



Organic Acidemia Association
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Organic Acidemia Association Newsletter

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Conferences, Conferences

This quarter, we have been busy attending and planning conferences. In March, I attended the American College of Medical Genetics and Society for Inherited Metabolic Disorders conferences in Albuquerque. Then in April, Shantel Matthews attended the Genetic Metabolic Dieticians International conference in Baltimore. In July we hosted our own (every-other-year) conference in Atlanta with the FOD (Fatty Oxidation Disorders) parent support group. You will see write-ups on all three in this newsletter.

I would like to take this opportunity to thank all the sponsors and contributors for our conference and other activities: Genetic Alliance, Emory, Southeast Regional NBS, Vitaflo, Ross/Abbott, Nutricia, Sigma Tau, Rare Disease Therapeutics, Applied Nutrition, Cambrooke, Coriell, Kakkis, MedDiet, and Turtle Mountain (makers of SoDelicious dairy free products), and numerous grandparents and parents who donated generously. Funds also came from the FOD, IOGA, and OAA.

I also want to thank everyone who helped with the Atlanta Conference: Jana, Kathy, Lee, Melissa, Cay, Frank, Beth, Menta, Janet, Erica, Raymonde (closing video) and all the wonderful volunteers from the CDC who helped with childcare. A special thanks also to: Ronnie, Rani and Rosalynn of Emory, and of course our speakers: Dr. Singh, Dr. Vockley, Dr. Venditti, Dr. Gropman, Dr. Kahler, Dr. Manoli, Dr. Sloan, (all shown below) and (not shown) Dr. Korson, Dr. Cuthbert, Ms. Nuse, Ms Stelton, and Mr. Goodmark. Most of their powerpoint slide presentations are on the website.

Carol Barton
Executive Director, OAA

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Update on La Vita E Un Dono

(Propionic Acidemia Research in Italy)

Our Association is still developing and Paola spends all her afternoons in fundraising, promotion of the name of the Association, ceremony cards printings, etc.... and I'm helping in organizing sport events and in checking the work of the researcher.

Our researcher, Dr. Martinelli, who was hired on December 1st 2009, has sent his first article to the Journal of Inherited Metabolic Disease and he's waiting to know when it will be published (we'll inform you all about it later) He came from Rome to our little city last winter and had a short presentation speech during an event for fundraising with a concert... the speech is on youtube, but it's in italian

Friday April 9th there was an assembly for the approval of the 2009 balance sheet, the main figures are: 100,000 euros collected in 2 years and 19,000 euros already donated to Ospedale Pediatrico Bambin Gesù di Roma for the first year of salary of Dr. Martinelli.

Other good news are the following:

- I'm organizing an annual golf event with the Italian Association of Golfers Engineers.
- Paola sold tickets for the "Walking through Davide's Paths" on June 2nd and we hope to improve last year's record of 4000

(3 euros each ticket) and sponsors which provided 1000 sport drinks, 1000 bottle of water, gadgets, etc...

- Alberto, dad of a little Italian baby boy with PA is helping and fundraising and writing sweet recipes on the internet.
- I'm also publishing pages on the Italian internet site and looking for a new version of the site with volunteers (hoping to improve the English part of the site also...)
- We are planning a visit in Rome this summer for a meeting with the researcher.

All this plus work fill our days and evenings and time goes by easily ... while our 4 parents are almost 75 yrs and start to need our help too.

We'll keep in touch

Massimo and Paola

Davide 11/24/1993 - 8/16/2007 PA

Simone 7/15/1996 - 9/28/1997 PA

Luca 11/23/1992 - 12/8/1992 PA

-- Associazione "La vita è un dono" ONLUS

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Erielle

8 months old
MMA Cbl -C



Where do I begin? We have a beautiful daughter - we are thankful that her disorder is treatable. This is our story.

I'm very hands on with Erielle. I noticed right away that she did not really gaze at me... She didn't really track... At first I thought she just didn't want to look at me.... I googled "baby won't look at me". I thought something was wrong. I even asked my pediatrician (who we no longer use) if I should be concerned... She said 'no, she's still young'.

Let me backtrack.... I gave birth to Erielle by emergency c-section on Dec 2, 2009. She was born 4 lbs 12 ounces, at 36.5 weeks. She stayed in the NICU three weeks for poor feeding issues. When we left the NICU she seemed fine... As the months went by I noticed she was the easiest baby— always slept, never really cried — but the thing that stuck out the most was her vision... I knew something was off... I was going to mommy and me classes and the Occupational therapist who was the instructor told me she thought she noticed something with Erielle's eyes that I should check out. After hearing that I knew I needed to look into it further and not just wait. We went to a pediatric ophthalmologist who said her eyes were structurally fine but said she was too young to know her vision, and to wait until she was 6 months. She was 3 months at the time...

My next concern I had was I noticed she had very sudden jerky movements, almost involuntary. Her eyes would also shake which I came to find out later is called nystagmus. This concerned me and I called a neurologist. The receptionist heard my concern in my voice and immediately scheduled Erielle for an EEG to check if she was having seizures. The neurologist

also took a blood work up he said 'just in case it is metabolic'. My husband and I had never heard the term metabolic.

Thankfully the results for the EEG came back negative but he said they found some unusually high levels of organic acids in her blood that would suggest a metabolic disorder. We were now very concerned and asked the doctor to please explain it again because we'd never heard of a metabolic disorder. Now I feel that is a part of our vocabulary. We are so thankful our neurologist did this metabolic work up because this could have gone on longer if I hadn't gone to see him.. He referred us to our geneticist at Miami Children's Hospital who is terrific. This is where Erielle now gets her treatment for her diagnosis of Cbl C. We are so thankful that there is treatment. Her daily regimen is like so many of the other stories, L-carnitine 3x/day, Betaine 2x/day, Folic acid 1x/day, B6 3x/week, hydroxycobalamin injections 4x/week. She is also protein restricted and is on propimex and pro-phree formulas mixed with rice cereal and Similac.

