



GOD BLESS AMERICA

Organic Acidemia Association Newsletter

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Do you ever ask yourself, "where has the time gone"? That is exactly how I'm feeling lately. It seems like it was just yesterday we were in Orlando at the conference, then returning to work on the newsletter and now it's almost mid-November and I'm just finishing it up! I apologize for my tardiness for this issue...I have created far too much work for myself lately!

I hope you will enjoy the selection of articles in this issue of the newsletter. We have two articles that include an update of an older OA child and introduces their younger sibling whom was diagnosed prenatally with having the same disorder. I often hear from families struggling with the decision to have another child after having one with an OA. This is a very personal decision that a family must face – but I'm sure after reading these two stories, you'll understand how much these children are a blessing for these families.

If you like newborn screening success stories, you'll enjoy the article from Kate Moran on her daughter Kayleigh. It is such a pleasure to share of how newborn screening does work! My only fear is that OAA will not hear from more of these families as newborn screening expands, because these families might feel they do not need the support. I think the Moran family is an example of how screening has motivated this family to learn and help others dealing with the same disorder.

I often hear from families that they do not like to read stories of a child that has died. I feel it is a healing process for a family to share this information and if the newsletter helps that I feel I must do it. Therefore the reality of *Sabina's story will be painful for some to read.

We report on exciting research news in this issue, as well as coverage of the conference in Orlando. We will have conference documents on our website soon, and will be offering a video of the conference for \$20. Thanks to Jamie Pitre, dad to Ashtyn, MMA Cbl C for your dedication to videotaping the conference for us. Stay healthy!

OAA is a nonprofit organization that supports parents with various metabolic disorders. We ask for a \$25/year donation (US funds) and \$35 for international members to cover the cost of our newsletter (plus \$5 for member roster). If the family cannot afford the cost of the newsletter, the



OAA Members Attend Metabolic/WCD Conference in Orlando

Over 75 OAA members attended this year's metabolic conference held in Orlando, Florida on October 3, 2002. What a great week to be in sunny Florida! I want to thank every family who took the challenge and traveled to Orlando with their children...this is not an easy task. Together with the World Congress on Disabilities Conference (WCD) and Disney nearby sure made for plenty of things to do and see. The conference started with a family reception by pool side at our hotel. (Continued Page 6)



Ronald McDonald visits childcare at metabolic conference in Orlando.

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Lauren June Delima, Propionic Acidemia, age 15 months

On Valentines Day 2001, Greg and I received the long-anticipated phone call from the geneticist about the result of my amniocentesis, only to be devastated with the news that our second child also has Propionic Acidemia. I can remember crying a lot and trying to fathom the reality of having 2 kangaroo pumps, 2 special formulas, double the hospital stays, and double the problems attached to having children with metabolic disorders! We met with the geneticist and a biochemical disease physician who were pushing us for a "loving termination" of our baby. After our meeting we immediately went to the Cathedral for comfort. We prayed to God to give us additional strength to endure our second big trial. Then we went home to our little Jenna who was 2 years old at the time. Seeing this beautiful creature that is oblivious to the problems we face, we knew our decision to proceed with the pregnancy could only be the right choice.

Two weeks before my due date, Lauren June Delima was born at 12:04 am on June 14th 2001. Unlike Jenna's birth where the hospital room was filled with family and friends, Lauren only had my husband and parents present. The doctors gave us 10 minutes to admire her and then scooped her away to Special Care Nursery to be attended to by more doctors. She spent 3 days there, then an additional 8 days in the hospital's private ward to be stabilized metabolically. Lauren did very well on her formula consisting of expressed breast milk mixed with Propimex 1 and Similac. She was developing on track and was a content baby.

On Valentines day 2002, Lauren was 8 months old and began her long-standing battle with high ammonia levels (100-144). Lauren would be admitted for 2 weeks, be home for 5 days, then get admitted again. This cycle of hospital admissions lasted approximately 4 months. Lauren was keeping her dietician and physicians on their toes trying to stabilize and understand her ammonia fluctuations. Due to her "crisis", her heart started beating 170 beats per minute, which works her heart very hard. She is monitored by a cardiologist who performs ECG and ECHO-Cardiogram tests on her every 3 to 6 months. The cardiologist informed us that if her heart does not

stop beating fast, she may develop a heart condition called Cardiomyopathy, which is a condition common to PA patients. She does not show irritability from having a fast heart rate, but we certainly hope her heart slows down to the normal beat soon.

Lauren is now 15 months old. She is crawling, cruising along the furniture and should begin walking any month now. She is connected to me at the hips, always wanting to be beside Mommy every minute of the day. She is quite a happy baby, when she is well. She loves eye contact and is very interactive. She looks up to her big sister so much. Jenna is her idol. If Jenna cries, she will cry. If Jenna runs around the house, Lauren will crawl and chase after her, screaming in delight, even though Jenna may fail to acknowledge her presence.



We visit the hospital every 2 weeks for regular blood work (Plasma Amino Acids, Albumin, CBC, Differential, Acylcarnitine blood-dot) and Urine Organic Acids. She weighs 28 pounds and is quite pudgy. She has monthly physiotherapy for her low muscle tone and slight developmental delays. Lauren has stopped eating and drinking orally,

ever since she had her period of hospitalization. She is bolus fed during the day and continuously throughout the night via the Kangaroo pump.

In retrospect, our outlook of having 2 kids with Propionic Acidemia was overestimated. If we had opted to terminate the pregnancy with Lauren, we wouldn't have known how to value her marvelous being. We have our moments of depression, but luckily when I am down, Greg is there to keep me strong, as I am for him. Our girls keep us longing to see the next day, so we can witness their progression. We truly feel blessed to have our 2 PA girls.

