Organic Acidemia Association
www.oaanews.org

Newsletter

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WHAT'S INSIDE

Where Does the Time Go?

Before we know it this year will come to an end. Since I'm getting older, time seems to going by so much faster!

I'm happy to report that our 2008 FOD/OAA National Metabolic Conference was a huge success. I would like to thank all of our sponsors (see page 3) and speakers who came to Pittsburgh to share their expertise with our families. I also would like to thank Deb Gould, my partner in organizing the conference….could not have done it without her! We had well over 150 in attendance for both days of the conference. We had a very nice hotel setting, just walking distance from the Pittsburgh International Airport. It was so great see so many of our families – some new faces, some old…. and so many little ones too….Thanks to for Joann Evans and Erin MacLean (MMA Mut 0 moms) for organizing our child activity room. They brought a variety of games and crafts to keep our little ones occupied and parents/grandparents could still be close to the conference rooms. Our lunch selection was outstanding thanks to Ellen Shank, a FOD mom who helped with all the preliminary logistics with the hotel. Deb and I were quite pleased overall and received positive feedback from both families and professionals. We are looking forward to planning our next conference, which will be held sometime in the summer of 2010. We are not certain where or who will host the next conference….but we are hopeful it will be somewhere central so as many families can attend as possible.

Gwen Abele and Jana Monaco presented our FOD/OAA Family Quilt on Friday after lunch the first day of the conference. The quilt is such a touching reminder of the lives of our kids. More information and the picture of the quilt can be seen on page 11. A website is also available to view each a photo of each quilt square. Thank you to Stacey Conley who stitched the quilts together --just in time for unveiling at the conference.

As always, it my pleasure to share the family stories in this issue of the OAA newsletter. Please let me know if you would like share or update your child's story in a future issue.

Kathy Stagni

Board of Directors

The Organic Acidemia Association(OAA) provides information and support to parents and professionals dealing with a set of inborn errors of metabolism collectively called 'organic acidemias'. The OAA is a volunteer organization registered with the IRS as a 501(c)(3) non- profit corporation. Donations to the OAA are tax-deductible. OAA publishes a newsletter three times a year, hosts an internet-based list-serv for information exchange and maintains a website. These services are funded by donations from corporation and individual members. Annual membership donation of $25 (U.S) and $35 (international) plus $5 for the family roster is requested, but not required. Our 501(c)(3) non-profit status qualifies OAA for United Way donations through their write-in option. If there is a write-in option, just write "Organic Acidemia Association" in the blank line on your pledge card. Donations can also be made at OAA's website through the "PayPal" and the "Network for Good" option.

- The information contained herein does not necessarily represent the opinions of our Board of Medical Advisors or Board of Directors.
- Letters and photographs sent to OAA become the property of OAA and may be used or edited at the discretion of the OAA staff.
- Names or information will be kept confidential only if specifically requested in writing.
- This newsletter does not provide medical advice. You should notify your health care provider before making treatment changes.

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2008 FOD/OAA National Metabolic Conference
Pittsburgh, PA – July 18-19, 2008

2008 FOD/OAA National Metabolic Conference Sponsors

Thank you to all of our speakers, volunteers and sponsors.
We could not have hosted this conference without you!

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A Special Thank You to Dr. Bob Cicco – AKA "Dr. Clown"

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Children's Hospital of Pittsburgh of UPMC Sponsors National Conference for Families of Children with Rare Genetic Disorders

Children's Hospital of Pittsburgh of UPMC Sponsors National Conference for Families of Children With Rare Genetic Disorders

PITTSBURGH – July xx, 2008 – Children's Hospital of Pittsburgh of UPMC is sponsoring and helping organize a national conference for families of children with rare genetic disorders.

Under the leadership of Jerry Vockley, MD, PhD, Children's Hospital's Division of Medical Genetics has become one of the nation's leading centers for the diagnosis, treatment and research of genetic diseases, attracting patients from all over the world.

The Fatty Oxidation Disorders (FOD) Family Support Group/Organic Acidemia Association (OAA) National Family Conference will be held Friday, July 18, and Saturday, July 19, 2008, at the Hyatt Regency Pittsburgh International Airport. More than 160 families and approximately 30 professionals from across the United States and Canada are expected to attend.

Children's is the sponsor of the two-day conference, which will feature talks from genetics experts from around the country aimed at educating families about the latest treatment and research information. Among the speakers are Dr. Vockley, chief of the Division of Medical Genetics at Children's, and several other experts from the division.

"Relatively speaking, the field of medical genetics is in its infancy, and through our research we are making new discoveries and developing new therapies every year. The completion of the mapping of the human genome also is helping us make tremendous strides in understanding and treating genetic disorders," Dr. Vockley said. "For patients with genetic conditions and their families, this national conference is a way to learn about these advancements and potentially access breakthroughs in treatment."

One of the topics Dr. Vockley will discuss at the meeting is expanded newborn screening for genetic disorders. Newborn screening is a simple blood test that can detect disorders that are not immediately apparent after delivery. Each state in the United States requires screening tests, but the specific tests performed vary among the states. The FOD Family Support Group and OAA, as well as Dr. Vockley, advocate expanding newborn screening to identify genetic disorders, which individually are rare, but collectively common, affecting three of every 1,000 children born.

Fatty oxidation disorders are genetic metabolic deficiencies in which the body is unable to oxidize (break down) fatty acids to make energy because an enzyme either is missing or not working correctly. If undiagnosed and untreated, these disorders can lead to serious complications affecting the liver, heart, eyes and general muscle development, and possibly death.

Organic acid disorders are a group of rare inherited conditions. They are caused by enzymes that do not work properly. A number of enzymes are needed to process protein from the food we eat for use by the body. Problems with one or more of these enzymes can cause an organic acid disorder. People with organic acid disorders cannot break down protein properly. This causes harmful substances to build up in their blood and urine. These substances can affect health, growth and learning.

For more information about fatty oxidation disorders, please visit www.fodsupport.org; for information about organic acid disorders, please visit www.oaanews.org; and for more information about Children's Division of Medical Genetics, please visit www.chp.edu.

