awhile since I have written anything over the Email List. First I want to say that Reiley and all (our other FOD kids) are in our prayers. Surgery is not fun — we just had one 9 days ago. Chris had to go back in and have his hypospadias repaired yet again. Thankfully he came through it with flying colors.

We have good news to report!!! He has been seizure free for over a year now!!! Happy dance time. He is almost weaned off of his topamax. His last liver function was at 98%!! Woohoo. We are getting there. He has grown 5 inches within the last 6 months. He is still only 43 lbs and now stands 4 foot. He is long and skinny. But other then that he is struggling with his breathing so we are scheduled to go see a pulmonologist this next month.

I know that sometimes we get so focused on the negatives that we can’t see the positive. I just thought that I would share our good news and hope that maybe someone that is having a hard time will read this and know that it does get easier.

We love you all
Lisa, mommy to Chris SCAD warrior, co-Q10 deficiency, seizure free for over a year
3 other kiddos unaffected
Royal Center, IN ctgirl42002@yahoo.com

Families getting together across the States ~
‘Texas Meet and Greet’
Two Reviews : Janet and Brittany

This afternoon was wonderful! Three families met at a yogurt shop and chatted as we enjoyed frozen yogurt and coffee. We had a 5-month old with LCHAD and a one-year-old with MCAD today, plus my "ancient" 18-year-old LCHAD daughter. Your kiddos will have company if we can all make it in August. And the shop has a WII setup, plus wi-fi if we need that. Definitely, come on down!

Seeing little Evie with LCHAD getting the right kind of medical care and thriving, and watching Landon explore the shop with his determined curiosity, was a real pleasure. Having Evie take a nap on my shoulder was just priceless. The shop owner took some pictures and will send me a copy for me to post. Evie’s mom Brittany took pictures too, and I’m sure she'll post them once they’re home in Louisiana.

Evie looks like a perfectly normal little girl who happens to have a feeding tube. She's got good weight, she's alert, she took her bottle without fussing, and she laughed at the bandana that I waved at her. The feeding tube allows her to do all of this, and it was wonderful to see that an LCHAD baby could do so well with proper medical care.

Landon looks like any other healthy little boy. He’s curious and adventurous, tried to climb the furniture and counters, and was quite the explorer. He circled back to his parents often but felt safe in checking out the shop on his own. His medical condition is not apparent at all. He seems like a boy who has things to do, people to meet, and MCAD is not going to hold him back. A surprise was that Jena had an agenda - she was very open about the emotional difficulty she had, not knowing that her limitations were physical, due to LCHAD, and not (as she wrongly assumed) because the other kids were somehow "better" than she was. Who knew she'd open up like that right away, on that particular subject???
I think it was good for all of us to meet, and to be able to talk about the things that affect us without having to stop and explain all the background. It felt great.

If anyone else can arrange a simple meeting like this in their area, I can assure you it's worth the time and effort to get there and meet other FOD families. We will do this again, definitely. I know of five families within a three-hour drive, and I hope to get us all together soon.

Many thanks to those who drove, and to those who couldn't make it this time - there will be another "FOD Social."

Janet
mother of Jena, 18, LCHAD/Mito
and John, 19, Aspergers/Who Knows?
Janet Longmore wordminder@yahoo.com

•••

This past Saturday, some folks got together for a little Meet-n-Greet. It was so wonderful to put faces to the names and get to talk with other FODers. Personally, some of the things that I took away from this meeting were truly life changing. I know that may sound like I am exaggerating, but it's very true. I have a 5-mos-old. We are still getting used to the idea that she won't be able to have many foods that other kids have. It has been difficult, too, because she has reflux and we are constantly feeding her. I guess the main thing is that, yes, her diet will be different from everyone else, but that doesn't make her weird or even sickly.

Since we caught her LCHAD through NBS we can do the right preventative measures to ensure that she does stay healthy. We are one of the lucky families out there. Another thing is that, yes, we can go out to eat, every so often. I love eating out, because it means that I don't have to cook and clean!!! haha) I was putting our entire family on fat restrictions and making everyone eat completely fat free. My mindset is changing, due to this meeting. We make healthier choices now, because of Evangeline. And now, we will just eat out less often, and then truly it will be a treat.

I did want to thank everyone who came, and being so honest about day-to-day life with an FOD. It was nice to see a normal, healthy, teenager with LCHAD. I guess I had it in my mind that Evie would be thin and sickly and not want to really have friends and even get out of bed! Ok, so maybe I am a bit dramatic!

Anyways, I have attached some pics that we took at The Yogurt Fusion, which if you are ever stopping through Denton, TX, it is a must!!! The people there are so friendly and the yogurt was amazing— not to mention the toppings you can add. Yummy! Anyways, thanks for meeting with us. We can’t wait to do it again soon! I highly recommend getting together with others in your area. It makes for an awesome time of fellow-shipping with other FODers.

Brittany Henagan
Evangeline Henagan (Evie) 5 mo old, 11lbs , LCHAD
Shreveport, La

Yogurt and LOTS of toppings!