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UPDATE, Jenna Lynn Delima, Propionic Acidemia, age 4 years

Jenna has made so much progress over the last 12 months I don't know where to begin describing her surprising turn-around. She has suffered substantial neurological damage and developmental delay from her initial crisis at 6 months of age. Like many parents with PA kids, we were told Jenna would be severely handicapped. Jenna did not learn to walk and talk until she was 3 years old. When she walked unassisted for the first time, the feeling of joy we had was immeasurable. She didn't stop there, her communication skills have developed just as quickly over the last several months. We can't stop her from asking questions, such as "Why not?" and "What's that?" She has a very friendly personality. She is determined to have every person she meets say "hi" to her. She will persist to get their attention until they respond with a big smile or "hello". Jenna has her moments of big sisterhood. When Lauren is crying, she will try to comfort her by offering her a toy or soother and if that fails, she will run to Mommy as a last resort. Jenna can be a little rough at times with her baby sister. Sometimes she forgets that Lauren can't walk, and all but drags her only to have Lauren fall and cry.

For the longest time, Jenna was immobile and uncommunicative that we thought her milestones would only be a dream. Watching Jenna play independently, such as pretend play or making her dolls talk to each other is so gratifying. Jenna is in preschool and loves every moment with her classmates. She gets so excited to attend class that she forgets to kiss Mommy and Daddy goodbye. To date we have not had any problems with her health

such as catching illness from the class. (Knock-on-wood).



Jenna continues to have inserts to help stabilize her feet. She was recently transferred to a new developmental program called Center for Ability where she is seen regularly by a physiotherapist, speech pathologist, and occupational therapist. Jenna's diet is predominantly her formula consisting of Propimex 2, Pediasure and Polycose. Her solids are restricted to 3.7 grams protein/day, which we use to calculate her soups (Lipton Tomato Vegetable and Minestrone). These are the few solids she is willing to eat orally, so we've stuck with feeding her the same food that works!

Our baby Jenna has grown so fast, that she refers to herself as a "big girl". Our life, which we thought would be full of pain and suffering, has been overwhelmed with love and support from our family, friends and the medical community. For that, we give them all our biggest THANKS!

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(Jenna's previous article - October, 2000 OAA Newsletter)



Lauren & Jenna Delima, Propionic Acidemia

OAA Fundraiser

Mary Anderson, mom to Christopher, MMA, Mut 0, who is conducting a fundraiser through a website at *Usborne Books*. A percentage of what is sold will go directly to OAA. You can order directly through this website:

<http://www.ubah.com/ecommerce/main.asp?sid=H1437&gid=923566>.

Mary is also willing to mail you out a copy of the catalog if you prefer to order that way or collect orders from your friends and family. She plans to combine the orders and should have them delivered by the Holidays. Please contact Mary directly if you have questions at 910-436-6556 or her email at: marysmark@juno.com. Thank you Mary for arranging this fundraiser for OAA.

In loving memory of our beautiful angel, *Sabina Geerts

(6-23-97 - 12-20-00)

D-2 Hydroxyglutaric Aciduria

My husband and I had been married for 6 years when we thought we might try to have a baby. Really soon after this, in October 1996, I first found out we were going to have a little miracle by the end of June 1997. The pregnancy was not the ones you read about, I got ill in the 18th week and was hospitalized. Since that moment I started worrying about the little one I was carrying. The doctors told me there was no reason to be scared, everything was going well, but the little voice inside me kept telling me differently. My own mother had lost two babies at birth and this was one of the things that worried me. Time went by and I past the critical moments of pregnancy and even began to feel more confident.

When I was 40 weeks pregnant, a lady in my Lamaze class had a baby which died after only 3 days. It was a girl and she had heart and brain abnormalities. Then it struck me: I was almost sure this was going to be the same case with my baby. The ob-gyn I had at that time unfortunately was an incompetent one and she did not even bother to hear me out. She only suggested I went to the hospital every other day to have a CTG done, which I did. Those tests were not good from the beginning; the baby's heartbeat was too slow and even that was taken lightly by that ob-gyn. And this went on for days, the nurses reacted concerned about the slow heartbeat and the ob-gyn did not even take a look.

After I had been having contractions for several days and nothing happened, on Saturday the 21st June I finally thought the time had come to embrace my little one. I had been having contractions for more than two hours every minute and we went to the hospital all excited and really hoping we would finally become parents. As soon as I was in the delivery room, the contractions stopped and nothing happened. The ob-gyn on duty was a bit worried about the heartbeat and contractions coming and going. He told us to come back the next morning as early as possible to see what was happening. He did an ultrasound that morning (which had not been done for several weeks) and discovered the baby was too big to be born naturally. There was no amniotic fluid anymore, she was lying with her buttocks down, and the placenta was just before the opening. So there was no way *Sabina could have been born in a natural way without serious complications for her and me. He decided to perform a caesarian as soon as possible.

Our beautiful daughter was born on Monday June 23, 1997 and we named her Sabina Marie José. Although everyone told me she was all right and perfectly healthy, I still had a strange feeling. I kept on telling them to take a look and asking if everything was really okay. The third day, I woke up and realized they had not brought her to me the whole night, in spite of my wish to see her and try to breast-feed her. They told me she had been sleeping the whole night and this worried me; I thought it was not normal for a newborn to sleep the entire night and to not get hungry. I began crying and a pediatrician came to see Sabina just to calm me down. Unfortunately there was nothing to be calm about. She



discovered Sabina had a heart murmur, she had seizures, she was looking yellow, and lots of other things were not okay. So they took her to the other ward. Soon we were transferred to another hospital, because this one was a small one with little research capacity. In the academic hospital lots of tests were done, my little girl was put on IV and feedings were stopped, they administered anti-convulsants to her (Phenobarbital at first) and it was incredibly horrible to see her turned into a patient instead of a newborn. At this moment she was only sleeping and I had even the feeling I could not make contact with her due to the drugs they had given her. However, when we went to the Intensive Care Unit, she was crying and we were told she had been crying for some time. As soon as I talked to her and touched her, she stopped crying! That's when I realized this little one had an enormously strong will to keep on fighting and that I was her mommy and she had chosen me to take care of her. And as I gently caressed her dark hair, I whispered "*Keep on fighting little one; I'll make it up to you*". And she did. She kept on fighting.