Sherry Jaquith, D2HGA, Age 17

My daughter Sherry was born with D2HGA. It was still a very novel disease at that time. I think there may be about 60 D2HGA's globally?

At birth, she was tiny. Even at 36, I was a new mom and not too up on what should and shouldn't be...and by the 28th didn't have time to find out! Birth was not complicated; I was induced on 6/5/91. The only oddity at the time was when cleaning her, her hair came out where they wiped her head. This alopecia and subsequent pre-malignant melanomas is from a disorder called Linear Subaceous Nevus Syndrome and is isolated only to her, none of the other children have it.

I mentioned to three different doctors that Sherry had abnormal eye movement. I was told "babies do funny things with their eyes." I was in the hospital on 6/23 with a post-partum infection from a dirty epidural stick. My best friend kept her for the night for me as she was off of breast milk. When she brought her back, she mentioned that she was doing funny things with her eyes.

When I was discharged, we went home and I had her dad get the video cam and I taped her eye movement, grabbed the tape, called the doctor and said something was wrong with her, I taped it and we were on our way in.

We didn't have an appointment but he did see us right way. For the first time was the "S" word..."It is very rare for a newborn to have seizures," Then he sent us down for a cranial ultrasound (which came back normal). By the time I got home, I had a message to call him immediately. My heart went to my stomach. He told me he viewed the tape. I was to bring her in for an EEG at 6am, then take that print out and the video with us to see a pediatric neurologist in Austin, TX.

Things went to hell in a hand basket from then one. Seizures continued to increase both in number and in severity so we were in and out of the hospital 5 times before she was 3 months old. (Our longest stay in-patient was 65 days) When she was 3 months old, we had been home from the hospital about 3 hours. I set her in her infant swing and went into the kitchen to get some tea. When I looked at her (kitchen and dining room were adjoined) I saw her color was deep red. I ran and picked her up, tipped her over to let any formula still in her mouth should she have spit up out. She was in a prolonged tonic (stiff) stage of seizure. She was purple/red and she wasn't breathing. Holding her was like holding a hard rubber baby doll.

By the time I called 9-1-1 she was breathing on her own, but she was still blue and her heart rate was over 200. (she was just a few days over 3 months then) We went to Spark's office from ER and we stayed there until there was a medical provider to meet us at home with monitors and oxygen. Didn't need to use it but 4 days as we were headed back to the hospital.

It was during this time, lab work came in that she had some form of Glutaric Acid but it was not quite like what they usually see in labs. I had the choice of Texas Children's' in Houston or Dallas, TX. I asked her doctor who had the best and he said Houston. Within 5 hours, we were in their ER after a quick trip by ambulance.

Once there, they confirmed my suspicion that Sherry had gone blind during her last seizure. We were in ICU for a couple of days, then PCU, and then sent up to a room. It so happened that the genetic/metabolic team were working with a research group in Europe, headed by Dr. Cornelius Jacobs. They were studying L-2-Hydroxyglutaric. This was Sherry's initial diagnosis and I was told she would not survive 6 weeks and very likely be able to survive even another three weeks. Typically, children with L2HGA did not have the type of presentation and severity that Sherry had.

It was some weeks later that Dr. Jacobs had come across some data published by Drs. Chalmers and Nyhan, et al, in 1983 on an adult male who excreted d2h in urine and had a protein losing enteropathy. The had no D2H found in blood serums or cerebral spinal fluid, nor were there any elevations of GABA. Dr. Jacobs had then identified Sherry as having the D-isomer of 2hga rather than L-isomer.

There was no protocol for treating it. We just did not know anything about it so she was give the same treatment regime as children with L2HGA. We had a formula base called Product 80056, Promod (protein) and Polycose (calories) that I mixed with distilled water to their prescribed measurements. By this time, she was eating rice cereal and oatmeal mixed with her special formula. She also loved bananas. She was put on Riboflavin which she projectile vomited after every dose so this was discontinued. She was also placed on carnitine. (we stopped giving her that when she was about 11 years old and maintaining a steady level on her own). We were already on Reglan for reflux and by that time we were on Tegretol, Phenobarbital, Dilantin and Lamictal for seizures. Being on 4 together were not maintaining seizure control. We have been on every available seizure medication on the market. We are currently on Zonnegran and Clonazapam and the biggest control means for her seizures and over-all health has been cornstarch.

Sherry has been on ketogenic diet and failed miserably because of inability to metabolize the high fat content and low protein and tightly restricted carbs. Myself and some others have found that they did better on high carbohydrate diets, lots of starchy foods, veggies and fruit. She gets a lot of pastas and potatoes and bananas. Sherry has had a lot of problems in between. She had her g-button put in when she was 1 1/2 years old. Also when she was 1 1/2 she had her sister Grace. She was the first amnio check for D2H and unfortunately had levels even higher than Sherry's. I lost her mid-term, about 23-27 weeks, on 12/28/92. I sent her body first to Houston and from there to Amsterdam. If I had to lose her, I wanted her life to have meaning by providing information to help Sherry and any other children that followed. Fortunately she did.

When Sherry was diagnosed, I had heard of gene therapy and asked about it...this was still very new. I was told that it would be impossible to find the defective gene and if they did would not be in Sherry's lifetime or too late to help. (Hah, look how far they've gone now with it!)

When Sherry was 3 years old, her little brother was born. The amnio on him showed he was negative for D2HGA but he had a different metabolic disorder that threw us all for a loop called Hydroxymethylmalonic Acidosis. Fortunately, we caught it during newborn

Sherry Jaquith continued on page 7

Sherry Jaquith continued from page 6

screening...as soon as he was born, his first urine was collected, dry-iced and flown priority to Amsterdam. Dr. Jacobs called Houston and they called me to bring him in. He responded to treatment and has been free from HMMA since. His levels were so ridiculously high, that we had a repeat level done when he was 8 years old and levels were still in normal range. We pushed for expanded newborn screening. It saved Nathan.