Janet and Evie

Jena, Evie and Landon
The United Mitochondrial Disease Foundation is pleased to tell you about a new research resource at the Mayo Clinic in Rochester, Minnesota: the Mitochondrial Disease Biobank. This is the first Biobank in the country specifically developed to study mitochondrial diseases. Mayo Clinic is collaborating with the UMDF in hopes of identifying individuals who may be interested in participating in the Biobank. A Biobank is like a library containing biological samples (such as blood) and health information for researchers to use. Instead of having to look for volunteers for each new study on mitochondrial diseases, they can get samples from the Biobank. The Biobank also gives researchers a place to share data and results. In general, individuals who have or are suspected to have a mitochondrial disease are eligible to donate to the Mitochondrial Disease Biobank. Their family members may also be appropriate participants. Participants must:

• Read a description of the project, and then sign a document agreeing to participate.
• Complete a short medical and family history questionnaire.
• Allow Mayo Clinic to obtain information from their medical record.
• Provide a blood sample.
• Allow Mayo Clinic to obtain any clinical samples (such as skin or muscle biopsy, urine, etc) that their health care provider is no longer using.
• Agree to be contacted periodically (no more than twice a year, and typically much less).

Please visit the Mayo Clinic Mitochondrial Disease Biobank by clicking here for more information about participation. Contact a member of the study staff to discuss eligibility questions, or concerns toll free at (877)594-2149, or mitochondrialdb@mayo.edu. The Mayo Clinic Mitochondrial Disease Biobank thanks you for taking the time to consider participating.

Devin Oglesbee, Ph.D.
Mayo Clinic Mitochondrial Disease Biobank
200 First Street SW
Rochester, MN 55905
Telephone: 507-293-1386
Toll-Free: 877-594-2149
Fax: 507-266-0236
Email: mitochondrialdb@mayo.edu

~ Undiagnosed Diseases Program ~

For anyone else that is interested in the UDP program - it takes patients of all ages, with all kinds of medical conditions - not just metabolic conditions. That being said - it only takes 50 - 100 cases per year, so many people are not accepted. They will attempt to identify other programs or studies that might be of assistance though.

The website for the undiagnosed program is http://rarediseases.info.nih.gov/undiagnosed, the phone number for referrals to the program is: 1-866-444-8806. The referral line is open 9-5 EST Monday through Friday. Referrals can be done by patient families (or adult patients may call on their own behalf) or physicians. If a family calls they must be able to provide contact information for a "referring" physician. The referring physician will be required to provide a summary letter and supporting medical records for the UDP team to review. Also for those that are interested in hearing more about the Undiagnosed Disease Program, there is an article with a clip from the Today show on MSNBC (http://today.msnbc.msn.com/id/34845829/).

NIH also has a couple of other studies that might be of interest:
76-HG-0238 Diagnosis and Treatment of Patients with Inborn Errors of Metabolism
02-CH-0023 Studies of Pediatric Patients with Metabolic or Other Genetic Disorders (also accepts adults)

To read about either of these studies, click on the above links or go to http://clinicalstudies.info.nih.gov, put the study number in the search box, and click on the subsequent link to read a description.
If the study is of interest you can call 1-800-411-1222 (between the hours of 8am-8pm EST Monday - Friday) for a screening and referral.
[suggested by Chris, Undiagnosed, possible FOD]
NEW Product from our 2010 Conference Premier Sponsor ~ Vitaflo USA

S.O.S.
for use as an emergency regimen in the dietary management of inborn errors of metabolism

**Description:**
S.O.S. is an age specific range of neutral-tasting carbohydrate powder drink mixes, for use as an emergency regimen in the dietary management of inborn errors of metabolism.

**Indications, Dosage and Administration**
To be determined by the clinician or dietitian and is dependant on the age, body weight and medical condition of the patient.

S.O.S. is available in four sachet sizes:

<table>
<thead>
<tr>
<th>Product</th>
<th>Sachet Size</th>
<th>Final volume make up to</th>
<th>Carbohydrate concentration provided</th>
<th>Recommended Age Group</th>
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<tbody>
<tr>
<td>S.O.S. 10</td>
<td>21g sachets</td>
<td>200ml</td>
<td>10%</td>
<td>1 year and older</td>
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<tr>
<td>S.O.S. 15</td>
<td>31g sachets</td>
<td>200ml</td>
<td>15%</td>
<td>1 – 2 years of age</td>
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<tr>
<td>S.O.S. 20</td>
<td>42g sachets</td>
<td>200ml</td>
<td>20%</td>
<td>2 – 10 years of age</td>
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<tr>
<td>S.O.S. 25</td>
<td>52g sachets</td>
<td>200ml</td>
<td>25%</td>
<td>10 years of age and older</td>
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**Guidelines for Preparation and Use**
All sachet sizes of S.O.S. are designed to be reconstituted with water to yield a final volume of 200ml. Once prepared the feed should be used immediately or stored in the refrigerator and used within 24 hours.

**Important Notice**
- Must only be consumed by people with proven inborn errors of metabolism under strict medical supervision.
- Not for use as a sole source of nutrition.
- Not for intravenous use.