She is enrolled in Early Intervention services and is currently in PT and Speech Therapy for feeding. She has also started vision therapy. We are thankful for all these services.

Erielle is such a happy, sweet baby. She loves to try to stand. Her trunk needs more strength and they are working with her in PT. She is low tone but has been slowly improving. She started rolling over a few weeks ago and has very good head control. She just started pushing up on her arms, which we were very excited about. She loves to grasp for toys. Her feeding is improving as well. The only challenges we face with feeding is the initial latch. She has trouble coordinating her mouth and tongue to initiate to feed. Once she does latch on she feeds very well. Feeding her baby foods is a challenge. She does not want to eat. She holds the food in her mouth instead of swallowing. We are working with the feeding/speech therapist to help her improve with her feedings.

We are fortunate to have started her treatment at 4.5 months. We are optimistic about her improving as her levels go down. Her homocysteine levels began at 167. She is now down to 41. Our doctor has recently increased her hydroxycobalamin injection to 4x a week instead of 3 to get the levels down at a faster rate.

Our main concern is her vision. We know she sees, but we are not sure how much. We have seen a few different ophthalmologists. The last one has given her glasses and said she is very farsighted. We are also patching her eyes alternating each day for 1 hour each to strengthen her eyes. She is tracking now and seems more interested in toys and objects in general. We are optimistic that her vision has been slowly improving.

Erielle is our beautiful daughter. She has a beautiful smile. We can't imagine our life without her, and although we didn't plan this as part of our lives, we are glad we are able to help her in any way that we can to make her life the best it can be.

We love you Erielle.

Adina and Daniel A.
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Adrian, 7 years, 3MCC
Gabriel, 2 years, 3MCC



My name is Fernando Lopez, and with my wife Lorena Mendez are the proud parents of two beautiful boys, Adrian and Gabriel. Adrian's history was published in the 2007 summer edition of the OAA newsletter.

Well its been a while and a lot of water went under the bridge. We chose to have a second child, Gabriel. Making that decision was one of the hardest things. Lorena and I thought about it for quite a bit. A lot of things went thru our minds, and lots of *what if...* but finally we decided it was time, and what with all that we learned with Adrian will really make a difference.

Gabriel was born January 21st 2008. It was a quite pregnancy. I took a lot of planning to receive the new member of our family. Here in Bolivia we don't have all the resources to test for this disorders and the medical staff is not prepared to treat any complication also. So we have to do a lot of planning. We made the decision to have a C section first thing in the morning so we could have plenty of time to collect the samples and send them to Buenos Aires – Argentina in a DHL to have them tested. So I did. We collected blood samples from the cord, a 12 hour sample and a 48 hour sample and sent them to have them tested. Besides that everything was perfect. Gabriel came to this world at 6:50 am and weighed 3.350 gram and measured 50 cm. (7.4 lbs & 19.7 inches). He was healthy, pink and beautiful. We went home after 2 days at the hospital.

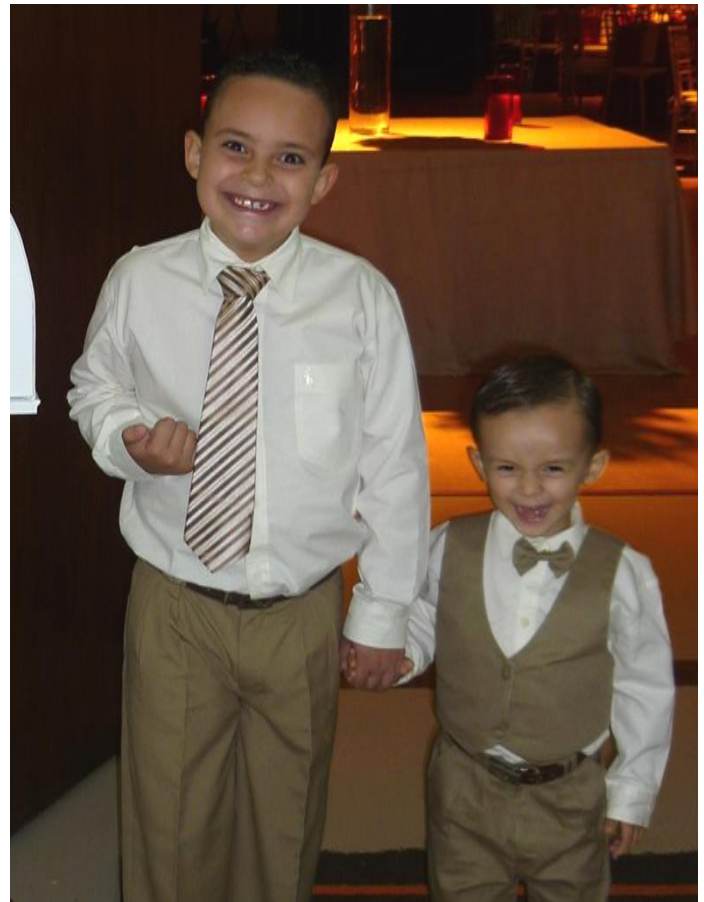
The next Friday I received a mail from the doctor in Buenos Aires to contact him ASAP. That night he told us that the tests came back positive for 3MCC, as his brother Adrian. And the same night we started the treatment with 5 days old. We cried, a lot. But after that, we got back in the saddle and started our life again.

Gabriel developed very well, and started to achieve his milestones without difficulties. The only thing that shook our world was his cephalic perimeter; it was always on the top 5th percentile. So we went with an ultrasound and a tomography, and everything showed he was fine, no fluids in the head, just he had a big head.

After that no trouble at all, well that is not true, because we have had the "usual" troubles you expect with a newborn, baby and later a toddler.