After a few weeks the final diagnosis was known; she had a rare inherited metabolic disorder, called **D-2 hydroxyglutaric aciduria**. At that moment, only 8 children were known to be affected by the same disorder. The pediatrician who told us this news said the prognosis was bad, and, according to him, the only thing we could do for her was to try and make her life bearable. Again,

we felt like there was no ground under our feet. But she kept on fighting and so did we. In the meantime, medication was adjusted; the Phenobarbital was discontinued and Dilantin was started. Sabina began to be more and more awake. At six weeks of age, she started smiling at me. The only thing that kept us from taking her home was her feeding problems; she vomited a lot and kept on losing weight. They decided she may need a jejuno-tube to feed her, but during that surgery, they discovered she had a pylorostenosis (narrowing of the opening from the vertebrae from the stomach to the intestine) and they removed this and decided a jejunostomy (surgical procedure to place tube into the small intestine) was not needed. She had to be fed by nasal-gastric tube (feeding tube placed through the nasal passage to the stomach) and we learned how to do so.

When she was 2½ months old, we finally took her home. After one week, we were able to remove the tube from her nose and she drank all of her bottles by herself and with much pleasure. She even began to look more chubby and feeling good. These were wonderful months. We even discovered that she reacted well to additional glucose in her feedings; she even had fewer seizures when she took enough glucose. In April 1998 she began to vomit again and we went to the hospital to check what was going on. She had reflux but they told us there was nothing to worry about. But she kept on vomiting and losing weight which was attributed to an atonic stomach. They suggested a jejuno-tube; this surgery was performed on August 18, 1998 and it almost killed her. The tube was misplaced; she got peritonitis, a perforated bowel and four major surgeries in one week, followed by 9 months of hospitalization due to other complications (thrombosis, sepsis, infections, etc.) and other incredible mistakes made by the medics. But she survived and finally on May 13, 1999 we were able to take her home again.

During the months that followed, we had to go to the hospital a few times, because of pulmonary problems, colds, and tonsils which had to be removed. Her immune system got weaker and the pneumonias followed one another. In October 2000 we finally went to see another specialist who saw her as a little girl and not as a case. He told us she had been given the wrong medication for too long; we would have to discontinue the Dilantin and Tegretol as soon as possible; it had broken down her immune system, caused bone problems (scoliosis and other irregularities) and had made her drowsy and less alert as she could have been without them. In the week we started to build down the doses, she started to sit by herself and grasp for toys; she even started making noises and laugh about them. This was just a confirmation to us that this specialist was right. Unfortunately his help came too late and in December her last pneumonia turned out to be fatal. On December 30th, a cold and snowy day, we just were able to lay her in the hospital bed and she sighed one last time and then slipped away. The words “keep on fighting, I’ll make it up to you”

could not keep her on earth, her time had come.

On January 4th, the snow had vanished miraculously; we buried her on a bed of roses, because the ground was too hard for a delicate rose like she was. During her funeral, “**Hero**” by Mariah Carey was played as this song is connected to her; whenever we had difficult times ahead like surgery, I sang a few lines to her, to help her keep on fighting.

*“.....So when you feel like hope is gone,
look inside you and be strong, and you’ll finally see the
truth, that a hero lies in you...”*

And a hero she was and is, a little tough lady, who made us more human and taught us many things, like unconditional love, what really matters in life and what does not. Her task on this earth was completed and we – the parents she had chosen to bear all this with her - had to let her go, with a terrible pain in our hearts. But we are proud to have been touched by this angel, who was too beautiful for earth. Sabina, till we meet again!

If anyone has questions, wishes to receive more info on D-2HGA, please feel free to contact me at m.geerts@zonnet.nl or just take a look at *Sabina’s webpage- www.sabina.to (under construction, soon to be completed).

*With love, Gert and Micky, proud daddy and mommy to
Sabina

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God’s garden

*God looked around his garden and He saw an empty space
He then looked down upon this earth and saw your tired face
He put his arms around you and lifted you to rest
God’s garden must be beautiful, He always takes the best
He saw the road was getting rough, the hills harder to climb,
So He closed your weary eyelids and whispered “peace be thine”
It broke my heart to lose you, but you did not go alone
For part of me went with you, the day He called you home
If tears could build a staircase and memories a lane,
I’d walk all the way to heaven and bring you home again
(some lines of her memorial card)*

PS: our special thanks to my “Sisters at Heart”; the mommies from the D-2HGA group who have been there for us through good and bad times! Thank God there is internet!

OAA, FOD (fatty oxidation disorders), PKU, Tyrosinemia and Homocystinuria families and professionals were in attendance. It was nice to put so many names to faces. The next morning we traveled a few miles away to the Orange County Convention center where our conference was being held in conjunction with the World Congress on Disabilities Conference. Trish Mullaley, Coalition for PKU & Allied Disorders handled the challenging job of organizing this conference, working with the WCD on logistics was especially difficult. We were very lucky to have a great childcare facilitator, Accent of Childcare come in and care for our children. Many fun activities were planned, and they even had a visit from Ronald McDonald!