**Storage**
Store in a cool, dry place. Sachets are intended for single use and should be used once opened.

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**Nutrition Update**

**Parent Snack Suggestion for Toddlers**

Caitlin still eats a jar of baby food cereal at night. I keep thinking I need to change it, but then I think if it’s not broke, don’t fix it. Breakfast is the most difficult time to get her to eat. This morning, I cut up a banana and some strawberries, and then stuck a toothpick in each one and she loved that! I’m going to keep that one in the snack rotation.

I also use what we call squeezy foods, which I find at Babies R Us. They are all pouches of pureed fruit and veggies. They are all organic and low fat. They work really well for traveling, especially when I am in the car without any of my older kids to help out with a snack. They are a little pricey, so I only buy them on sale and use them when we need a quick snack! The companies that make them are Plum Foods and Revolution Foods I think. They also make something called Sammy Jammies which are lowish in fat and a good treat as far as Caitlin is concerned.

During the winter, I gave Caitlin warmed Carnation Breakfast drink made with the no added sugar type and skim milk when the rest of us were having hot chocolate. She drinks that now sometime too, but cold. One other food I’ve been meaning to share is a brand of low fat chicken nuggets I found. They are all white meat, baked and you just reheat them. They even have the American Heart Association seal on them. A company called Pilgram’s Pride makes them. I will admit only to my FOD friends that I actually cried when I found them in the store. For some reason, grocery shopping gets me emotional about food and FODs, and finding something so kid friendly and still healthy enough for me to feed Caitlin just made me happy enough to cry! It sounds so silly now but maybe some of you do that too?!

Becci in Grovetown, GA       Becci Sommer  rebajosy@bellsouth.net       mom to many kids including Caitlin, 3, MCAD
Parent to Parent Suggestion: Dealing with Anxiety and Depression

I don't know if anxiety and depression can be caused by the disorder but I think HOW we think, handle and/or deal with our situation can affect us health-wise. If we are stressed, anxious or depressed, this can cause us to decline in health and if not taken care of, can become a very vicious cycle where depression and health just keep getting worse.

I try to focus not on what I can't do but on what I CAN do. My kids don't have a lot and have gone without some things because of lack of finances. But they know they have a roof over their head, food and clothes and they focus on that. They also understand that mom can't do a lot of the things that they can. I try to focus on the positives. My kids and I have just as much sitting and playing board games time vs running and playing ball time. I also have sat in the middle of them while they were running all over and I was used as their "safe" spot in tag! You might not be able to run or do the physical part but you sure can participate in some way! Kids understand quite a bit and will understand that you can't do the physical stuff. But you watching them will mean the world to them too! Cheer them on as they play horse or basketball, football or whatever physical activity. If possible, think of a way that you can be a part of their activity without you doing anything physical like the safe spot in tag.

I don't know the ages of your children or what they like but here are some other not so physical activity type things that you can do:

- safe spot in tag
- hold jump rope and they jump
- play hopscotch but they take turns doing your jumping...you just throw the rock
- video games
- board games
- arts and crafts
- cheerleader when they are playing sports
- red light green light - you stand at one end of room or yard, they are at the other. You yell green light they walk or run, you say red they have to stop. Anyone moves after you say red, they are out. The first one to reach you wins.
- dog bone - pick something to be a dog bone, sit down. One person puts head down (they are the dog) and closes eyes. Someone hides the bone behind their back, in their legs, etc. Then you tell the person with their head down to guess which person has their bone.
- Read together
- act out plays, create plays or get one that is already made.

There are a few suggestions for you. Hope something in there works for you!

Kelli Dietrich – has Unknown disorder  dietrichclan@charter.net
mom to:
Sami - 21
Cody - 17
Alyssa - 12
Meagan - 9 - Disorder of Mitochondrial Metabolism / Disorder of FOD / Secondary Carnitine Deficiency / Anxiety Disorder NOS / Selective Mutism / SPD / PDD
www.freewebs.com/meaganpie
Leah - 5 - Unknown
Our angel baby ^i^ Amanda Jo  http://amandajo.memory-of.com

Love
Messages

Please remember our families in your thoughts and prayers throughout the year
[For entire list please refer to our Jan 2010 issue]

‘The strongest principle of growth lies in human choice’

~ George Eliot
‘Transforming your Life after the Death of a Child’

The death of a child is an excruciating and life-changing experience for any parent and their surviving children and family. Those that have never had a child die speak the truth when they say, “I can’t imagine what you’re going through.” There are no words that can fully express that gut-wrenching anguish and sorrow a parent feels searing through their mind, body and spirit when they are told their child is dead.

Having those very words spoken to my husband, Dan, and me on July 21, 1985, I can attest to that shattering of my heart and world. And with Kristen’s 25th ‘anniversary’ now passed, I would like to share a few of my grief journey ‘learnings’ and how they helped me move toward ‘healing’ my fractured heart.’ Because parental grief is unique and individual and based on various factors, my experiences may not match other bereaved parents’ grief journeys, but hopefully something will resonate that may help a parent move beyond barely surviving your child’s death to living once again with love and joy ~ albeit differently ~ and in your own time and way.