Sherry is still cortically blind, she can sit independently. She lost the ability to bumper-rump, which is how she moved around in 2001. Her vision has come and gone but mostly stays to within a one foot range up to one meter. Depends on how her seizures are at the time.

She has good word comprehension. She does not speak, but she uses gestures, expressions, tones and handclaps to communicate. She can finger-feed herself and she can get a spoon to her mouth and out if you can hand it to her...heck, she will TAKE it from you... she does not like to be fed if she can do it herself.

It has been a bumpy time from the time she was born until now. Thank God for Nathan because at almost 14 years old, he is a big help to me with his "Big Sissy Who Is Little" as he used to call her when he was little.

Sometimes things get scary. She has quit breathing several times during the early years; we have had epileptic statis, metabolic crisis. She has had a number of surgeries. she has had a fundoplication and nissen, she has an ileostomy, she has a vagal nerve stimulator (which is absolutely useless for seizure control...and after surgery to correct defective wiring and stimulator-it has yet to do well. the wires fractured and this is again a problem coming up with the new wires), she has a portacath implanted but it is not positioned so we can't access it, this is going to require an additional surgery.

She has the spondyloenchondromatosis, linear subaceous and epidermal nevus syndrome, intractable seizures, cortical blindness, severe developmental delay, movement disorder, ileostomy, and she is the most beautiful wonderful child that any mother could ask for. When she smiles your entire heart lights up. She has an indomitable spirit and courage that you rarely see in adults. I hate having IV sticks and she no longer even flinches.

I cry for the child she could have been and rejoice for the one she is. I still grieve for my little Grace and always will because I loved her and wanted her so much, something just aren't meant to be... you make decisions out of love and they are hard to live with. Every milestone achieved is a celebration, every birthday is a victory. I cry for her when I know she is in such deep pain and never complains, sometimes I cry when people are crude and have said things about her in front of me, but those are tears of anger which for them are extremely dangerous tears! I still have times when I am afraid for her but know that I can't dwell on those things that do, we just push on ahead because this is how we live our life.

I found myself with a great responsibility and a great joy and I know that all of us feel this way about our very precious gifts.

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Damian, 3-MCC, Age 4 months (Newborn Screened)

Damian was born on April 27, 2008 at 3:41 pm and weighed a healthy 8 lbs. 9 oz. He is our sixth child and all our children had been perfectly healthy so when the nurse took him to do his first newborn screening test, we really didn't give it a second thought. And I didn't have to give it a second thought until Damian was five days old. That's when the pediatrician called us personally at 7:00 pm. I instantly knew something was wrong. She told us that Damian's newborn screening had come back abnormal for 3mcc. I was in such a state of shock that I didn't really ask her any questions. She asked us a few questions about how he was doing (was he sleeping too much, difficult to wake, any vomiting, etc.) and since he seemed to be doing fine, told me that I had to take him to our local children's hospital first thing in the morning to get a second screening done and have a urinalysis. We also had to take him to see her the next day to she could verify that he was in fact doing okay.

Of course, once my mind wrapped around what I had just been told, the first thing I did was look 3mcc up on the internet. That was a big mistake!!! All I found were horrible scenarios!! That night there was no sleep for me!

After getting the tests done the next morning we went to see the pediatrician. She confirmed that Damian was perfectly fine. She also explained that the horrible things I found on the internet were what could happen to a child who had 3mcc and was not diagnosed early. Diet and supplements can prevent all those things from happening. She told me not to worry too much until we got the results from the urinalysis and second newborn screen. But of course, I worried about it every minute of every day!

After about a week, the results came in and again confirmed the 3mcc diagnosis. The doctor ordered some blood tests, which in another week came back with the same thing, Damian had 3mcc. We were seen by a geneticist who helped us understand a bit more about 3mcc and what Damian's future held for him. They also had me tested to make sure that it wasn't me that had 3mcc (it can pass through the placenta) but my tests came back negative. He was also put on L-carnitine, which he has to take 3 times a day and we were referred to a metabolic specialist at the Children's Hospital of Philadelphia. We are now waiting for test results to come back for 4 of our other children. We only know for sure that our 2 year old daughter is negative because she was newborn screened for it. Our state did not begin testing for 3mcc until about 4 years ago.

Damian is still perfectly healthy and thriving. Without the newborn screening diagnosis things could have turned out much worse. Newborn screening may have very well saved our son's life! Thank you for helping promote awareness of newborn screening.

Sincerely,
Laura
Mom to Damian
motheroffour32@gmail.com

Research Update

Update on Gene Therapy for Propionic Acidemia

Michael A. Barry, Ph.D., Professor, Departments of Medicine, Immunology, and Molecular Medicine, Mayo Clinic

The Barry Laboratory at the Mayo Clinic is working on a project to test if gene therapy can be used to treat propionic acidemia (PA). To test this, PA mice from Dr. Miyazaki are being used as subjects for delivery of the PCCA gene to their livers. One of the PA mouse models has both copies of the PCCA gene knocked out. These mice are born, but do not survive past 36 hours due to total absence of functional enzyme. To date, the Barry laboratory has tested three different gene therapy vectors systems to treat these severely affected mice including two types of adenovirus vectors and adeno-associated virus (AAV) vectors. After the mice are born, they are injected within 6 hours of birth with one of the gene therapy vectors. By several approaches gene delivery by adenovirus or AAV has extended the lifespan of the mice up to 3 times their normal spans. This demonstrates that gene therapy can indeed mitigate the toxicity of PA.

While this demonstrates the potential of gene therapy, PA mice ultimately still succumb to the disease. We hypothesize that this may occur because these mice are already born with severe metabolic disruption, so the gene therapy is essentially "chasing" an ongoing metabolic crisis. Given this, we are testing if we can apply the drug interventions that are in current use in PA patients to stabilize the metabolic crisis in the mice to give time for the gene therapy to correct the genetic defect. Ironically, testing these approaches in neonatal mice is harder than in humans. For example, it is very challenging to attempt to restrict protein in the diet of a neonatal mouse that can normally only be fed by nursing from its mother. Likewise, carnitine supplementation and Carbaglu treatments are complex in small animals. While challenging, we are testing the combination of these approaches with gene therapy. In summary, we believe we actually have a PA model that may be more stringent than the setting encountered in patients. Given that we observe significant genetic correction in this difficult model, this suggests gene therapy may have utility for treating PA patients.