Ashtyn Pitre, MMA Cbl C and Brendon Dix, MMA Mut 0

This year OAA had another outstanding group of speakers. We started the morning with Cris Trahms from the University of Seattle in Washington. She spoke to us about Proactive Parenting. The notes from her speech are included in this issue of the newsletter. Next, we heard from Dr. Mark Korson from New England Medical Center on Correlation's Between Mitochondrial and Metabolic Disorders. Our next speaker, Dr. Guy Touati from Paris, France showed us a video tape on the French experience in educating children and adults with inborn errors of metabolism treated with low-protein diets. We then broke for lunch and many families toured the WCD trade show. There were hundreds of vendors booths to visit on a variety of disability topics. After lunch, we returned to hear Dr. Piero Rinaldo, from Mayo who *empowered* us to learn the biochemical language associated with ketosis in organic acidemias! I have to admit that as complex as this was, Piero did an excellent job explaining it in great detail to us...now, if I could only repeat it! Direct from a red-eye flight from California, Dr. Susan Winters inspired us with the "history" of Carnitine and the many successes that it has brought to families with organic acidemias. Thank you Dr. Winter! Dr. Winter's presentation on Carnitine brought lots of questions from parents with many lining up with questions after her presentation. We then broke up in small groups, with Lynne



Dr. Piero Rinaldo from Mayo empowered us during his lecture

Wolfe speaking to the MMA families and Dr. Touati speaking to the 3-MCC families. OAA invited Dr. Toru Miyazaki from the University of Texas, Southwestern to present his research to the Propionic Acidemia families. Many PA families have been working hard at fundraising to assist with his goals.

We ended the day with a closing slide show ceremony created by Deb Gould from the FOD Parent Support Network. Deb did a great job setting up our families in a circle of ribbon that read "We Are All In This Together" written on it. A slide show of "Faces of FOD and Allied Disorders" was shown set to the Gloria Estefan song, "I See Your Smile". It was a lovely tribute to our families and I thank Deb for having the energy to put this ceremony together. Many families stayed throughout the weekend attending other WCD sessions, including several on newborn screening. At this point, I can't say when our next conference will be, but I will definitely be looking for a representative to handle the details!



Conference attendees holding "We Are All In This Together" ribbon at closing ceremony in Orlando.

Low Protein Food List for PKU Book-Updated Version

The Low Protein Food List for PKU, first printed in 1995, is undergoing a major update for a new printing that will take place this November. This second edition will include all of the new food data that has been collected over the past 7 years since the book was originally printed - hundreds of new low protein items and many other updates.

To reserve your copy of this limited printing, we urge you to place your order as soon as possible. Prepayment also will help cover the printing costs and will bring you a savings of \$3 off the eventual price of the book (which will be \$50 plus shipping after November 15, 2002). Cost for the book is \$47 + shipping (\$5.00 United States, Canadian \$7.00, International \$10.00 and Washington State residents add \$4.45 tax).

The books will be distributed by SHS North America, but for payments before November 15, 2002, please send your check to : Virginia Schuett, National PKU News, 6869 Woodlawn Ave. NE #116, Seattle, WA 98115-5469

When the book is ready, it will be sent to you from SHS. After November 15, 2002, orders must be placed directly with SHS (1-888-567-7646) and credit cards will be accepted through SHS.

To place your advance payment send your check or money order made payable to **National PKU News**. Please include your name, address, city, state, zip, phone, email address.

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Cambrooke Foods

New for January, 2003 – A Frequent Buyers' Club designed to give rewards to regular customers! This program will give customers who order monthly, convenience benefits, as well as yearly savings. Please call Customer Service at option 2 using our toll free number for more information.

Good News for everyone who has been waiting for the new Cream Cheese products. Plain Cream Cheese, Herb and Garlic flavored Cream Cheese and Cheese Wizard – a Cheddar flavored cheese spread is now available. Try the Cheese Wizard with toasted Artisan Bread rounds. Everyone will love this **melted** on their favorite steamed vegetables! Porridge is also available to order. It can be used in the traditional way as a hot cereal or as an ingredient in baked goods. Try the "MocNugget" recipe on our website to get your creativity charged.

Coming soon...Speed up your meal preparations with two new easy to prepare pasta and sauce combinations – Orzo Alfredo and Roasted Garlic and Broccoli Couscous.

We are happy to announce our new ClinicStore Program which has been initiated by two U.S. Metabolic clinics and one Canadian clinic. These clinics are maintaining a store of Cambrooke Foods' products to provide directly to their patients. The Clinic Store concept which was piloted in the US by Emory University has proven to be a much welcomed and successful program. Ask your clinic if they can provide this service to you.

Visit our website regularly for new products and join our mailing list (easily done by e-mailing us or calling us) so you will be advised of special offers. Returning to diet? Call us for suggestions to ease back into a "low pro life".

Order 24/7 through our call center, toll-free at (866) 4 LOW PRO / (866) 456-9776 or over our website at www.cambrookefoods.com. If this is not convenient for you, you can mail or fax your orders to us.

Other Low Protein Resources

Dietary Specialties
1248 Sussex Turnpike, Unit C2
Randolph, NJ 07869
Phone (toll free): 888-640-2800
Fax: 973-895-3742
Web site: www.dietspec.com

Applied Nutrition
273 Franklin Road
Randolph, NJ 07869
Phone: 800-605-0410 Fax: 973-361-6707
Web site: www.medicalfood.com

SHS International
P.O. Box 117
Gaithersburg, MD 20884-0177
Phone: 800-365-7354 Fax: 301-795-2301
E-mail: nutritionservices@shсна.com
Web site: www.SHSNA.com

Ener-G Foods
5960 First Avenue, South
P.O. Box 84487
Seattle, WA 98124-5789
Phone: 800-331-5222 Fax: 206-764-3398
Web site: www.ener-g.com

Med Diet Labs
3600 Holly Lane N, Suite 80
Plymouth, MN 55447
Phone: 800-633-5550 Fax: 763-550-2022
E-mail: meddiet@med-diet.com
Web site: www.med-diet.com

The Dietary Shoppe, Inc.
184A East Evergreen Avenue
Philadelphia, PA 19118
215-242-5302
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Kayleigh Moran, Methylmalonic Acidemia, Mut 0, Age 3 (Newborn Screened!)

Our daughter, Kayleigh, was born on September 22, 1999. She is our third child. Our oldest is Shane, he is 12 years old. Next is Meghan, she is ten. Neither Shane nor Meghan have MMA. And when Kayleigh was born, there were no signs that she was sick either.

She was (and I might add) still is “the perfect little baby.”