The Death of a Child is not something to ‘get over’

A parent’s grief process is a lifelong journey and not a one-time event that is over at the magical one-year anniversary. Your child grows up in your mind and with each missed milestone depending on the age of their death (ie., learning to walk, starting school, getting married, having children, having a successful career etc), you will recycle your present loss along with past losses of every kind within the context of your own personality, your role in the family, and other present stressors, just to name a few factors. Grief will impact every aspect of your being spiritually, emotionally, physically, cognitively and socially and each aspect will need to be processed over and over again in order to integrate it within your life and your family’s life – but you will NEVER get ‘over it!’

Grief is not a step-by-step linear process

Dr Elisabeth Kübler-Ross never intended her grief theory to be taken so literally, generalized across all loss and grief, and have it cemented as a process that moves from higher intensity denial, anger, bargaining and depression to a final acceptance and peace at being back to ‘normal.’ Unfortunately, many still view grief that way and it causes major complications for those trying to do their own ‘grief work.’ There is no cookie-cutter approach or right way to learning to live without your child’s physical presence. Working through any anger, guilt, grief depression, etc, can feel like you’re on a spiraling rollercoaster tossing you forward and back, up and down and feeling as if it will never end ~ it is not an easy, fast or predictable process. The age of your child, circumstances surrounding the death, your relationship with your child, etc will be different for every parent ~ so don’t expect your process to follow the same path and in the same timeframe. Going with the flow of your own personal journey and giving yourself that permission to take what fits for you and disregard the rest is vital.

Going around grief is not an option

No parent ever wants to cope with a child’s death, but in reality it happens every day around the world ~ children die. You ask yourself “How am I ever going to go on?” Unfortunately, there is no way around grief – one must go through it in order for ‘healing’ or reconciliation and integration within your life to occur. Those early on in this process may not see ‘healing’ or integration as even possible dimensions right now ~ I understand that all too well ~ but ‘healing’ is possible, yet it’s often felt long AFTER it’s actually begun and then continues down the long winding road of life. Over time and a lot of grief work, one is able to move outside of oneself, moving beyond survival to living again. As posed in many grief books the question before you is “Do I become bitter or better?” ~ the choice is yours. From my own personal experience, one CAN live their life with renewed faith, hope and love!

Grief is Intergenerational

What we learn about death and coping with loss as a child in our family-of-origin, in our spiritual/religious and school communities, and from other significant people and environments in our lives impacts how we process our own child’s death. For many families their grief goes underground because talking about death is taboo and the topic becomes the ‘elephant in the room’ ~ everyone sees it but doesn’t acknowledge it or express how they feel or what it means to them. Some may dive into work or try to numb themselves through alcohol, but that only delays, prolongs and complicates an already complicated process. Just because you learned to ‘stuff’ your grief as a child doesn’t mean you have to do that as an adult in the present and future. You have a choice and change can be part of that choice. As difficult as it is to do, you do have the power to forge your own way of ‘healing’ in a healthier and more constructive way. And I hope all children today learn that lesson early on in their own lives!
Ongoing Support is Vital
Family, friends and co-workers often don’t know what to say or do around bereaved parents. The unthinkable has happened and much of their uncomfortable feelings come from knowing it could have been them! And oftentimes, after awhile many think you should be further along in your grief than you are - based on that false idea that there’s truly a set timeline and destination to grief – that is why Ongoing Support is so very important for parents and their families. Being able to share your pain, as well as your joy (and yes one CAN laugh in the midst of grief), with another bereaved parent, a support group, a clergy, or anyone that you trust with your innermost thoughts and feelings is vital – someone that will listen with compassion and an open heart without judging your process or telling you to move forward in your life before YOU are ready.

Our children live within us Forever
When we love someone, grief is a fact of life and living. When a child dies, we may feel as if the grief is insurmountable, yet just because your child is not physically present doesn’t mean they aren’t ‘here.’ Having experienced my own spiritual awakenings and ‘love messages’ from my daughter I KNOW Kristen will always be with me. Being open to experiencing Divine synchronicity and grace is not limited to those that practice a specific religion, however – it can occur with anyone open to ‘healing’ one’s heart and spirit.

I hope this brief article on my ‘learnings’ will validate some of what you as a grieving parent may be going through ~ and that you have others in your life that will allow you to grieve in your own way and in your own time ~ moving you toward celebrating your child’s life with renewed meaning and purpose in your own life.

Deb Lee Gould, MEd
July 1, 2010
[submitted to Tyler, TX Compassionate Friends newsletter and local MI newspaper (shortened version)]

Deb Lee Gould, MEd, is a bereaved parent and Grief Consultant in Okemos, MI and offers pro-bono one-on-one grief support to parents and other adult family members living with the death of a child of an age and from any cause. She received her Masters in Counseling in 1993. She also is Director of a nonprofit and international Family Support Group for rare metabolic disorders. Please contact her at 517.381.1940 or deb@fodsupport.org for more information or her office location. Deb’s ‘Holistic Intergenerational Grief Model ™ Healing of a Fractured Heart’™ can be found on www.fodsupport.org/coping_healing.htm

How Families are creating awareness for FODs & Raising Funds!

I had a very proud "MCAD Mommy" moment today that I just had to share with all of you!