Another aspect of this work is our observation that the background genetics of the mice appears to strongly influence the severity of the disease. As we have bred the PA mice with a particular strain of mice, PA symptoms have increased to the degree that some mice with only partial PCCA deficiency cannot even breed. These mice, which happen to be the ones we have tested gene therapy in, are essentially a worse case scenario where it is difficult to produce long-term disease correction. We are currently breeding the PA mice onto other genetic backgrounds. We expect that PA symptoms will be reduced on different genetic backgrounds and that we will see longer term effects of gene therapy in these models. If this is the case, this has implications in humans, since it suggests that variations in other genes may influence the primary symptoms of PA as well as response to drug or gene therapy. If so, one may be able to screen for not only mutations in PCC genes, but also in these modifier genes to "tune" drug and gene therapy to match each individual's genetic background.

Developing a new treatment for hyperammonemia in PA and MMA: Carbaglu

N-carbamylglutamate may decrease ammonia levels in propionic acidemia and methylmalonic acidemia patients

N-acetylglutamate (NAG) is a chemical produced in the liver that assists in removing ammonia from the body via the urea cycle. NAG deficient patients develop hyperammonemia which can be life-threatening. A person may be born with a genetic defect in N-acetylglutamate synthase (NAGS), the enzyme that produces NAG, or develop a secondary NAG deficiency such as in propionic acidemia (PA) and presumably methylmalonic acidemia (MMA). In these organic acidemias accumulation of propionyl-CoA in mitochondria of the liver decreases NAG production. Valproic acid treatment can also decrease NAG production.

Dr. Tuchman and his colleagues recently showed that a NAGS-deficient patient taking Carbaglu® (N-carbamylglutamate) had their urea cycle functions and ammonia levels restored to normal. This was done by comparing amounts of [13C] radiolabeled sodium acetate in the patient's urea before and after Carbaglu treatment. They therefore hypothesized that PA and MMA patients who develop hyperammonemia might also benefit from taking Carbaglu. To investigate this hypothesis, they treated a PA patient with Carbaglu who showed a good increase in urea production as well as a decrease in glycine glutamine and alanine levels. These results indicated that Carbaglu helped normalize the urea cycle in this patient. They now have a reliable method for measuring the effect of Carbaglu on nitrogen metabolism and the results from the patients strongly suggest that Carbaglu could be an effective treatment for either inherited or secondary NAG deficiency. Dr. Tuchman and his group would like to reproduce these results in more PA and MMA patients to see if Carbaglu can be developed into a new treatment for high ammonia in the most common organic acidemias. Hyperammonemia is only one of many possible uncontrolled metabolic factors in PA or MMA, but elimination of high ammonia could be of benefit.

NEW DRUG STUDY FOR PATIENTS WITH HYPERAMMONEMIA

If you, your child, or someone you know has a diagnosis of carbamyl phosphate synthetase I (CPSI) deficiency, N-acetylglutamate (NAGS) deficiency, Propionic Acidemia (PA), or Methylmalonic Acidemia (MMA) you or they may be eligible for this study. Eligible patients must be:

- 1 to 70 years of age
- Have a diagnosis of one of the following conditions: CPSI deficiency, NAGS deficiency, PA, or MMA
- Be willing to travel to Washington D.C. for a 4 day study (travel and lodging paid by Children's National Medical Center)

```Your participation may help provide an additional treatment option for people with these conditions who suffer from elevated blood ammonia levels.

For information on cabaglu and the above studies, contact:
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GeneDxOffers DNA Testing for Organic Acidemias

GeneDx is a DNA diagnostic laboratory located in Gaithersburg, Maryland that is dedicated to providing outstanding services to people with rare genetic diseases, their families and the health care professionals who take care of them.

GeneDx was founded in March 2000 by Sherri Bale, Ph.D., FACMG and John Compton, Ph.D., both former research scientists from the National Institutes of Health. Initially, GeneDx introduced DNA-based tests for diagnosing patients with rare skin diseases. Today, testing is offered for over 150 different genetic disorders, including DNA testing for metabolic conditions.

GeneDx currently offers testing for the following organic acidemias: methylmalonic acidemia, methylmalonic aciduria and homocystinuria, cblC type, propionic acidemia, 3-methylcrotonyl-CoA carboxylase (MCC) deficiency and glutaric aciduria type 1, isovaleric acidemia, HMG-CoA lyase deficiency and holocarboxylase synthetase deficiency. In the near future testing will also be available for isobutyryl-CoA dehydrogenase deficiency.

DNA testing is often used by families and physicians to confirm a diagnosis of a specific organic acidemia in an individual whose diagnosis is based on biochemical test results. The entire gene is studied to look for mutations in the affected individual. Persons with an organic acidemia are usually found to have two mutations; one mutation on each copy of the gene. Once the two mutations in the specific gene are known in the affected individual, testing of his or her family members (carrier testing) may be offered. Carrier testing enables relatives to determine if there might be an increased risk for them to have a child with the same disorder. If a family member is found to be a carrier of the mutation, their spouse or partner may then be tested to look for a mutation in the gene. If both members of a couple are identified as being a carrier of a mutation, they have a 25% chance of having a child with that specific organic acidemia in each pregnancy. For such couples, who are identified as carriers of a known mutation, GeneDx can offer prenatal diagnosis, if desired.

GeneDx is committed to providing the highest quality service. We have highly trained and qualified staff, whose areas of expertise cover all of the widely diverse aspects of clinical and molecular genetics. Our experts include a board certified Ph.D. geneticist who specializes in metabolic disorders and a board certified genetic counselor with 5 years of experience in coordinating a metabolic clinic and caring for persons with metabolic diseases.

Our staff is available to discuss your case and can also make testing recommendations to your physician. For more information about GeneDx and DNA testing for a specific condition, please visit our website at www.genedx.com.

North American Metabolic Academy
September 21 to 27, 2008
The Airlie Center, Warrenton, Virginia www.airlie.com

The rarity, uniqueness, and variability of metabolic disorders, as well as the need for an individual approach to treatment of each disorder, make treatment of inborn errors of metabolism very complicated. Moreover, clinical training of medical geneticists to care for patients with these disorders has lagged behind the entry of affected patients into the health care system.

In order to address the urgent need for educational collaboration, the Society for Inherited Metabolic Disorders (SIMD) has established the North American Metabolic Academy (NAMA). NAMA will provide a forum for providing medical genetic and biochemical genetic trainees to develop a base of knowledge of inborn errors of metabolism and exposure to the diagnosis and management of metabolic disease. Taught by an internationally renowned faculty in an informal setting that emphasizes interaction with other trainees, participants will learn an approach for understanding and managing metabolic emergencies and long-term treatment of biochemical disease. Ongoing access to an interactive web site will make NAMA a long-term opportunity for learning for participants.

Established in 1978, SIMD aims to increase knowledge of and promote research in inborn errors of metabolism in humans and to stimulate interactions between clinicians and investigators in inborn errors of metabolism. The Society seeks to foster training and maintenance of a core of qualified investigators and practitioners in the field and to promote public understanding of inborn errors of metabolism. These objectives are achieved by facilitating communication and interaction among experienced clinicians and investigators and by advocating for patients and research through public policy forums.

Traditionally, general clinical genetics training has included exposure to biochemical genetics, and many general geneticists are often called upon to help care for individuals with biochemical disorders. With the paucity of experts dedicated to inborn errors of metabolism, it is likely that medical geneticists will continue to play a significant role in delivery of care to these patients. However, many of these disorders are not well known to most geneticists, and adequate clinical exposure to them exists only in specialized metabolic centers.

In an informal setting that emphasizes interaction with other trainees, an internationally renowned faculty will educate participants in an approach for understanding and managing metabolic emergencies and long-term treatment of biochemical disease. The program includes seminars on disease recognition and diagnosis, workshops to integrate understanding of normal metabolism and pathophysiology, and case-based workshops on diagnosis and management. Ongoing access to an interactive web site will make NAMA a long-term opportunity for learning for participants.

Update on Andy Greenland, MMA Cbl C, Age 23

It's been about 10 years since we told you about Andy, and we wanted to give you and update! Andy was diagnosed in 1985 where we live in Baltimore at Johns Hopkins Hospital with CblC at 3 months. He has been very stable metabolically over the years – he did have partial complex seizures several times per year from 1990-1998 or so – and he has been seizure free since then. He is at about an 8 year old level developmentally. He has no central vision and limited peripheral vision – but he manages very well with the vision he has. He is currently on Betaine, weekly IM B12, carnitor, folic acid, and vitamins for his vision. He is good friends with his younger brother, Alex, who is 21 years old and attends Northeastern University in Boston.

He completed school at Maryland School for the Blind in 2006 and is now living and working in northern Maryland at Penn-Mar organization – he divides his work time between a local nursing home where he spends time visiting with residents (he loves them and they love him) and working on cleaning contracts at local hotels. He has a job coach for now to help him stay focused and complete all tasks accurately.

All in all, Andy is doing very well – he has work that he likes, he lives on his own with supervision, he has his passions of baseball and music (especially doo wop – and especially on YouTube). He is great with the playstation and the computer and he navigates through baseball and other web sites quite nimbly. He loves going to Orioles games and he has met a number of the players. He's a big fan of all the Lion King movies and music. He loves to play baseball with his dad and is quite a decent bowler. He is very stable medically, and slimmer and healthier now than he was a couple of years ago. For his health we owe a great deal of gratitude to Dr. Charles Venditti and Dr. Jennifer Sloane at NIH and the MMA study they are doing.