Kayleigh was delivered C-section with no complications. She did everything she was supposed to do. She ate well, slept well, pooped well. Everything was perfect – until that phone call. I will never forget it as long as I live! I get chills just thinking about it.

It was a Saturday morning, I had been home from the hospital for ten days, my husband was at school, Kayleigh was sleeping and Shane and Meghan were out at different activities. Marty knew I was getting “cabin fever” and had suggested we go to the mall when he got home, I eagerly agreed. I was just getting ready to hop in the shower when the phone rang. I ran over and picked up the phone. It was Kayleigh’s pediatrician, Dr. David Pollack. He said that the newborn screening that was performed came back positive. She needed to go to Children’s Hospital immediately. She needed to be seen by special doctors immediately. From that very moment my heart sank and still to this day I worry sick over her.

Not five minutes after I hung up the phone, Marty came home. I was in the shower, so he listened to the answering machine (it had recorded our whole conversation). We packed Kayleigh up and off we went. I can’t even remember what we did with our other children.

We had no idea what we were in store for. We went straight to the emergency room where the doctors were expecting us. I don’t remember which doctor it was we saw first but whoever it was told me I had to stop breastfeeding. I would never be able to breast feed Kayleigh again. We needed to know exactly how much protein Kayleigh was getting, and we wouldn’t know this if I was breast-feeding. After seeing many different doctors, each one giving us only a little information, we were admitted. Looking back, I realize now that they only wanted to tell us

what they were sure of. But what they weren’t sure of was a lot.

There we were, with our perfect angel in Children’s Hospital. What do we tell the kids? What do we tell our families? This was so foreign, how could anybody understand? We couldn’t comprehend what was happening.

The doctors began to educate us. I think they said they only knew of seven cases. All of the children but one had gotten quite ill. They did, however, emphasize, that our daughter was “well” and that this could be the one thing that could make a difference. Today I am convinced our daughter is doing so well – because she never had an “episode.” ***The newborn screen saved my daughter’s life.*** When you read everyone’s stories you can see, there is a definite difference in the children who have not suffered an episode! The doctors told us that anything could have an effect on Kayleigh. They couldn’t stress enough the importance of keeping her healthy. I can laugh now, we were so worried about germs. We went out and bought cases of sanitizer. I would wash my hands, hold on to the paper towel



and wouldn’t touch a thing (not a light switch or door knob, not even the faucet to turn the water off!) Meghan’s hands actually started to bleed, that’s how much we washed before touching Kayleigh. It was amazing how concerned the doctors were. Today we have the most beautiful and still- perfect little angel. She is now three years old. She has suffered many ear infections, horrible colds, a horrible diaper rash, teething, and an operation. She’s been to Ireland. And through all this has not suffered one episode. (Mom, however has grown a few gray hairs). Kayleigh is crawling, pulling herself up to a stand and is trying to say some words. She definitely has “Da-Da” down pat. And we think she is saying “Dane,” for Shane. She loves to imitate with her mouth. She is quite funny. I am comfortable in saying that I do not think her metabolic disorder has affected her in any way, as far as I can see. She eats (not the greatest) but she does eat and j u s t l o v e s h e r bottles. It’s time now to get her onto the cup. This is

where I get nervous. I've heard the term life-altering. Yes, this definitely has been life altering. Having Kayleigh has been truly rewarding to our whole family. I wouldn't change it for the world. She is the sweetest, dearest little bundle of joy. Always so pleasant.

This is where I have to put my husband on a pedestal! Honestly, he immediately began educating himself with the help of this magnificent team of doctors. In this short time he has tackled insurance, doctors, prescriptions...the list goes on and on. He is persistent, and never gives up. Kayleigh is very lucky...if there is anybody in this world who can make things better for her...it's her daddy. He is my rock and has really held it together for me. Our children, too, have been truly remarkable. Both of them love Kayleigh dearly. It's remarkable how much they are aware and want to be involved with her health.

My advice to anyone who has a child with a metabolic illness would be to educate yourself as much as possible and ALWAYS, ALWAYS be on top of your child's care.

Over the past year, Kayleigh progress has been awesome. She no longer needs the four different therapies she was receiving (speech, feeding, occupational and physical). She was assessed and is right on target for a three year old. She sings a million different songs, dances, and can even count backwards! She eats rice, crackers, spaghettios, cereal, toast, chips and pretzels. She drinks her formula and even drinks a little water. If I could only get her to sleep at night! Kayleigh has not been hospitalized since September of 2001! Praise the Lord.

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What is an OAA Listserv?

A Listserv is a internet system for group communication and conferencing. In order to participate in OAA's Listserv conferences, you will need an email address.

You too can join this discussion group, where you'll read messages from over 150 members. You may ask to join the listserv by emailing oaanews-subscribe@topica.com, or visiting OAA's website at www.oaanews.org.

Instructions will then be emailed to you as to how to send messages. We average about 4-5 messages a day.

A Special Offer for Special People

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- This newsletter does not provide medical advice. You should notify your health care provider before making treatment changes.

Update: Katie Clanton, Propionic Acidemia, Age 4

We first wrote an article on Katie (PA) for the June 2000 issue. Katie turned 4 years old on September 19, 2002 and continues to amaze us growing up and dealing with PA. So we thought it might be time for an update.

Since her diagnosis at one month old we had no idea what would be ahead for us. We did not know what long-term effects would result from her initial crisis and all the hospital stays to follow. We did not know if our daughter would ever talk, walk, go to school, or, most important, eat her very strict medical diet. All of this was very overwhelming for first time parents. It was decided I could not return back to work full time and we began working with her doctors to find out what works for Katie.

Katie has always been very stable metabolically, but we do continue to keep up with how much protein is in every bite of food, how many ounces of drink and even a "Poopy Log." We even seem to take notice when she simply sneezes. Anything can potentially send us to the hospital with her due to a high ammonia level. We are extremely fortunate to live only twenty minutes from Children's Hospital and Katie's specialist, Dr. Lane Rutledge.