During our Community Yard Sale today, Gareth decided to have a lemonade stand. It was his idea, and he was clear that he wanted to do it for a charity. He was allowed to pick any charity he wanted, and he chose the FOD Family Support Group to help the "kids like him". He made the signs and was the perfect little salesman (even going as far as telling one lady that his lemonade was cheaper than the girl's down the street - lol)!

I am sooo proud to report that Gareth earned over $57 all by himself today for the group! At .25 cents per cup, that is a LOT of lemonade and a LOT of very GENEROUS donations! He handed out flyers about the FOD Group to everyone who stopped at his stand. It was awesome!

Thanks for letting me share my proud moment with all of you!!!
Kim, Mom to Gareth, 7 MCAD
Bethlehem, PA
Kim DiPaolo garethsmommy@yahoo.com

Gareth’s (MCAD) Lemonade Stand
Raising FOD Funds...cont’d

Mckenna’s (MCAD) Book Sale
[Raised almost $2000 for the FOD Group!
And some was used for Conference Scholarships]

The Story of how ivPolePals was created by one of our LCHAD Families!

To purchase:
FOD Group ivPolePal

ATTENTION FOD FAMILIES ~ FUNDRAISING EFFORT AT ITS BEST!

I will donate 95% of my proceeds to FODSUPPORT toward our RESEARCH FUND!
Ever hear of Silpada Jewelry? No, well let me introduce you to the beautiful fine sterling silver jewelry we have to offer!
All our products are .925 fine sterling silver. What’s that you ask?
.925 is 92.5% pure silver mixed with 7.5% COPPER!
(NOT nickel or brass, which makes many individuals’ skin turn green or black)
This will NEVER happen with Silpada jewelry.
EVERY piece is handcrafted and exclusive in design!
AND, we’ve just received the 2010-2011 new products!
Please go to my website and check out over 500 pieces in the new catalog! Then send me an email with your order and your phone number and I will contact you personally for payment information.
Every order is shipped directly to you for just $4.00!
LET’S REALLY MAKE THIS HAPPEN! THE OPPORTUNITIES ARE ENDLESS WITH SILPADA!

LAST YEAR I WAS ABLE TO DONATE OVER $2500!!!

Brenda Goodman (FOD mom)
Independent Representative for Silpada Jewelry
Fine Sterling Silver Jewelry
email: doublebn@aol.com
home: 216.292.5938
website: mysilpada.com/brenda.goodman
If your Physician needs more information about L-carnitine (Carnitor®), dosages, or has other questions, please have him/her contact Sigma-Tau Pharmaceuticals, Inc., and ask for the Medical Information Department or state that he/she has a question about carnitine. The phone number is 1-800-447-0169.

Q: Carnitine has been very helpful for my child, but sometimes I smell a ‘fishy’ odor off the top of her head. Why does that happen?

A: The fishy odor comes from trimethylamine, the substance that gives old fish the odor. TMA is at the end of the carnitine molecule. We have an enzyme in the liver and elsewhere that makes TMA into TMA oxide, which has no odor. This enzyme can be overwhelmed, and sometimes there is a genetic deficiency of it. Either way, if there is more TMA coming into the body (from the gut) than can be handled, the TMA gets excreted everywhere—urine and sweat especially.

Only about 15% of oral carnitine is absorbed in that form. The remaining 85% stays in the gut; some of our gut flora will make TMA from carnitine. When that happens, some of the TMA may stay in the gut, giving a fishy smell to the diapers. Some will be absorbed, and the liver has to deal with it. If a person on carnitine gets a fishy odor you know you are giving more carnitine than can be handled, so the first thing is to lower the dose a bit. Certain broad-spectrum antibiotics (ie., metronidazole) can rearrange the gut flora, which might increase the amount of TMA being made, or might decrease it. Getting a transient GI illness (leading to diarrhea for a few days) can have the same effect.

Vitamin B2 (riboflavin) helps TMA oxidase, but I’ve not heard of it being helpful at lessening the odor, except sometimes in people with a genetic deficiency of the enzyme.

Choline, which is very abundant in seafood and some other foods, is another source of TMA, so people who are having trouble with TMA may benefit from less choline in the diet. Most of our children on carnitine aren’t eating much fish, so it’s really not a consideration for them.

Diarrhea and fishy odor are the two main side effects from oral carnitine. Both usually respond to a lower dose. It’s usually possible to return to a higher dose after things have settled down after a few weeks. I’ve not encountered mouth sores due to carnitine. Giving carnitine with food can help with the diarrhea.

IV carnitine doesn’t produce the odor or the diarrhea.

Finally, for people with the genetic deficiency of TMA oxidase, there are some measures which can diminish the odor—less choline in the diet, certain anti-deodorants which can trap or neutralize the TMA, antibiotics to alter gut flora, and avoiding tight clothing (which keeps the odor from dispersing—a big problem in the winter). If the odor is due to carnitine, lowering the dose will take care of it.