My first reaction when I read about the study in the OAA newsletter when it started was – no way do I want to spend a week with Andy miserable and stuck in the hospital if we're not sure it's going to benefit him in some important way. At that time, Andy was living at home and I was driving him to work at 6am every day, and I was pretty generally exhausted. But when his house came through, it seemed like a perfect time to check him completely checked out by experts who see lots of MMA cases. (When Andy was diagnosed, the docs at Hopkins had seen only one other child with CblC - and we were very fortunate they had seen her!)

Jen Sloan, who was coordinating the study, was immediately warm and welcoming – she had me come in ahead of our first visit in January 2007 to get the lay of the land and complete the paperwork. We found the gym on the 12th floor so Andy could play basketball between appointments. Jen and her team set us up at a local hotel so it would feel more like a vacation than a hospital visit.

It was an eventful week – the second day Andy showed some potential abnormalities on his heart and liver, so we needed more tests on the third day. Happily, the subsequent tests had more positive results. Each day was pretty full with appointments, and any spare time we had Andy was on the computer in the 9th floor waiting room or playing basketball on 12. He got to know the 9th floor staff, the phlebotomists (Joyce was his favorite), Dr. Paul, the Orthopedist, and Dr. Brooks, the Ophthalmologist who sees kids with MMA. Jen Sloan was a gracious and generous point person, and she even took time to print color lion king pictures for Andy.

The results of all of the studies were very helpful – Andy's triglycerides were way above normal, and we needed to change his diet dramatically and get his weight down. Dr. Venditti was impressed by Andy's overall health but concerned about the potential long term effect of high triglycerides.. And, we learned that Andy may be the oldest male in the world with early onset MMA CBlC. We were kind of proud of that – Andy still tells people that he is the "oldest in the world".

We returned in January 2008 for our second annual visit – Andy had been looking forward to it for months – seeing his friends, Jen especially. And the staff remembered him and Jen again had Lion King pictures for him. Andy's results were much better this time – he had lost about 40 pounds, his triglycerides were close to normal. His other studies looked pretty good as well. He was a little off metabolically (not high enough B12 level, too high in homocystine) and so we increased his B12 injection regimen from every other week to weekly.

Dr. Venditti and his team have been very helpful in increasing our understanding of MMA CblC and its implications for Andy – as well as telling us about potential experimental treatments for vision improvement down the road. Even though Andy is a pioneer, one of the oldest people with early onset MMA CBlC, we are reassured that he has a terrific team of knowledgeable and caring people looking out for him.

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FOD Family Support Group members at the conference.

OAA/FOD Quilt Project

"In This Together"

Our quilt was made to be displayed at the 2008 OAA/FOD Conference. Each square was designed and created with the greatest love to honor children born with an Organic Acidemia or a Fatty Oxidation Disorder. Squares were received from all over the United States and Canada.

When we talked about this quilt project awhile ago, my overwhelming feeling at the time was to stitch together a wonderful, cozy quilt, with all our stories, and be able to wrap it around each of you and warm and comfort you and help relieve your anxieties and stress. A tall order, but this is what I had in mind when we first conceived the idea! Maybe that is not physically possible, but when you look at it and enjoy reading the stories of "all our children", remember this was the original intent. That and honoring the vision of our dear friend, Jana Monaco, our graceful warrior in Washington, who has been able to articulate the need for new born screening all across the country.

Let this quilt be a visual reminder of the children and adults and all their families who already have been affected, and live day to day with the real possibility that their child might not make it to adulthood, a parent's worst nightmare.

View squares at: www.freewebs.com/angardens/apps/photos/

I love you all and honor you!!

Gwen Abele
50 Waverely Oaks Rd.
Waltham, MA 02452

You can still add your child's quilt square. The squares should be 6 1/2 by 6 1/2 inches. Include a little story or background for the journal that will travel with the quilt. The squares can be mailed to Gwen at the address above.

Joann Evans and Erin MacLean represent OAA at the recent UMDF Conference in Indianapolis.

Jana Monaco with Montel Williams at the 2008 NORD Gala.

NORD Gala - Rhonda Oberhelman, Tori Wheatley (IVA), Lesli King (Sigma Tau), Tom and Jana Monaco

Tyler Reimers, MMA Cbl A, Age 20

My name is Tyler Reimers. I am 21 years old. I was born and still live in Hillsboro, Oregon with my Mom, Dad and 15 year old brother Mark. I was diagnosed with Methylmalonic Acidemia CblA at 6 months old, after my first crisis while I was in a coma by Dr. Buist. After I came out of coma and my family was able to take me home. During ages 1-4, I sometimes became very sick, some of those times I had to go to the hospital. I didn't grow as fast as the other kids. I also didn't eat very much as a kid, so from about 7 months to 4 years old, I had to be on an NG feeding tube just to get the minimum amount of food to survive, because I just refused to eat. I also developed some speech problems. My parents took me every week up to the OHSU to get help for me for my speech and eating problems, so I would be able to attend elementary school. I got off the feeding tube around 4 years old. I learned to drink my formula in a sippy cup, but it would take me at least an hour to drink 4 ounces.

In elementary school, I was still the smallest and shortest kid in my class. I would sometimes leave class to go to lower level classes in the school with other teachers. I played baseball from kindergarten until fourth grade. In 5th grade I finally got to 50 pounds and had a big party to celebrate. When I got into Jr. High my height started to level out. I was not the shortest in my class anymore. At the beginning of Jr. High I started at about 4'11 and was 5'2 at the end of Jr. High. In the 8th grade I started to get back into sports. I joined the wrestling team during the winter and at the end of the season had about a .500 record. I wrestled at about 90 lbs. In the summer I started tennis and competed in a team tennis tournament. In high school joined the wrestling team and tennis team. I lettered all 4 years in wrestling and 3 years in tennis. I did notice that during sports I would get more fatigued faster than my teammates and opponents.

Toward the end of high school, I replaced my formula drink with a vanilla carnation instant breakfast everyday. I am still a very picky eater and have a very limited menu. I never eat meat, but I eat a lot of French fries and bread. I like mostly salty foods and dip my food in different condiments. I take 6 pills of Carnitor and give myself 3 shots a week of Hydroxycobalamin for my MMA. I am currently attending Portland Community college and in about a year or so, I am planning to transfer to Portland State University. Since I had an IEP, I am able to get extra help in college like a note taker and extra time on tests. Because of fatigue, memory and learning issues, I only take 2 classes a term, so it will take me longer to get through college.