Katie started early intervention at 18 months until age 3 at Children's Health Services a program at Children's Hospital. In this program we had access to physical, speech and occupational therapists, as well as a Child Life Specialist. They helped teach Katie and us the way to help Katie grow up with a positive attitude in dealing with all the things that come along with this disorder. She also attended a *Kindermusik* program that got her around other children. Being an only child, we also had concern with her social skills. We started her in the Mother's Day Out program at our church one morning a week and slowly worked upward.

Today, Katie is in 3K Preschool full-time and Mommy is back at work full-time. Katie is developing right on schedule and can only be described as a miracle!!! We have been lucky in that Katie has always been a good eater and

drinker, even her special drink. She is allowed 17 grams of protein from natural food a day, drinks 8 oz of Propimex -2 a day, 4 ml Carnitor twice a day and since she no longer is on the Prophree she gets a V2 of Flintstones Vitamin and Calcium supplement a day.

Katie loves school and is very smart. She attends a class with fourteen other children. Her teacher is great in communicating with me in regards to Katie's diet. She does not want Katie to be left out of anything and we try to plan ahead for things like pizza and ice cream parties. Katie does attend a private school where the parents provide

lunch and snacks. This has been to our advantage in that Katie is able, most of the time, to have food items the other children are eating. Her teachers will return what she does not eat so we can keep up with how much protein she is actually getting daily.



The signs that Katie might be getting sick are becoming harder to

pick up on and it is very scary to depend on someone else to know if Katie needs to go to the hospital. Katie is great and seems to really understand why she can't eat certain foods: "They will make her feel bad." She does not even cry when we have to go in for lab work. We see her specialist and nutritionist every six months (if all is well) and evaluate her diet and growth. It is group effort that we could not do without her doctors, teachers, family, friends, and other families in the same situation. We are truly blessed we have Katie to brighten every day and make us smile.

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RESEARCH NEWS

Creatine Metabolism and cbl C

Creatine and creatine phosphate are naturally occurring substances in humans that are important for energy storage and provision within body cells. A portion of the creatine needed is synthesized within the body while the remainder is taken up with food for example meat and meat products. Purified creatine supplements on the other hand are available in food health stores and many body builders and athletes take creatine supplements on a regular basis to improve muscle build-up and function respectively.

Synthesis of creatine from its precursor guanidinoacetate within the human body depends on the provision of so-called methyl groups (-CH₃ groups). These methyl groups are provided by the chemical conversion of methionine to homocysteine. In a chemical recycling process homocysteine is then converted back to methionine. This chemical process can only function if a special form of vitamin B12 (i.e. methyl-cobalamin) is present. In children with cblC, formation of methyl-cobalamin is disturbed due to an unknown defect of intracellular cobalamin (vitamin B12) metabolism resulting in significant elevations of plasma methylmalonic acid and homocysteine.

We hypothesized that creatine metabolism and in particular creatine synthesis may be altered in children with cblC. In a small project we studied 4 children and 1

adult with cblC in comparison to healthy children. In individuals with cblC we found significantly elevated plasma levels of guanidinoacetate and low to low-normal plasma levels of creatine indicating impairment of creatine synthesis.

These results may be interesting for two reasons: First, some of the neurologic symptoms in cblC may be explained by a lack of creatine and accumulation of guanidinoacetate which is known to be toxic to neurons in the brain. Second, supplementation of creatine may help to alleviate some of the symptoms of cblC and improve metabolic control. It could be speculated whether creatine supplementation may also have an additional effect on blood homocysteine levels. However at this point we have to be careful regarding the interpretation of these results until we have finalized the study and evaluated all results. The findings and their interpretation will be published in due course in a medical journal. Reprints will be made available through the author.

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RESEARCH STUDY FOR MMA, COBALAMIN C

News from the Research Front - The Rommens Laboratory of The Hospital for Sick Children in Toronto, Canada are interested in determining the cause of cobalamin C deficiency. Our approach is to study families with members with cobalamin C deficiency in order to track the location and identify the affected gene or genes within the genetic blueprint. Our long term goals are to provide for more direct diagnosis and improved options for treatments. For more information on our study, please contact Ms. Janet Atkinson at the following email address: jatkinson22@hotmail.com.

Laboratory of Johanna Rommens, PhD
Programme in Genetics & Genomic Biology
The Hospital for Sick Children, Toronto, ON CANADA
Email: johanna@genet.sickkids.on.ca
Tel: 416-813-7095

Propionic Acidemia Foundation Update

A lot has happened since we started Propionic Acidemia Foundation (PAF) in January. With your help, we have raised over \$86,000 for Dr. Miyazaki's research and we are still going strong. Some of you got a chance to meet and hear from Dr. Miyazaki about his research at the convention in Orlando. Research is quite complicated and hopefully his breakout session helped explain what they are working on and where the research is headed.

On behalf of the PAF, we would like to thank the following PA families for their donations/fundraising to UT Southwestern Medical Center: Aubrey Delima, Diane and Tom Fick, Judy and Ed Lemire, Frank Lerman and Carol Simon, Clyde and Linda Schlein, and Michelle Sciss. Every donation helps and puts us one step closer to our goal. If you are interested in fundraising ideas, please email us at PAF@pafoundation.com. Our new web-site is up and running at www.pafoundation.com and we welcome your comments and suggestions.

Fondly,

**Janice Boecker, Jill Franks, Sue Millett, Ruth Milne,
and Kathy Stagni**

Update: Stephen Monaco, Isovaleric Acidemia, Age 5 and Introducing newborn sister Caroline - Isovaleric Acidemia

It has been a year, since we introduced ourselves to the OAA and shared our story about Stephen. I thought October would be an ideal time to give an update, since we are celebrating Stephen's 5th birthday on the 26th of October. Stephen appeared to be a normal, healthy child until May 30, 2001, when he went into a metabolic crisis after a stomach bug. It was then that Stephen was diagnosed with Isovaleric Acidemia. Unfortunately, his crisis resulted in severe brain damage, which to this day, doctors cannot explain, because it is not the norm with IVA. We have spent the year acclimating ourselves to life with a handicapped child and all of his needs and coming to terms with such a tragedy in our family. We have all been on an emotional, roller coaster, facing many of the typical calendar firsts with both laughter and tears. Needless to say, the past year has been one of great changes for our family. The latest is the birth of our little girl, Caroline Elizabeth, on September 20, 2002 weighing in at 7lb 15oz. Like Stephen, she too has IVA.