Stephen G. Kahler, MD
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One Children’s Way
Little Rock, Arkansas 72202-3591

Levocarnitine (generic DRUG form) was approved for distribution by the FDA several years ago. This generic form (as well as the brand name Carnitor®) needs a Prescription from the Dr. Please also note that Carnitor® and the generic form of L-carnitine are NOT the same as the over-the-counter carnitine supplements often bought at healthfood stores — those products are NOT regulated or approved by the FDA to be used for metabolic disorders (read the article on http://www.fodsupport.org/pharmaceuticals.htm). The term ‘generic form of a drug’ should NOT be used interchangeably with the term 'over-the-counter supplement.'
Q: What are “acylcarnitines” and why are elevated levels bad?

A: Carnitine moves fat particles, also called acyl groups, out of cells when too many build up because they aren’t being processed for energy correctly. The combined carnitine/fat molecule is called an acylcarnitine. The fat particles can be different lengths, and high numbers of acylcarnitines can indicate a block some where in fatty acid oxidation - hence an FOD like MCAD. Doctors use the amounts of the different length acyl-carnitines to help determine which FOD you have. The numbers can go higher when eating too much fat, or exercising without enough carbohydrates, or exercising too much, or not taking enough carnitine. The carnitine also flushes the extra acyl groups out of your body in your urine. Too big of a buildup of the fatty acids can make your body too acidic sometimes, and cause an acidosis which can make you really sick. Any or all of those things could happen, but all the FODs are different acylcarnitines, so the best thing to do is discuss it with your doctor.

Best Wishes, Chris (FOD, 48, MI) Allison C Bliton acbliton@umich.edu

A: Acyl-carnitine (esterified carnitine) is the bad stuff that can build up in the body of FOD patients. In MCAD, the medium chain fatty acids are not broken down properly and carried away from the cells. Carnitine helps bring the fatty acids into the mitochondria of a cell to be broken down for energy. Also it helps remove the left over parts (think of ashes) or esterified carnitine, from the cells to be removed from the body via urine.

Phil father to Jenna 5 yrs old MCAD Long Island NY WalkGood walkgood@gmail.com

Q: Are Fatty Oxidation Disorders (ie., LCHAD, SCHAD, MCAD) just one of many Mito Diseases?

A: Saying "mitochondrial disease" is like saying "cancer" - it’s an umbrella term used to describe a whole group of diseases. FODs are one 'class' of diseases that fall under the mitochondrial disease umbrella. The reason that FODs are sometimes classified as mito disease is because with FODs, there is some type of glitch in the beta oxidation process (the biochemical process that breaks down fats) and beta oxidation occurs in the mitochondria.

Most of the time, when "mito" is mentioned, people are referring to some sort of glitch in the electron transport chain (aka, ETC, oxidative phosphorylation or 'oxphos' process). The ETC is composed of five enzymes, which are known as complexes I, II, III, IV and V. Often, mito testing reveals a deficiency in the activity of one or more of those "complex" enzymes, and so a mito patient with an oxphos problem might be described as having a "complex I defect" or "complex I and complex III defect", etc.

Beta oxidation and complex I are very closely related, because the output of the beta oxidation process (e.g., short chain fatty acids) are fed into complex I as part of the beginning of the oxidative phosphorylation process. So, a problem with one of those processes can cause trouble for the other. That's why many "mito" patients (with a primary oxphos glitch somewhere) also have secondary FOD issues.

With many of the FODs, research has revealed the specific protein that is lacking or working properly and, in many cases, the gene(s) that cause(s) the problem. With a few exceptions, that's not the case with most mito diseases that cause trouble in the oxphos process. Lots and lots of research and understanding is still needed for all types of mito, including FODs!!

Mary Beth, GA Mary Beth Morris gatechbee@gmail.com
5 children with mito myopathy and secondary FOD issues (once thought to be SCAD)
Welcome to New Babies!

Adam and Barb Richmire welcome their newest daughter, Jenna (VLCAD) born on May 22, 2010 in Williamsburg, Ontario Canada. Jenna was 7lbs 3 oz and 47½cm long. Her sisters Alexandra, Mary and Louise and brother Ian are SO happy to have her here! richmirefamily@hotmail.com

John and Kristen announce the arrival of Hailey Clara Youngblood (possible SCHAD?) born in Louisville, KY on Feb 15, 2010. She was 8lbs and 7.3 oz and 20 “ long. Her sister, Isabella, 3, (SCHAD) has a new playmate!

Our new son, Lucas Nelson Foster Epp (unaffected) was born on Sunday Jan 31 at 7:25am. He was 8lb 7oz and 21 1/4” long. His big sister, Danica , 2 ½ yrs (MCAD) loves him bunches! All went well with the delivery, and the hospital staff were excellent at following our specialist’s protocol instructions for blood glucose testing etc after Lucas was born. Anthony & Lynette Epp Saskatchewan, Canada lynette_epp@hotmail.com

Valynne Grabow was born on Jan 23, 2010 in Cleburne, TX. Caden (age 7, possible TFP carrier of dad’s unknown mutation) and Emily (age 3, TFP carrier) are very excited! boo1974bear@yahoo.com

Shelly is also Mommy to Bryce, Caleb and Noah ~ angels watching over their family