If you have any questions, my e-mail is Wrestlertyler@aol.com

Tyler Reimers
Janet Reimers (Mother)
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503-648-0613

(Editor's Note: At the conference, Tyler handed me a check for $1000 for the OAA/MMA Research Fund. Tyler raised $200 from the OAA Schwan's fundraiser and had about $300 in private donations from family and friends that did not want to order from Schwan's. Then Tyler matched the $500 from his own money that he earns as a wrestling referee. Thanks so much Tyler for donating for Dr. Venditti's MMA research!!!)

Conrad Cota (Age 25, MMA Mut-0) and his new bride at their wedding 4-27-08.

Shelton Hall, Age 3, Glutaric Acidemia, Type 1, Visits Give Kids The World for his Make A Wish Trip.

Bailey Baio Angel Foundation

Angel Foundation

http://www.baileybaioangelfoundation.com

This new Foundation was started by Scott and Renee Baio to promote newborn screening in all fifty states. They also plan to raise funds through promotional activities and sales to support children and families affected with GA1 and other organic acidemias through the creation of provisional support programs including food, vitamin and emotional support efforts.

Zachary Wyvill, Glutaric Acidemia, Type 1, Age 5

Hello from the Wyvill family: David, Cindy, Zachary, and Nathan. Born in California in April 2003, Zachary has Glutaric Acidemia Type 1 (GA1), which was diagnosed after a neurologic crisis in infancy. He has severe brain damage typical of this disorder, meaning his motor skills are devastated and he has dystonia affecting his whole body. He is a smart little monkey, with a sense of humor and an infectious grin. Our story was first made public as part of the newborn screening movement. Zachary was featured on the front page of the Wall Street Journal, on ABC's Evening News, and in several local newspaper and magazine articles. Most importantly, he was one half of the "two Zacharys" story which was started by Mike Waldholz at Wall Street Journal, and used by the March of Dimes in California to hammer home the need for comprehensive newborn screening legislation. In this way, we joined the rising tide of the NBS movement and rode the crest of that wave to success in California's legislature.

Zachary is also a twin. Brother Nathan is not affected by GA1, although he is a carrier like Mom and Dad. Nathan is also a funny, smart, quirky kid who is a great model for Zachary. The boys interact like brothers do. Nathan will graciously offer his brother up for something he himself doesn't want to do, such as: "Nathan, it's time for your haircut!" "No Mommy, Zachary can go first…" This happens a lot, but don't worry, Zachary gives as good as he gets. I remember when the boys were about three, and they were getting into their car seats. Zachary would wait until Mom was distracted, and then he would cry and look accusingly at Nathan, which was a double whammy of getting Nathan in trouble and getting comfort from Mom. I'm sorry to say I fell for that more than once before figuring it out.

Zachary is generally a healthy kid, and now sees his metabolic geneticist and neurologist once a year (and at any hospital visits). Medically, we have been fortunate to have had only a few hospitalizations beyond his initial crisis, the longest of which was two weeks. Zachary's hospital stays usually involve whatever cold or virus is making the rounds at school. We have it down to a science now—David and I have an overlapping system of 30-hour shifts that allow us to have 24-hour coverage for Zachary in the hospital as well as both of us available when the doctors do their rounds. We have found it essential to be prepared with the emergency protocol. We also use tricks like getting admitted through the pediatric ER and knocking out as many tests as we can while there (like the head CT he always needs due to shunt), bringing Zachary's food from home, and once "on the floor", getting things (tests, orders, procedures) done well before day shift leaves.

One mark of his progress is that Zachary no longer needs any "heavy duty" medications. When we first came home after his crisis in December 2003, Zachary took 25 doses of medicine every 24 hours. Now, almost five years later, he takes one, sometimes two (just Carnitine, and occasionally something for reflux). He also has a lot less vomiting. Again, when we first came home in December 2003, Zachary spit up or vomited every day, often several times. Over time it became cyclical—I charted it on the calendar, and like clockwork every two weeks we would start another 7 – 10 days of throwing up. After about 18 months, we actually burned out our little steam cleaner! Then, slowly, the cycles started to stretch out. The biggest difference came from moving away from formula onto a grain based diet. That's when we started burning out the blender instead J We were able to stop the overnight feedings,

Zachary is on the left (stripes in shirt) and Nathan is on the right.

as he could handle enough calories during the day using the heavier food. Now we have a Vitamix blender, and it can handle Zachary's diet easily. So if he is vomiting, it's a clear sign that something is wrong and we get right on it.

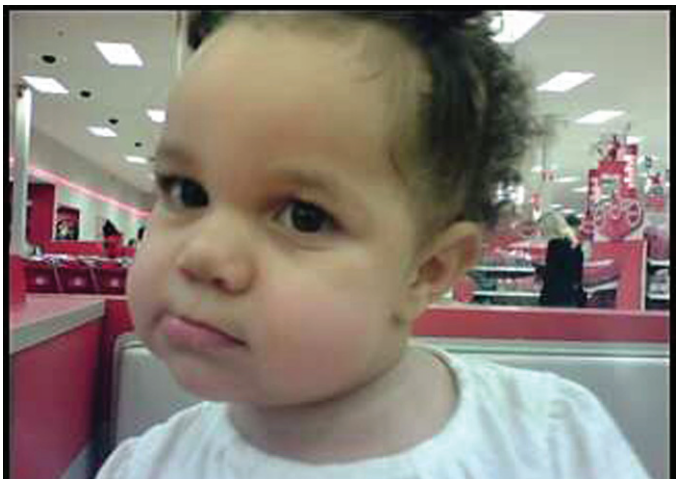
In addition to the diet change, I also credit Zachary's movement lessons with much of his progress. Zachary has been doing PT and OT since infancy, and continues these services through school. But the real changes came when we brought in some new modalities. In just over a year, he's gone from constantly extending, unable to sit comfortably in a wheelchair (or anywhere else); unable to consistently relax his body, supports his head, or use his arms, to a child who is able to be peaceful in his own skin. He's started rolling from back to belly, and has greatly improved head and trunk control. He's not spastic all the time, and is sleeping better. He started taking lessons with two Anat Baniel Method practitioners last July, and is a happier, more comfortable kid because of it. In the last couple of months, we've also incorporated Masgutova Method reflex integration work into Zachary's program, and that shows great promise as well.

One area where we're really having some fun is family recreation. For our vacation this summer, we rented a Landeez beach wheelchair for the week from Shared Adventures, a non-profit in Santa Cruz. Since Zachary is still child-sized and the chair wasn't, we just strapped a car seat in place and off we went. We learned the car seat trick while figuring out a way to get Zachary into a bike trailer. We got a Wike special needs trailer this year, and the bench seating really didn't work well for Zachary because he needs more trunk and head support while riding. So we picked up a cheap car seat and secured that into the trailer. It worked like a charm, and "wiking" has turned into one of Zachary's favorite things to do. Zachary has a special needs stroller, which we use for outings in the community. Not great for positioning, but good for getting around. We've also realized the benefit of taking Zachary on carnival rides while he's still small enough for us to hold (at 44 inches and 41 pounds, that might not be too long!) He absolutely loves all things vestibular, and the faster, the better. Zachary is quite a daredevil!

These days, our biggest challenge is education. Finding the right environment for Zachary has proved difficult enough that our IEP team has brought in the Diagnostic Center of Northern California, part of the state Department of Education. Zachary is on his third school in as many years, and it's still not "appropriate." Everything is a trade-off. For example, Zachary is non-verbal, so he needs to have an augmenta-