Fortunately, we decided to do prenatal testing with an amnio, which gave us the diagnosis. With this knowledge, Stephen's doctors went into full force establishing a protocol of care for her to begin at birth. I was induced a week early, and Caroline was taken to the NICU upon delivery, where she immediately received an IV and her first dose of carnitine. She was then transferred to the National Children's Hospital in DC enabling the metabolic doctors to directly oversee her care. They started her on some Prophet formula within hours of arrival and later added Similac and I-Valex-1. Due to the volume, she needed an NG tube at times until she was a little more interested in eating. Being separated from her for two days was extremely difficult and heart-wrenching for me, but I knew it was in her best interest and she was in good hands. Tom traveled back and forth from one hospital to the other and home for two days, and to our surprise, Caroline was doing so well, that she was discharged after only three days in the NICU. We were so happy to bring her home and have our family all together. We take Caroline to Children's often for weight checks and labs and to assess her diet, and she continues to do very well. Caroline is now on a combination of breast milk, I-Valex, and Similac, and I've recently been given the O.K. to attempt some nursing. She also takes carnitine and glycine four times a day. Despite her disorder, Caroline is a

wonderful blessing from God and a very special addition to our family.

Stephen has come a long way since last year. He used to be extremely irritable and fussy, but is now calm and tolerant and appears much more aware of his surroundings. I can honestly say that caring for Stephen is much easier today than it was a year ago. He would constantly cough and gag on his saliva, which would cause a great deal of nausea. We would have to vent him several times a day to prevent him from vomiting. We



were usually successful, but quite often, we weren't quick enough and he vomited anyway. Of course, laundry was endless, and sleep was never sound for us, but we were really concerned about him aspirating or getting metabolically unstable. He has improved immensely in that area, making life much easier for us. Stephen continues to be fed via g-tube, but seems to be a little less orally defensive, and back in March, he began to smile and vocalize on

occasion. Who knows where those sounds might lead to in the future! He responds with smiles to some rough tickling or when I speak to him, and looks toward sounds. Stephen's strength has increased allowing him to bring his head forward or raise it when sitting. He seems to respond to intense physical stimulation and is very expressive with his face. His therapists agree with us that Stephen appears to take in more than he can put out. He is on Phenobarbital and Klonopin for seizure control, Prevacid for reflux and of course, carnitine and glycine. His recent labs were better than ever, and given his good growth and stability, he will remain on I-Valex-2, and Prophree. We will soon be discontinuing the Promod and adding Pediasure or skim milk.

We are happy to say, that Stephen has had only one hospitalization since his crisis.

He was admitted back in April with RSV. With my quick action in taking him to the ER, his EMS Outreach plan and help letter, Stephen stayed for only two days. Stephen continues to receive home PT and OT and he has had three courses of hyperbaric oxygen therapy or "HBOT." Despite its controversy, we intend on having more treatments, when time permits. For it is after each

round that we notice subtle changes in Stephen. We have also researched another form of therapy called Brain Net, based out of England. It is a patterning therapy, in which the child is assessed, and an individual program is set up for the parents to do with the child on a daily basis. We will attend the training with Stephen in February. It too is questionable, but we want to provide Stephen with every avenue possible to develop to his full potential. This will enable us to complement his traditional therapies in a more effective manner.

In our spare time, or lack there of, we have been very proactive in raising awareness of metabolic disorders and the importance of expanded newborn screening. We told our story locally for Save Babies through Screening back in May and we also attended a Senate subcommittee hearing in June headed by Senator Dodd of Connecticut. It too was on expanded newborn screening. Stephen's presence there, made a significant impact on the senator and the audience, because they were able to see first hand the cruelty of these disorders when gone undetected. A parishioner in our church is a Cox Broadcasting commentator and is working on a story about Stephen to be aired across the country, where their affiliates are located. So, stay tuned! Our goal is to bring some kind of good from this personal tragedy, so that Stephen's suffering will not be in vain. Our knowledge through Stephen's ordeal has already made a tremendous difference in Caroline's life.

As a family, we strive for a sense of normalcy knowing that "normal" has a new definition for us. Our boys, Nicholas and Alex, have weathered the changes with great strength and courage of which any parent would be proud. They have a gentle sense of love and appreciation for Stephen and are completely in awe of their little sister. They don't seem to blink at all the doctor's appointments anymore, but rather accept them as part of life. Our goal is to provide them with the same sense of love and security that they have always had and to teach them, that despite hardship, life goes on. We took our first family vacation since Stephen's crisis this summer to the beach with two other families in the neighborhood,, and we managed to have a great time. It was pure, simple fun!

We are extremely grateful to be surrounded by loving and supportive family and friends, and a wonderful team of specialists at Children's National Medical Center, caring for our children. The OAA community has undeniably been an incredible source of strength, support and knowledge. We have learned so much from everyone and are especially grateful to the IVA families who have shared their experiences with this disorder. It is their encouragement and words of wisdom that have helped me prepare for Caroline and know that a person can have a "normal" life with IVA. I was able to put aside my fears, look beyond the disorder and feel the joy of my baby's arrival.

Thank you to all, especially Rhonda, Carol and Beth!
May God bless us all!

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Proactive Parenting and Self-Management Skills
From Compliance toward Shared Management of Treatment
Cristine M. Trahms, MS, RD, FADA
University of Washington, Seattle, WA

Objectives:

1. To propose a Parenting Leadership Model
2. To define the Parenting Leadership Model as an age-appropriate intervention model for supporting and promoting self-management behaviors
3. To provide implementation guidelines for the Parenting Leadership Model.