Lydia Faith Beever joined us on July 14 weighing in at 6lbs 10oz. We did not know if she would have MCAD so it was decided that I would deliver at the University hospital and hour away. Logan was born at the same hospital because of his prematurity (6 weeks) and was in the NICU for a week when we found out he had MCAD. We had a protocol letter from our son’s genetics office stating how often to check for blood sugars and how often to feed. I would nurse her and then give formula out of a cup every two hours until my milk would come in. The nurses kind of just let us do our thing and were great. Her blood sugar did read around 49 which I thought was low (they said that anything above 40 was ok) so we had them check at each feeding until it went back up. We had DNA testing done at the same time the NBS was done. We left the next day! I was surprised they let us but it was easier to be at home. We received NBS results four days later and DNA results five days later. She does not have MCAD but is a carrier. I was very shocked for I thought for sure she would have MCAD and was prepared to take care of her like we had done with Logan. At delivery, the cord was wrapped around her neck and I was so thankful to be at a hospital that would be equipped to take care of her. That delivery room filled so fast with nurses and doctors. She did not have any complications after delivery. We are happy that she does not have MCAD but we were prepared and accepting if she did. Logan is adjusting and loves his baby sister. We are enjoying them so much and are so grateful to God for overruling in her life.

Jamie & Melinda melindabeever@gmail.com

Logan MCAD 2
Lydia 3 weeks
CT
**Creamy Bow Tie Primavera**

Prep Time: 15 min  
Total Time: 35 min  
Makes: 6 servings

**What You Need:**  
8 oz. bow tie pasta, uncooked  
1 cup broccoli florets  
1 cup sliced carrots  
1 pkg. (8 oz.) PHILADELPHIA Fat Free Cream Cheese, cubed  
3/4 cup fat-free milk  
1/4 cup KRAFT Reduced Fat Parmesan Style Grated Topping  
1/4 cup chopped green onions  
1/2 tsp. Italian seasoning  
1/4 tsp. garlic powder

**Make It:**  
PREPARE pasta as directed on package, adding broccoli and carrots to water during last 5 minutes of cooking time. Drain.  
MIX cream cheese, milk, grated topping, onions and seasonings in large saucepan; cook on low heat until cream cheese is melted and mixture is well blended, stirring frequently.  
ADD pasta and vegetables; toss lightly.

**Nutrition Information:**
- Calories: 220  
- Total fat: 2 g  
- Saturated fat: 1 g  
- Cholesterol: 10 mg  
- Sodium: 290 mg  
- Carbohydrate: 37 g  
- Dietary fiber: 2 g  
- Sugars: 6 g  
- Protein: 13 g

Julie mom to Lexie, MCAD  
St. Paul, MN  
jmhagen23@hotmail.com

***I am always trying to come up with new healthy recipes for my family and daycare kids and figure my blog is way to keep track of them and to share them with family and friends. Feel free to take a look at it.- I can always add your recipes to it too! I will keep updating it so feel free to check back often.  
http://www.healthykitchens.blogspot.com/**

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**Low Fat Baked French Toast**

makes 8 large slices

**What You Need:**  
1 large egg  
1 large egg white  
3/4 Cup fat-free milk  
2 T sugar (white or brown, to taste)  
1 1/2 tsp vanilla (can use less, we like the flavor so use lots of this)  
8 slices of day-old (cheap!) wheat French bread, fat-free, about 3/4" thick

**Make It:**  
1. Heat oven to 450 degrees F. Slice the bread and set out to dry while assembling ingredients.  
2. Lightly coat a large baking sheet with cooking spray, set aside.  
3. In a shallow dish combine eggs, milk and vanilla.  
4. Dip bread slices in egg mixture, being sure to flip each slice to get both sides. Bread should not be falling-apart soggy, but thoroughly wet.  
5. Set slices 1" apart on baking sheets, bake for about 10 minutes, check for browning on the bottom and flip browned slices over. Bake for an additional 5-9 minutes until browned and centers are puffed.

**Nutrition Information:**
- Total fat: 3 grams per serving, protein 9 grams.

I couldn’t figure the overall calories because the bread used will affect that. It would be around 100 calories per slice for bread I used, I’d guess.

Janet  
mother of Jena, 18, LCHAD/mito  
and John, 19, ADD/Aspergers  
and Zoe, 15, vegetarian and nifty kid  
wordminder@yahoo.com

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I had to share this special cake that my mom made for all of us for Mother’s Day. Brooke absolutely LOVED it!  
**Ingredients:**  
*Angel food cake (about 6 pieces of cake torn up)  
*Non-fat, sugar-free pudding (flavor of your choice - my mom used chocolate pudding)  
*Low-fat Cool Whip

My mom took a 9 x 13 cake pan and spread the torn up pieces of angel food cake along the bottom of the pan. Prepare the pudding and put that on top of the angel food cake pieces. Refrigerate. Prior to serving spread a thin layer of Cool Whip on top. Cut into squares and serve. She had made it last year with angel food cake, vanilla pudding, fresh strawberries, and Cool Whip so it’s pretty flexible on changing it up.