Early treatment really made a difference. We struggled, and still do, with Adrian. But all the effort paid. He is finishing his first grade at school and is a good student. He gets 60 over 70, (85% of grade and I don't know how to put them in A, B, C and D as you are used to). But all is done with a lot of effort, from us and especially from him. He still has troubles with his fine motor skills, and also with his gross motor ones too. But he is a little fighter. He has some difficulties but also has some remarkable gifts, just like everyone else.

We are very thankful with a lot of people that helped us along this journey, our parents, our brother, the doctors, and a really special thanks to our OAA family for been there to help.



Fernando and Lorena Lopez
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Stephanie 17years old MMA Mut O

Luke 9 years old MMA Mut O



Our daughter Stephanie was born 7 weeks early. She weighed 3lbs 5oz. I had preeclampsia. She stayed in the hospital for a few weeks, until she could eat and grow. Several pediatrician visits were noted that her growing was very slow. The doctors reassured me it was because she was premature. Her diet was Similac and I was starting to introduce some cereal as well. She spit up a lot and we thought a little cereal might help with that.

At 6 months old she woke with what seemed like the flu, vomiting and sleeping a lot. That evening she was brought to our local ER and then transferred to a children's hospital by ambulance. Her blood results were too much for them to handle. The helplessness I felt seeing my baby leave in the ambulance being taken away is one I will never forget. I can tell you the exact events of that night as if it were yesterday. Two weeks later she was diagnosed with MMA Mut O. During that time she may have had a seizure, was in a comatose state and also received a blood transfusion. She had a NG tube which she came home with but only needed for 1 day. I remember going to the library to try and find any info on MMA and found nothing, although that was before internet.

When she was a child we struggled with her eating and using more calories than she was taking in. We had her in a small private school to try and protect her from germs. She has had some hospital stays lasting 2-3 days and 1 or 2 that lasted 4-5 days. She has ADHD that we treat with Concerta and anxiety that we treat with Lexapro. Most of her anxiety comes from hospital stays and blood draws. She also takes 6ml of Carnitor (generic) 3x's a day and I give her a multi-vitamin. She is a Junior in public High School in a LD class. After puberty she became an excellent eater and I cannot keep enough food in the house. Her most recent labs showed she needs more protein. Many days she craves protein and I am teaching her to choose her protein wisely. She also takes 2 oz of Propimex-2 a day that we mix with oatmeal. She gets to skip her Propimex one day a week. She tries to snack every 2 hours because when she gets to

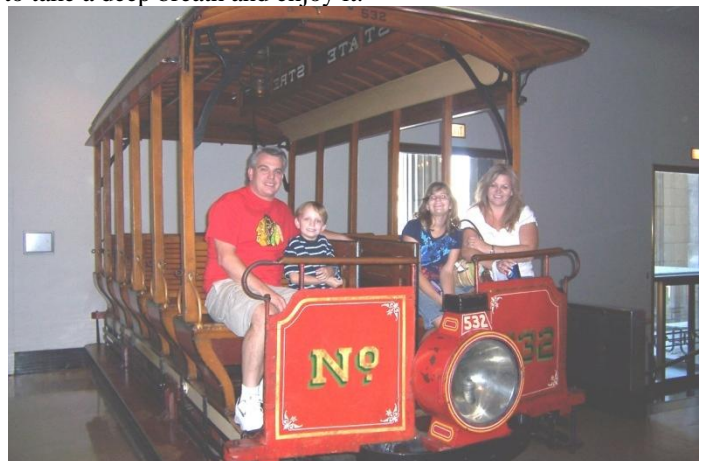
hungry she doesn't feel good. With all of our devotion to Stephanie, we were not sure about another child. But Stephanie wanted a brother or sister.

Her brother Luke was born a beautiful healthy 8lb baby. I had a very healthy pregnancy. Our genetic doctors informed us of genetic testing but did not push the subject which I really appreciate. After Luke was born the nurses were watching his ketones and did lab work that indicated he did have MMA Mut O. I have to say Luke's care was somewhat easier because we were more prepared and experienced. He strived faster and he never had to get really sick before we knew how to care for him.

He is on about 2 oz. of Propimex-2 a day that he eats mixed with French Onion chip dip. We dip his favorite cheese chips and he likes it. He knows he needs it and does not resist. He also takes 6 ml of Carnitor (generic) 3x's a day and also a multi-vitamin. We have had some trouble just recently with his growing. His recent labs showed he needed more protein and that may be why he is not growing well.

He is starting 4th grade in a regular public school classroom. He has an IEP to cover his medical issues. I work close with the school nurse and she calls me almost daily to keep me updated with what viruses are going around. She even calls parents, who have a child from his class home sick and asks them to keep the child home an extra day. She is wonderful. He has had several hospital stays. Sometimes just a fever or ear infection will bring him in and sometimes he has been quite sick and was able to get better at home. He does very well in school and is very intelligent.

Everything we do as a family is done at a slower pace. When we vacation we take many breaks for snacks and to rest and try not to overdo things. In September Stephanie will be granted her Make A Wish, which was to go to California. We will visit Disney, Universal Studios, Sea World the beach and go horse back riding. Though I am nervous about it I will remind myself to take a deep breath and enjoy it.



Someone once said to me, I don't know how you do it. It must be so hard. I told her it is all I know and it becomes a lifestyle. We are thankful for the blessings in our life.

Dan & Lori Wisch
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Vivian

Yesterday gone
Yesterday too soon
Tomorrow come
Tomorrow gone

My heart is full of sunlight
Sunlight disappear in my soul.
Pain come
Pain disappear

Joy break through my thought s
Joy is a thorn in my flesh
Nothing more.
Lost, the day I had to let you go.

Grace for you
But ungracious the emptiness in my soul
Showered with uncertainty and distress
Sorrowful heart divided with a drowning pain

Rock of my life
Jesus Christ Emmanuel
God with us?