Effective parenting strategies incorporate an understanding of the child's developmental status and progress. The process of the development of self-management skills is in a state of positive flux as parents incorporate the child's increased cognitive and physical skills into the management strategy.

Parenting Leadership Requires

- Special parenting skills related to the disorder and its management
- Parenting skills for typical challenges of growing up
- Maintaining family life
- Supporting overall health outcomes

The **Parenting Leadership Model** shows the dynamic nature of the parent-child relationship during effective treatment. Initially, the parent provides all of the necessary care to the child. As the child grows in cognitive and physical skill development, experience, and management competence, the parent transfers some of the responsibility for self-care to the child. The parent becomes the 'manager' and the child the 'provider' for these tasks that are appropriate to the child's abilities. The parent is available to support the child's 'provider' skills and stands ready to re-assume some of these tasks for a short time if it is necessary.

Parenting Leadership Model

- Indicates dynamic action of parent-child relationship for effective management
- Shows directions of shifting responsibility
- Parents guide progression skills and responsibility
- Both parents and child have a role to play

As the child becomes more confident and competent in self-management, the parent and child negotiate the next step. The parent becomes the 'supervisor' and the child becomes the 'manager' of specific tasks. The parent is, again, poised

to resume the managerial role or specific tasks for a short time, if necessary. However, the parent and child must both understand and agree that the child does not regress to a previous stage; the parent provides additional support during times of stress and the child continues to progress in self-management skills and self-management responsibility development.

Parents as CEOs of Care

- Parents provide all necessary care to child regardless of child's age
- Parents gain skills in understanding the disorder and its management
- Parents monitor the child's growth in skills and cognitive development

Parents as Managers of Care

- Child becomes 'provider' for age- and skill-appropriate activities
- Parents support the child's 'provider' skills
- Parents are ready to re-assume some tasks for a short time if needed because of illness or other life complications

Parents as Supervisors of Care

- As child becomes more confident and competent in self-management, the next step is negotiated
- Parents become 'supervisors' and child becomes 'manager' of specific tasks
- Parents are poised to resume managerial role if needed

Parents as Consultants of Care

- Parents supply information, support, decision-making guidance, and resources
- Child assumes responsibility for care as the CEO

Systems needed to support the Leadership Model of Parenting

A system for monitoring the disorder that is integral to daily life and activities

- Weekly family meeting
- Chore schedule
- Daily activity and food/medications log

A system for involving the child at skill level.

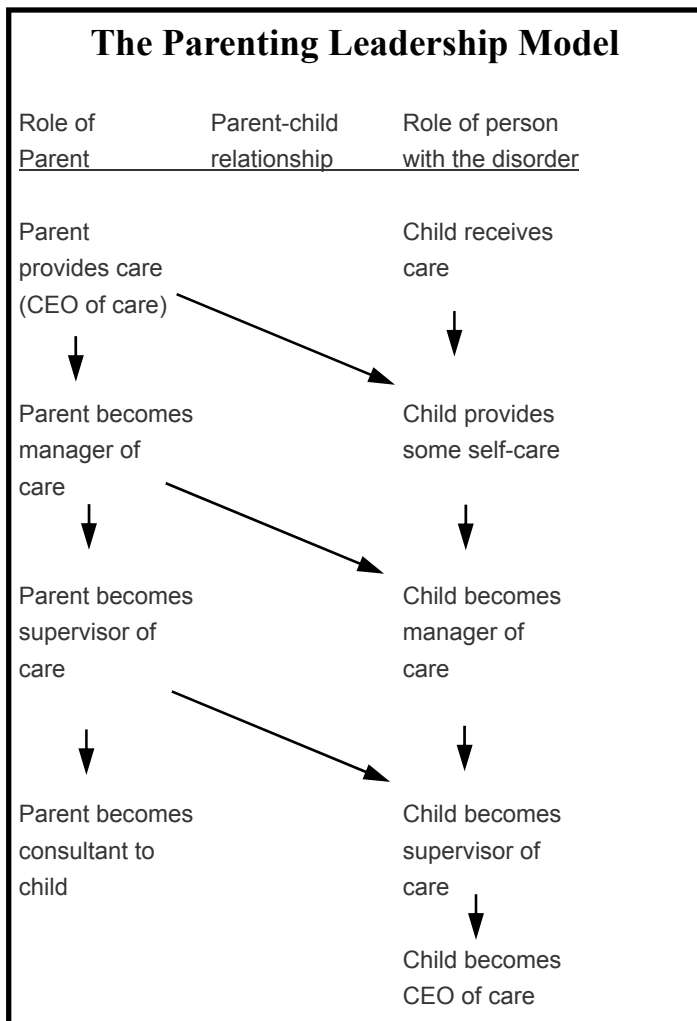
The child's tasks are based on the child's physical and cognitive abilities

- A toddler may 'count' the number of crackers
- A third grader may 'make' his formula
- A fifth grader may 'pack' his lunch

A system for evaluating the child's success/error and remediating errors

Point out evidence of successful management

- Formula is consumed without a reminder
Point out consequences of poor management as they occur
- Develop a strategy to be sure formula is consumed



Cris Trahms speaks to OA families in Orlando

Web Sites of Related Interest

- Adult Metabolic Transition Project –
University of Washington, Seattle
<http://depts.washington.edu/transmet/>
- USDA Nutrient Database for Standard Reference
http://www.nal.usda.gov/fnic/cgi-bin/nut_search.pl
- National Respite Locator
<http://www.chtop.com/Locator/index.htm>
- NORD's Medication Assistance Program
<http://www.rarediseases.org/programs/medication>
- Children's Cardiomyopathy Foundation
<http://www.childrenscardiomyopathy.org/>
- Home & Community Based Waiver Programs
<http://medicaid.aphsa.org/waivers/hcbwaiverdatabase.htm>

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