Virginia Luchau  
vdahlen@microsoft.com

Brooke, 2 ½ years, MCAD

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I discovered a Fat Free Brownie mix - a product called **No Pudge Brownie Mix**

If you can’t find them in your local store here is a website. I recommend them to anyone looking for a quick, easy and fat free treat for their kids.  
http://www.nopudge.com/  
I found it at my local grocery store and they were so easy to make. You just mix the package with fat free yogurt and bake. And they actually taste like a brownie - I even had co-workers try them!  
Shannon Reynolds  
McKenny 19 mths (VLCAD)  
Porter 3 yrs (unaffected)  
Wilmington, NC  
sreynolds03@gmail.com
If you have a responsibility for or interest in the health and well being of young adults with chronic medical conditions and disabilities, you may be interested in receiving the “Transition Digest”. This free e-mail monthly newsletter typically includes information about emerging trends, promising health care transition practices, lessons learned, materials for youth and parents, transition related publications (from a broad range of journals), websites, meetings, and questions from subscribers. It does NOT address medical management, but rather focuses on issues like improving systems of care, promoting teen’s autonomy and medical decision making skills, assessing transition readiness and facilitating the transfer between pediatric and adult providers.

If you are interested in receiving the Digest (at no cost) send a request by e-mail to jgr@ichp.ufl.edu.

Past issues of the Transition Digest (from 2009 and 2008) are available, as PDFs at http://hctransitions.ichp.ufl.edu/listserv.html

Health care materials developed by the Institute for Child Health Policy can be seen at: http://hctransitions.ichp.ufl.edu/hct-promo/

•   •   •

Genetic Alliance recently learned about this resource and wanted to share it with you: Story Network is here—Your story is part of the Network. Real stories from real families living well with a child or teen with a health condition or disability. Enjoy stories, poems and pictures from families and share your own. Read “Hero Badge”, “The Slap”, “Carolina’s Story” and more. Be part of a community of strength and hope. Please tell families and colleagues to visit and spread the word about the Story Network: http://cshcn.org/support-connection/shared-stories-network

Alyson Krokosky, MS | Genetic Information Coordinator
Genetic Alliance | 4301 Connecticut Avenue, NW | Suite 404 | Washington, DC 20008
Phone: 202.966.5557 x218 | Fax: 202.966.8553
akrokosky@geneticalliance.org | http://www.geneticalliance.org

•   •   •

The Social Security Administration (SSA) has announced that it is adding 38 more conditions to its list of Compassionate Allowances. The new conditions include some rare diseases that primarily affect children. Compassionate Allowances are a way of quickly identifying medical conditions that clearly qualify for Social Security and Supplemental Security Income disability benefits. It allows the agency to electronically target and make speedy decisions for the most obviously disabled individuals. http://www.ssa.gov/compassionateallowances/newconditions.htm

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~ NEEDED FOR THE JANUARY 2011 ISSUE ~

FAMILY STORIES

PROFESSIONAL ABSTRACTS/ARTICLES OF ALL KINDS (Drs, Nutritionists, Genetic Counselors, Social Workers, etc.)
Please note that we also have an FOD KidsKorner/Adults Gallery and other Pictures on our homepage. To submit a pic please email Deb.


Thank you to all that have bought products from companies on the Internet that support the FOD and CafePress.com program of donating a certain percentage to Groups like ours. All of those links are on our homepage, right sidebar boxes.

Professional Donations: An Anonymous Foundation – generously assisted with helping @20 Families attend the 2010 Conference, as well as future conferences and our other Trust Funds. Sigma-Tau Pharmaceuticals, Inc. Chuck Hehmeyer of Raynes McCarty. Microsoft Matching Gifts Program. Booklovers – as part of McKenna Widmann’s (MCAD) Book Sale Family Fundraiser.

We greatly appreciate donations to help with postage and copying costs, website fees, supplies, conference costs, phone calls around the world, and raising funds for FOD Clinical Training and FOD Research. US Checks can be made payable to ‘FOD GROUP’ and mailed to Deb.

We also have a PayPal link on our homepage. ALL US donations are tax-deductible. Our Tax ID # is 83-0471342.

2009 Donations/Expenses for the FOD Group
[donations/interest from Jan 1, 2009 thru Dec 31, 2009]

- FOD General Fund - $1,252
- FOD General Trust Fund - $53
- FOD Clinical Trust Fund - $58
- FOD Research Trust Fund - $1,779
- FOD Petty Cash Fund (balance) - $76.84

Total 2009 Expenses thru 12.31.09 $6,123

The 2009 return is on our site’s homepage

All Grief Consult donations are deposited into the General Fund, as are Bracelet and Ribbon Sales, CafePress.com, iGive, Goodsearch, and any donation that isn’t designated for the other Funds. The General Trust Fund is to save/earn interest for the 2012 Conference and other annual costs. Once the Research and Clinical Funds reach a substantial amount, we will be able to offer grants to clinicians and researchers in the US.

Thank you to Erika Wallace - erikawallacepa@yahoo.com
(Mailing Lists), Mary Lingle - Mcartwrite@aol.com
(Web Page) and Brian Gould - (newsletter) for all your hard work.

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.

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Please ADD me to your mailing list
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Please include ideas for future issues or your questions