Zachary Wyvill continued on page 15

MEMORIALS



Hannah Lynn Huff
March 19, 2005 - April 10, 2007

On March 19th, 2005 Hannah Lynn Huff was born, little did we know how our lives would change but change they did. A year before, on December 30, 2003, Hannah's sister, Ashleigh was born and with her birth we were introduced to a disorder we had never heard about, MMA. We brought Ashleigh home and we were overjoyed but three days later our joy would turn to anguish, Ashleigh would not eat and when she did, she would spit up and then she would not wake up. We took her to the hospital at 2am on her third day at home and an hour later we were on our way to Emory. Ashleigh was place d on life support and on January 8th, 2004 we had to make a decision I still find hard to fathom, we had to remove her from life support and say goodbye.

We spent the next year learning all we could about MMA; we would be prepared if and when it happened again. Then on March 19th, 2005 Hannah arrived. She was tested immediately and we were told that she too had the disorder. But this time we were prepared, we knew what to do and things would be much different. And for the first 2 years Hannah brought so much joy into our lives. She was a brave girl. She took in stride all that her disorder heaped upon her, her micky button, her B-12 shots four times a week, the regular trips to the doctor and the occasional hospital stay. Then a glorious day arrived, March 19th, 2007, Hannah's 2nd birthday and we breathed a sigh of relief for we were told that the first two years were the most critical. Then came April 5th, Hannah, for the first time in her life was sick. She was not her normal smiling, happy self, we knew something was wrong so we did not hesitate; we bypassed our local hospitals and took her to Emory.

The first couple of days were the hardest, Hannah did not respond well to treatment but that all changed on the third day, she was sitting up and hollering. The doctors told us she would be fine and we could take her home in a couple of days. Then at 7pm on April 10th Hannah relapsed, she stopped breathing once but came back but than at 8:36pm she was gone. We were devastated…….we still are. How could it go so wrong! How could it happen twice! So many questions: so few answers.

It has been 512 days since Hannah died and although we still cry every day and we miss her and her sister so very much we cannot help but be grateful for all Hannah and Ashleigh have taught us. Ashleigh showed us that although her time was short her purpose was served; she taught us about MMA and prepared us for the arrival of Hannah. Hannah taught us to cherish every moment because they will never come again. Hannah showed us bravery and courage far beyond that you would think a 2 year old would be capable of. Hannah gave us a joy and happiness that we will cherish the rest of our lives.

Hannah was unique. She touched everyone she met and she was a teacher to the doctors that took care of her. MMA was a virtual unknown disorder in our city before Hannah came. Now there are at least 2 doctors that have a better understanding of MMA and know both its symptoms and treatment options and for that they have Hannah to thank, not bad for a 2yr old. You came into our lives when we needed you the most. You helped us heal the wounds from the loss of your sister, Ashleigh. For two short years you were our world and our joy. The brief moment we spent with you was the most precious and dearest to us. I shall never forget how you loved to play in your walker, played pat-a-cake by grabbing our hands and clapping them together, or how you would jump up and down in our arms until we were exhausted. We often told you that you needed your own entertainment committee because you loved to be entertained. We loved taking you with us while we did our shopping and how you sat patiently in the shopping cart while playing with your toys. When we walked in the room and said "Hannah bear" your eyes would light up and the biggest grin appeared. That smile could make any dark day bright again.

Those were the precious times that we shall never forget and forever treasure. They say only time will heal the pain of loosing you, but it's hard to imagine it will. Our time for creating memories with you are gone. This is your time to be with your big sister, Ashleigh, so go and play her and make memories together. Say "hello" to her and tell her we miss her too. This is not "good-bye" but rather we will see you soon. Thank you for making our world just a little bit sweeter and brighter for a moment. We miss you bear……but we will see you again. Until then, run with Ashleigh, laugh often and take care of each other until we are together again. We love you both very, very much and while we wish you both were still with us we know that you served your purpose and for that we are grateful. Take care babies……mommy and daddy will see you soon!!

Joey Ramos, Undiagnosed
3/24/1981 - 4/1/2008

Our little Joe Joe
How would we know
How much we would love you so;

What you endured
Amazed us all;
You stood strong
You didn't fall;

You are our hero
And we will never forget
'The fight for your life
You never quit:
You'll remain forever in our hearts
Even though our lives are apart;

You taught us life, love and joy
You were a wonderful gift and
You were our "little" boy;

But God needed you up above
We have to believe its because of his love;
He knew you were struggling in this temporary life
Now you are whole and without strife;

We miss you so much; beyond belief
And we struggle now in our sadness and grief
But we know we will meet you again someday
So until then, we know you are okay

Love,
Mom and Dad

Zachary Wyvill continued from page 13

tive communication (AAC) system in place before mainstreaming will be successful. This year Zachary has a great teacher who is not flustered by assistive technology, but she doesn't know how to choose the right tools for Zachary and depends on the AT specialist (who is little help). Also, in this school, he has lost his typical peers. So he's getting some of the technology support he needs, but missing out on the social piece which is also so important. So, we keep plugging away and pulling in whatever resources we can. It's going to be a long haul, but we're committed. We fully expect Zachary to graduate high school and go on to college in the future.

Over the last five years, we have developed a deep appreciation for the disabled community. If not for those who worked on ADA, IDEA, the Tech Act, and other legislation, Zachary would not have the opportunities he does today and our family might not have the support that we depend on. It amazes me that personally; I was completely unaware of this community until my family became a part of it. From legislative advocacy to medical and therapeutic services, from educators to social workers, from social and recreational organizations to sympathetic shoulders to cry on, I am so grateful for the people we've met along the way. People with disabilities, and especially children with disabilities, continue to inspire us at every turn. Our family's goal is to pass it along and touch other lives in a positive way, as ours have been touched by so many.

Many thanks to Kathy Stagni for allowing us to share our story here. Long days and pleasant nights to you, and God bless.

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Plymouth, MN 55441

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Remember to wear your Newborn Screening Pin to create awareness

At Left: Tori Wheatley (IVA) is the headliner on Sigma Tau's Carnitor Poster - presented at the NORD Gala and the FOD/OAA Conference.

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