Not this Lord, not this
Lord, so sudden
So sudden
Not enough time

Love everlasting
But suffering too much to deal with
Memories fresh,
Memories open

Laugh with a mask
Smile with a falsehood at the world
They want me to forget you.

Never will I forget
I will keep your memory close.
Very close to my broken heart.

Born out of me
But back to our Maker
Borrowed time
Time missed with you

Jesus waited for you.
Mommy cried to Jesus to save your life
But He knew that you could not go on.
I had to let you go.

“Mommy's angel. I am so sorry.
Mommy can't help you. I am so sorry.
Mommy sees your suffering.
Mommy will let you go to Jesus.

Safely in His arms I let you go.
Mommy loves you so much, always.
Softly you breathe out your last air.

This un-bearable sorrow will with time pass too
But without you life will never be the same.

Sleep now softly
Tomorrow the sun shine again
Mommy's angel
Softly in mommy's arm.

Rest now
Softly now to Jesus.
Sleep in heaven with God

Sunshine again.
Laugh now with Jesus
Jesus love's you.



A poem of a mommy's grief and loss of her precious darling angel. In memory of Vivian (PA) 2002/01/19 – 2010/04/28.

We miss our daughter so much. Her place is empty, but we grieve with hope to see her again one day. in heaven God willing.

Thank you to Organic Acidemia Association for your support over the year's. We have learned to deal with life in a different way and could do it all over again.

Blessings
Joss and Ciska van der Linde
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Gene therapy for mut MMA in Mice using Liver-Targeted Delivery

Nuria Carrillo-Carrasco, Randy J. Chandler, and Charles P. Venditti ** email: venditti@mail.nih.gov

In a previous newsletter, we have described the manifestations of mice with mut MMA: they resemble the most severe form of the disease and perish in the first days of life. We have used these mice to prove that gene therapy could be a viable treatment for MMA. To summarize, when we used an adeno-associated virus (AAV) to deliver the Mut gene, 95% of MMA mice that received gene therapy survived beyond a year, while all the untreated MMA mice died. We have taken further steps to improve the design of the gene therapy vector to be closer to those used in human trials. Our results were recently published [Carrillo-Carrasco N., Chandler R.J., Chandrasekaran S., Venditti C.P. (2010) Liver-directed rAAV gene delivery rescues a lethal mouse model of methylmalonic acidemia and provides long term phenotypic correction, Human Gene Therapy, 21(9):1147-54] and are described here.

We developed a new gene therapy vector that combines the same AAV virus with a DNA sequence that directs the expression of the gene in a tissue specific fashion, in our case, only by the cells in the liver. We then injected the MMA mice soon after birth with this “liver-directed” gene therapy and had impressive results: the treated MMA mice survived for more than a year, while the untreated MMA mice uniformly perished. Furthermore, after monitoring the growth and metabolic parameters in the MMA mice that received liver directed AAV gene therapy, we found that the effectiveness of this approach was comparable to our previous gene therapy study.

Why is this an advance? Currently, there is at least one active human gene therapy study in the U.S. that uses a liver-directed approach with a similar type of AAV to treat a different disorder called hemophilia, a severe genetic disease that predisposes patients to frequent and severe bleeds (web site for information on this gene therapy study:

www.gemcris.od.nih.gov/Contents/GC_CLIN_TRIAL_RPT_VIEW.asp?WIN_TYPE=R&CTID=203).



By developing a gene therapy treatment for MMA that resembles one already in use, even though it is for a different disorder, we can rely on the experiences another group has had relative to safety, delivery route and general tolerance of the patients to gene therapy. It should be emphasized that the hemophilia gene therapy trial mentioned above is treating patients with simply a peripheral IV infusion of virus, a relatively non-invasive means to deliver the gene therapy.

The proof-of-principle animal studies we have reported are among the necessary steps needed to optimize the gene therapy so that it can be safely and effectively offered to patients with MMA. Our encouraging results have therefore narrowed the gap for the translation of gene therapy for MMA, and hopefully other OAs, to the clinic.

Low Protein Cooking Demonstration

Atlanta Conference 2010



The special low-protein food demonstration by Erica Stelton of Cambrooke Foods featured really yummy recipes and samples.



NIGMS Human Genetic Cell Repository Coriell Institute for Medical Research

A few weeks ago I had the pleasure of attending the OAA Conference in Atlanta to represent the National Institute of General Medical Sciences Human Genetic Cell Repository at the Coriell Institute. I met many wonderful families who kindly shared their stories. I listened with great empathy to the parents who bravely shared their personal struggles with guilt over their child's diagnosis and I listened with anger and frustration to the young parents who have had their emergency protocols blatantly ignored when their critically ill child presented to the local hospital ER. I want to thank all of the parents and families who stopped by to candidly share your experiences and help me to gain a deeper understanding of the complexities individuals with inherited metabolic diseases are faced with daily.

For those who I did not get a chance to talk with, I am the genetic counselor for the NIGMS repository at Coriell. The NIGMS Human Genetic Cell Repository is a biobank that collects blood or tissue samples and clinical information from individuals with inherited genetic diseases and makes cell lines and DNA available for scientists to use in their research. Samples and corresponding clinical information that are donated to the repository are anonymized and made available to qualified researchers all around the world through an online catalog. Having a centralized source of well-characterized cells lines and DNA allows scientists to spend more of their time and funding on studying how cells function, identifying new mutations, and developing ways to diagnose, treat, and possibly prevent metabolic diseases.

Our goal is to continue to build our collection of fatty acid oxidation disorders and organic acidemias to create a larger, more diverse and more valuable resource for scientists studying the causes of and potential treatments for inherited metabolic diseases. More details about the diseases currently represented in the repository are in the table at the right. There are many diagnoses for which we do not have any samples.

If you are interested in donating a sample to help us build this valuable research resource for fatty acid oxidation disorders and organic acidemias, please contact me either via email tschmidl@coriell.org or by phone at 856-757-4822 for more information.

Thank you again for sharing your stories and thank you to those who have already donated samples!

Sincerely,
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ORGANIC ACIDEMIAS	
2-Methyl-3-hydroxybutyric aciduria	0
2-Methylbutyrylglycinuria	0
3-Hydroxy-3-methylglutaryl-CoA lyase deficiency	0
3-Methylcrotonyl-CoA carboxylase deficiency	0
3-Methylglutaconic aciduria	2
beta-Ketothiolase deficiency	0
Glutaric acidemia type I	0
Isobutyrylglycinuria	1
Isovaleric acidemia	1
Malonic acidemia	0
MMA – Cobalamin A, B (CBL A,B)	4 CBL A, 1 CBL B
MMA - Cobalamin C, D (CBL C,D)	1 CBL C/ D
Methylmalonic acidemia	1
Multiple carboxylase deficiency	1
Propionic acidemia	47

OAA 2009 Financial Summary

Opening Fund Balance		
OAA operating fund	\$ 12,243	
MMA research fund	\$195,787	
Total		\$208,030
2009 Contributions		
OAA unrestricted contributions	\$ 37,616	
MMA research directed contributions	\$ 50,587	
Total		\$ 88,203
OAA Operating Expenses		
Accounting services	\$ 2,770	
Conferences, conventions, meetings	\$ 3,993	
Printing	\$ 3,141	
Postage and shipping	\$ 3,487	
Internet	\$ 948	
Other expenses	\$ 1,457	
Total Operating Expenses		\$ 15,796
Research Grant Expense		
NIH, Dr Venditti's MMA research		\$253,840
Ending Fund Balance		
MMA Research Fund	\$ 19,131	
Total	\$ 7,466	\$ 26,597

Medical Foods Advocacy

Imagine. Connect. Act.

Imagine having insurance coverage for medical foods (medical formula and foods modified to be low in protein) no matter where you lived, how old you were, and where you worked. The Medical Foods Equity Act, a bill that has been introduced in the U.S. Congress, would accomplish all of these things.

The Medical Foods Equity Act would:

*Require ALL insurance companies to cover medical foods (both formula and foods modified to be low in protein) for all inborn errors of metabolism. This includes coverage through federal programs (such as TriCare) as well as self-insured plans that are exempt from state mandates

- * Cover nutritional supplements/vitamins to treat IEM's.
- * Cover the cost of medical foods for both children & adults.
- * Require all insurers, including federal programs such as Medicare and Tricare to cover.
- * Protect states that currently have better coverage/ programs for medical foods. In other words, if your State currently provides formula and/or food at no cost to you, your state would not be allowed to discontinue this when the federal mandate passes.

This bill needs your support! In the Senate, the bill number is S.2766 and has 2 co-sponsors. In the House, the bill number is

HR.4926 and has 27 co-sponsors. Many offices could still become co-sponsors – especially if they hear from you as a direct constituent! If you do not know who your Representative is, please go to <http://www.npkua.org/index.php/your-legislators> to look it up and get their phone number.

Here is all you need to say:

My name is _____ and I live at _____(give entire address). I want Congressperson _____ to co-sponsor S. 2766/HR.4926, the Medical Foods Equity Act.

If you have a personal connection:

My child has a rare metabolic condition. Left untreated, the condition can cause _____.

The treatment for this, and many other inborn errors of metabolism are medical foods - medical formula and foods modified to be low in protein. As long as my child drinks their formula and eats their medical foods, they can grow up to be healthy and productive citizens.

The Medical Foods Equity Act would require all insurance companies to cover the cost of medical foods for PKU and other metabolic diseases. Although the Newborn Screening Saves Lives Act requires states to screen for PKU, there is not adequate coverage for the required treatment. The bill has bi-partisan support in the House. Say thank you

GMDI Conference

The conference went really well. The booth was received very nicely by the approx 250 dieticians that attended. I was surprised to see dieticians from Poland, Canada, Argentina, France, England, Portugal and Australia! They all enjoyed the quilt, jelly belly's (all are gone!) and the pamphlets/info.

Every single 2010 OAA newsletter was taken and I had to put out the old ones from 2008 yesterday afternoon. Every single jelly belly was taken. Almost all the conference reminder cards were taken. Many pamphlets and cards for both OAA and FOD were distributed. One RD wanted some more of the wristlets for her patients - so I let her have a handful of them.

I spoke with John from Cambrooke foods and thanked him for the support of our conference and he is looking forward to it. Sandy from Applied Nutrition wants to make sure you get some low protein food products to put up at the conference. So, I guess she will be contacting you all about that.

Laurie from GMDI thanked us for being there. And Dr. Singh said she was happy that we came as well. I really think it was

good that the OAA and FOD were represented. PKU Alliance and the MSUD support group also attended. Thank you for sending me to the conference. It was a pleasure to represent both organizations!

Shantel



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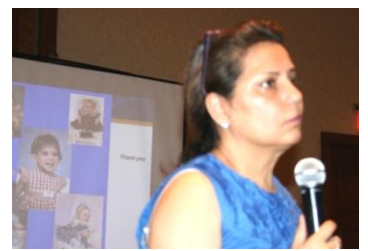
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Atlanta Memories: Conference 2010



2010 OAA Conference

By: Lee Stagni, Dad to Melissa (PA)

To truly appreciate the strides that the OAA has made over the years, it can be helpful to look back.

While it was 11 years ago, I can remember the first parent/professional conference like it was yesterday. The date was June 19, 1998. Our daughter Melissa was 10 years old. The conference focused on MMA and was organized by the amazing Menta Pitre and her local “support network” of family and friends. The conference brought together over 130 people representing 29 families. Everyone there appreciated being able to connect faces and names and hear from physicians and other medical professionals who were committed to helping us (parents) help our kids.

Flash forward to July 2010. For the third time the OAA has come together with the Fatty Oxidation Disorder (FOD) support group to co-sponsor a national metabolic conference. Emory University School of Medicine graciously served as our host as well as the Southeast Newborn Screening and Genetics Collaborative. The event was held at the Emory University Conference Center which was an excellent venue. The conference consisted of two days which were jam-packed with information and “networking” opportunities.

Personally, it has been six years since I’ve attended a conference. I’ve had a variety of excuses for missing them – some valid and some not. But I have to admit that I was simply AMAZED at the progress made since my last conference! Most impressive was the depth and breadth of medical support these disorders are now receiving ... and the progress that is being made toward improved treatment and even a potential future cure. Speaker presentations have been posted on the OAA web site so you can see first-hand the same information that we learned. Beyond that, I would like to take this opportunity to share with you some of my observations.

DAY ONE

Day One began with a brief general (welcome) session and then the two organizations broke into their own separate “tracks”. The OAA track began with an enlightening presentation by Dr. Jerry Vockley, Chief of Medical Genetics at Children’s Hospital in Pittsburg entitled *Disease or Not Disease – That is the Question!* His talk centered around the advances in genetics and posed the question of whether what we are treating is actually a “disease”. He discussed the value of Newborn Screening and noted the frequency of organic academia disorders in the US as 1:230,000 for MMA, 1:138,000 for PA, and 1:76,000 for GA and compared that to the frequency of PKU which is 1:20,000. He also discussed the value of clinical trials as a method of monitoring progress made in identifying and treating disease. Dr. Vockley closed with a powerful quote from industrialist, businessman, entrepreneur and philanthropist Andrew Carnegie who said, “No man will make a great leader who wants to do it all himself or get all the credit for doing it.” So very true!

After a break the group had the pleasure of hearing from Dr. Chuck Venditti who is the Director of the Organic Acid Research Unit at the National Institute of Health and the

primary researcher focused on OAs. Dr. Venditti has been a long-time member of the OAA physician medical advisory board and has been the recipient of a number of OAA financial research grants which result from the work and dedication of Marty Moran and his MMA Research Fund.

Dr. Venditti shared a summary of the exciting results of his laboratory research using his mouse model to inflict with MMA and then “cure” then using gene therapy. He pointed out on many occasions that there is much more work to be done before his research can be applied to our kids – but made sure that we all realized the potential that his lab results hold for MMA and all other OA disorders. At this point I couldn’t help but think back to that first conference 11 years ago when there was no research going on – and frankly little positive hope given by the medical experts. We have come so far in such a short period of time. Frankly this is something that I never thought I would see in my lifetime.

The presentation also revealed new strategies in “cell therapy” where skin cells are transformed into stem cells and then these “correct” cells are implanted into the liver resulting in a “cure”. He predicted that the next five years will be very exciting as current research treating hemophilia will break new ground with cell therapy – opening the door for human trials that he might leverage.

Dr. Irini Manoli, who works on the team with Dr. Venditti, discussed practical applications of dietary management and interesting studies involving energy/caloric intake requirements at various ages. The goal of the study is to determine how to establish a dietary planning balance between the two spectrums of malnutrition and overeating.

Who could eat lunch after these presentations? We all did, enjoying a fabulous buffet offered by the conference center. The OAA breakout session continued in the afternoon beginning with a presentation from Dr. Rani Singh from the Division of Medical Genetics at Emory University and Dr. Carla Cuthbert, chief of the Newborn Screening and Molecular Biology Branch of the Center for Disease Control (CDC). Dr. Singh discussed the challenge of nutrition management in organic academia disorders. As parents of OA children we are all well-aware of that fine line between giving adequate protein to thrive while not crossing that line that results in metabolic decompensation. Her presentation affirmed the various approaches for chronic treatments (every day management) and acute treatment (during illness). Dr. Singh offered a wealth of practical information everyone could apply each and every day.

Dr. Cuthbert gave the group an overview of newborn screening and diagnosis of organic acidemia disorders. Her presentation reviewed the process of sample collection, testing and follow-up diagnostics. For those familiar and unfamiliar with NBS, the presentation was a great reminder of the value of testing and follow-up as a preemptive measure, including “in-vitro” testing for known carriers.

Dr. Mark Korson of the Tufts Medical Center in Boston was next on the agenda, sharing with the group his progress in
(continued next page)

promoting education and awareness for metabolic disorders in the medical community. Dr. Korson's METABOLIC OUTREACH SERVICE has been responsible for getting metabolic disorders on the radar with medical students and hospital staff physicians. Since 2007 his program has generated over 5,000 impressions among this target population with excellent forward recall by the doctors. He is an avid believer and promoter of "parent as a teacher" approach and has used videotaped parent testimonials as part of this outreach service. Dr. Korson commented that it is the real, practical parent experience that is most memorable with the medical students and staff doctors leading to improved recall of presenting symptoms by the group. In my opinion, Dr. Korson's work is vital in the long-term treatment of OAs because physicians must recognize the disorder quickly and treat it aggressively if we are to minimize neurologic impact from initial onset.

The final speaker of the first day Gail Nuse, a speech and language pathologist who has decades of direct experience working with children who have feeding, oral-motor and communication difficulties. Her presentation was intriguing because all OAA parents are challenged with feeding. What I learned is that what I've experienced personally with my daughter's eating issues is not unique. The various techniques she offered were interesting and offered ideas for parents with younger children who are dealing with this issue in real-time.

Following Gail's presentation, the group joined Erica Stelten of Cambrooke Foods for a lively cooking demonstration. While I didn't attend the session, I heard from others that it was excellent. After a relaxation break, attendees gathered for a "taco" buffet dinner and some R&R in the conference center game-room that offered a cash bar, six bowling lanes, and a big-screen TV with Wii game controllers. Fun was had by all.

DAY TWO

After a great continental breakfast, both OAA and FOD attendees gathered for a series of presentations that were of interest to all. Dr. Stephen Kahler, long-time member of the OAA medical advisory board and professor of Genetics and Metabolism at the University of Arkansas, opened the day with a talk on autism and metabolic disorders. His presentation was a fascinating comparison of autism and inborn errors of metabolism especially as they relate to altered brain connectivity (wiring) and timing. Of course the most interesting part of Dr. Kahler's presentation are his many stories that

represent his vast knowledge and experience with treating inborn errors of metabolism. Dr. Andrea Gropman, an attending neurologist at the Children's National Medical Center and associate professor of Neurology and Pediatrics at the George Washington Medical School was next. Her presentation offered the group an overview of neurological complications related to our children's disorders, important strategies to monitor, and management issues such as seizures, muscle disease, and developmental delays (MR). Her presentation offered information and clarification that I had not previously seen.

After a mid-morning break, the collective group heard from Craig Goodmark, an attorney with the Atlanta Legal Aid Society. Craig focused on a topic of great importance to each of us – special education and the individual education plan (IEP). He gave the group information about the law, the legal rights of our children, and how to approach the school when they are not cooperative. The one excellent tip that he shared is his recommendation to use the "power word" with educators – POLICY. When you are getting an answer that you don't like, ask them to show you their Policy that was used to make that determination. I plan to use it the next time I find myself at a standoff. All in all, Craig did a wonderful job making a complex topic memorable and easy to understand.

Following another excellent buffet lunch, the attendees heard from Dr. Jennifer Sloan of the NIH discussing family, sibling and transition issues. She reviewed the "diagnostic odyssey" that we have all experienced ... from symptoms to diagnosis, to ongoing life management. The final presentation was offered by Dr. Rani Singh who discussed the work of her team in establishing nutrition guidelines for patients with inborn errors of metabolism. The goal of this work is to establish a standard protocol for dieticians to follow that has an established basis in practice with the hope that such a process can improve the outcome of our children.

After each group took commemorative pictures with attendees sporting either their blue (OAA) or yellow (FOD) t-shirts, the conference wrapped up with a speaker roundtable where attendees were able to ask open/probing questions of the panel. As you might expect, the questions involved each parent unique situation and the challenges they face every day managing their child's health and development. The closing ceremony was a touching tribute to our kids entitled FACES of FOD and OAA – 2010. What a fitting conclusion to a wonderful couple of days!



ACMG and SIMD Conferences Report

(day by day diary)

Wednesday, March 24, 2010

I'm representing OAA and FOD at the SIMD and ACMG conferences in Albuquerque, NM. The Genetics Alliance had an opportunity to earn a scholarship to the ACMG conference (American College of Medical Genetics) and I am one of 10 people who got to go. Most of those sessions are not about metabolic diseases, but it should be interesting anyway. There's an orientation meeting for the Genetics Alliance this afternoon, then the conference starts tomorrow.

Next week, the OAA and FOD are sharing an exhibit booth at the SIMD (metabolic professionals). I have lots of flyers and handouts to give the professionals to raise awareness of our groups. The booth will be open on Monday and Tuesday of next week and Wednesday morning.

Thursday 3/25/2010

I attended meetings all day today. I started with a breakfast where the advocates met the head of the ACMG. Then I attended lectures about medical ethics, NBS, data collection, telemedicine, and more ethics. We finished in the exhibit hall where lots of exhibitors read my tag as academia instead of acidemia. The name tag was right, the exhibitors can't read. I spoke to quite a few about what organic acidemias are. Most of the exhibitors are sales representatives with little medical background. Since this is the non-metabolic part of the genetics conference, many of the professionals are also unfamiliar with our errors. I've explained about how we are a parent support group for those whose kids have organic acid errors, more times than I can remember. I've had to describe diet many times, too. I was in meetings from 8 am to 8 pm!

I spoke with Dr. Rinaldo twice, spent a bit of time with Franks adaptive yoga teacher (who is a Genetics Counselor), and saw Dr. Kahler. Dr. Rinaldo introduced me to a few other metabolic docs, but he agreed that most of them won't be arriving until the SIMD conference on Monday.

I heard about a new online resource under development. Go to nbsclearinghouse.org and check it out. Its aimed at both professionals and parents and has links to lots of articles about our rare disorders.

The other tidbit I learned is that the Senate medical foods bill has now been introduced in the House. The National PKU Alliance is posting updates on their website (npkua.org).

Friday, 3/26/2010

Today I heard about a study in Boston that involved adult genetics. In their training program, about one quarter of the patients seen by their residents are adults, and of those adults, another quarter are those diagnosed in adulthood with what is termed a childhood disease. Less than 10% are transitioned from the children's clinics. Dr. Greene asked the presenter how many metabolic cases they were seeing and the reply was not many, in fact most were PKUs who had grown up and been transitioned out of the children's clinic.

Dr. Greene and I continued the topic outside and she expressed interest in the issue of getting adult metabolic patients care. She feels that there are many adults now who are being diagnosed with what would have been caught by NBS (if it had existed years ago). I mentioned my concern that so many states do not cover the necessary medical foods for adults, including the state that my daughter lives in now, and that while her state has many clinics for children, my daughter has to travel 3 hours to the only clinic that will see adults. I realize that some families have to travel overnight to get to their closest clinic.

In the exhibit hall I spoke with Tara, a Genetics Counselor for Coriell, which is trying to collect cell lines for most of the inherited metabolic errors. She said they still are desperately seeking samples. She said they may only have about five cell lines on average for our errors. She really wants our families to donate samples to them, to benefit research. For more info, contact tshmidl@coriell.org (www.coriell.org) or check out her article in this issue of the newsletter.

I also got more info on the cord blood registries that are so popular now. The most important thing I learned is that siblings have a 75% chance of matching. They have to prepare the recipient with chemo and radiation so it's a big deal for the kid. They have an 85% survival rate from the transplant. They do not say what the cure rate is. Most telling to me is that the company I spoke with only did 11 cord blood transplants in 2009, down from 19 in 2007. Most of the transplants last year were for Sickle Cell and none for OAs.

Saturday, 3/27/2010

It was a busy day today, and a long one. The advocates met for the last time for breakfast, then I went to the first session on gene sequencing in the gigantic auditorium. After that I went down to the exhibit hall which is full of posters.

Unfortunately I didn't finish reading all 360 posters before they started to pack up because I was drawn into a conversation with an author. Her poster was on Maternal PKU Syndrome and diet compliance during pregnancy. We discussed how the special amino acid modified formulas don't mix with morning sickness, and how my daughter discovered that she could only drink a certain amount before it would come back up.

In the afternoon was the first of the metabolic sessions. I started to see more of "our" docs. Dr. Vockley gave a presentation on presymptomatic treatment of FODs, then we had a break, after which Dr. Vockley gave another presentation on a new cholesterol error. We also heard about the effectiveness of Kuvan in the treatment of mild PKU and the lab techniques used to diagnose GA1. Kuvan is a new drug available for PKU which is actually a naturally occurring cofactor in that metabolic pathway. It works best for the milder patients, and the docs have so far been unsuccessful in identifying all mutations which respond best.

We even had a pop quiz in the last session. Dr. Rinaldo was sitting next to me and TRIED to help explain things to me. I felt better after the quiz when I realized that I answered the same way as the majority of the other people (they showed the results then and there). Also, when I was confused, the other answers

also indicated the audience was also confused. At one point (when I was getting totally dazed by the lecture), Dr. Rinaldo leaned over and told me that most of the people in the hall were probably not understanding either.

Parents, you need to know there are professionals who lurk on our listserv. Two doctors came up to me and jokingly commented on my entries from the last few days.

Sunday, 3/28/2010

Today we had a bunch of talks on autism. It seems that a lot of our kids have it, probably from the brain damage of the organic acidemia. Tonight we had a reception and I sat next to Dr. Rinaldo by accident. As has been happening with him, he has been introducing me to people who turn out to be ones I needed to meet. This morning he introduced me to Dr. Cuthbert of the CDC, who had previously asked to become the OAA's newest Scientific Medical Advisor. Tonight he introduced me to a doc with experience with maternal IVA, who lives not far from my daughter.

Monday, 3/29/2010

Another long day but at a different venue. This is now the SIMD conference (Society for Inherited Metabolic Disorders) in downtown Albuquerque. We breakfasted with quite a number of docs and their wives. The first lecture was at 8 am, then the exhibit hall opened at 10. As I stated earlier, FOD and OAA are sharing a booth.

We gave away magnets, brochures, bracelets, postcard announcements of our July 2010 conference, and registration forms. We also gave out bear packages of Jelly Bellies that are both low protein and low fat. At one point a printed article on bone mass in PKU adults mysteriously showed up in our booth. I found the article interesting since our kids are also on special formulas like the PKU patients. This concern has since been verified by a professional and our "kids" are indeed at risk for bone issues at any age, even as children.



We heard about the new NBS test for SCID (bubble boy disease). Dr. Venditti's group had 3 presentations, all on his MMA studies and all interesting. He's giving a similar talk at our family conference in July. There was a presentation on Carbaglu, which is hoped to help with ammonia control of PA, but has been difficult to actually study due to other measures being taken during crisis.

For dinner we celebrated a Passover Seder with a large group of SIMD members and their spouses. There was a sixth grader there who not only was able to ask the traditional questions, but was able to read them in Hebrew. He spoke loudly and clearly, except I don't understand a word of Hebrew. Not everyone in the room was Jewish but we all felt a sense of family. They even accommodated my religious beliefs by providing grape juice, and I noticed that my hubby and I were not the only people drinking it.

Tuesday, 3/30/2010

This morning Dr. Van Hove gave a presentation on glycine encephalopathy. Later, during the refreshment break, we spoke about how my daughter is sensitive to glycine and doesn't take it, even though it is considered standard treatment for IVA. He has run into 3 other patients (with other disorders) who also become, as he described it, "agitated" when taking it. He agreed that each of our kids is different and responds differently to treatment.

At dinner, Dr. Greene met with the support group representatives and expressed the desire of the SIMD to coordinate with the parent groups as a team. They are also concerned about not having enough new metabolic trainees and the upcoming retirements of many of the pioneering doctors in the field. They would love for the support groups to sponsor research fellows. Even though the fellow might originally do research directly related to a specific disease that the parent support group might not be interested in, that trainee would then graduate and go into service treating all metabolic disorders.

The final scientific lecture of the evening was about the possible effects of two or more carrier mutations on disease presentations. That meeting was followed by a business meeting where a date was set for the next conference.

Wednesday, 3/31/2010

Today was the nutritionist presentations. We have an article about their PA treatment guidelines study in our April newsletter. Basically, they sent out questionnaires to clinics and compared treatments currently in use. 100% were using carnitine, but after that there were differences in treatments. Since many kids present differently, this could be one reason. They discussed doing diet records with blood sampling, frequency of blood tests, TPN (feeding by IV) during crisis, and protein and formula prescriptions.

We packed up the exhibit booth but not before a LOT of professionals exhibited interest in attending our upcoming OAA/FOD conference. They all said they'd pass the word along because they all thought it was important for their patients to attend and network with each other. A frequent comment echoed the FOD slogan: *We're all in this together.*

Thanks again to the OAA, FOD, Genetic Alliance, SIMD, and ACMG for the opportunity to attend these conferences.

Carol Barton, Executive Director
Organic Acidemia Association
Mom to Beth 28 IVA



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OAA Internet Google Group

OAA's main mission is to empower families with knowledge about organic acidemias. If you would like to connect with other families who share the same or similar diagnoses, please join our OAA Group. Visit the OAAnews.org web site to sign up. This is a private list not open to the general public (but you never know who may be "lurking").

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