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From the Editor...

We hope that everyone is staying warm this winter ~ we came through the state’s (NC) worst ice storm in early December and now we’re all thawed out! Dan and I are from NY and IL, respectively, so we’re used to snow, but ice is another story ~ unfortunately we lost our 40-ft Bradford pear (Kristen’s ‘memorial tree’) in our front yard, but overall we came through it okay. We’ll plant a new tree in her memory this spring ~ one that doesn’t grow so fast and huge!

You’ll notice that this issue is ONLY online and that’s because of several reasons, but mostly because of funding. As with any organization, budget cuts are hitting us hard. Unless we get a windfall of donations (not tax-deductible however), all of our twice a year printed newsletters will only be accessible ONLINE from now on. If funds are available, we will try to mail out the Family/Professional Lists and a July 2003 issue, but we won’t know for sure until June. So be sure to save your past Lists and newsletters for your personal files. We will TRY and print a July issue but we’ll just have to wait and see.

Thank you once again to ALL of our Oct 2002 Metabolic Conference Speakers (Drs Roe, Korson, and Winter and Metabolic Nurse Practitioner Lynne Wolfe and Registered Dietician Cris Trahns) ~ all of their presentations from the Orlando, FL joint conference with the World Congress on Disabilities are online so be sure to check them out. You will need acrobat reader for some and Microsoft Office 2000 for the others that have powerpoint presentations. Because we have them all online there will be no summaries included in this newsletter issue.

Thank you also to Dawn Allain, CGC, and her colleagues who update us on important NBS issues/concerns in WI and congrats on your new baby! And to Lynne Wolfe, Baylor’s new Metabolic Nurse Practitioner, who explains carbohydrate metabolism and blood sugar monitoring. Soon we also hope to be posting new Nutrition and Medical articles on the website from possibly Dr Rani Singh from Emory and Dr Ibdah from Wake Forest University.

Thank you also to our Families that shared their struggles and challenges with us in this issue by way of their stories. We welcome ALL of your stories and pictures and we will try to either print them in the newsletter or place them on the Family Stories, Newborn Screening, or Love Messages page on our site. We would especially like to encourage families dealing with some of the less common FODs (i.e. HMG, SCHAD, Carnitine Acylcarnitine Translocase, TFP, CPT 1&2 etc.) to share their experiences. We’re also always looking for more lowfat recipes, poems, and pictures. Thank you to Maria Martha Fernandez (Argentina, Juan, VLCAD) for her great MCT Oil dessert recipes! They will be posted soon on the Nutrition and Recipe page on our site.

Professionals ~ PLEASE let me know if you’d like to share your knowledge and expertise. We can always use more information and research articles or ongoing FOD studies on our website as well. Additionally, THANK YOU to all the Professionals (researchers, dieticians, counselors etc.) who returned the ‘Professional Questionnaire for FOD Referral Purposes.’ If you haven’t already please complete this one-page questionnaire on our website (Online Forms) so we can update our files, even if you are already listed on the printed Professional List.

Also be sure to read about Sheri Merrill’s fundraising efforts to help our Group. If you’d like to become involved in offering Pampered Chef products, contact Sheri at Shermerrri@juno.com.

NBS Advocacy issues continue to gain GREAT exposure (via print, radio, and TV) with everyone’s continued efforts to make their states, hospitals, medical practices etc., aware of the NEED for expanding Newborn Screening in order to SAVE LIVES! Be willing to voice your opinions and take a stand ~ get out there and share your stories, no matter which FOD (or Organic Acidemia, etc) your Family deals with in order to SHOW that…

‘We Are All in This Together!’
Dear Deb: We live in a wonderful small subdivision on Strawberry Drive, with 2 other streets named Blueberry and Wildberry! Thanks to a special group at the end of our street, they held a 1st time Strawberry Jam Fest ~ it was great!

On Saturday, Sept 28th, it started at 2pm with a fire truck for the kids to climb aboard, honk the horn, and talk with the firemen. Then came horseback rides, pillow sack races, egg on a spoon, hot potato, the jumping castle, clowns, musical show for the kids, hamburgers, hotdogs, pop, cotton candy and when it got dark, minnow races, 50/50 draw and a live band! The kids and adults had a wonderful time, with that last of them going to bed around 5am.

Our granddaughter, Alyssa Jenna-Ann died suddenly July 22, 2000, when she was 8-mos-old. It was 7 months later that we learned it was MCAD and not SIDS. Jennifer, Bill and Austin were all tested and Austin, now 6, was diagnosed with MCAD as well. Jennifer, then 4 months pregnant, was worried about the new baby. When Jaiden was born, she was kept in NICU and treated as though she had MCAD until reports came back that said she was a carrier.

Last summer, my husband and I made a beautiful pond in the front yard with a Rose of Sharon bush at the top center that was given to us by friends when Alyssa died( see picture on Kids Korner page). They each have a stone with their name on it and an angel bear. People are always out walking and riding bikes and our pond has always been admired by all ~ and we always talk of Alyssa and Austin.

The proceeds from the Jam Fest were to be donated to a special cause in the neighborhood and when they heard our story, the FOD Family Support Group was instantly chosen. Little did I know that while everyone was sitting around listening to the band, that I was called up, as well as my husband and our daughter, Jennifer. They asked me to talk about MCAD ~ so with a quivering voice I spoke, and then thinking all night long, “I should have said this or that…” But I did my best. Fortunately, I had red lights in my face and couldn’t see a thing! I introduced Austin, Jaiden and Jennifer and tearfully gave a thank you.

This Group was given to us, along with Alyssa’s autopsy report. We are the 1st case in the Windsor, Ontario area. Austin sees a genetic specialist in London and has a wonderful pediatrician who has always put Austin first. At times, I pick up information from the site and pass it along to the doctor. I keep a file going for Austin and Jennifer and tearfully gave a thank you.

I find the news of your son (Deb’s son, Kevin is now almost 17, MCAD) to be an inspiration for us. It’s great to see how well he is doing. We can only pray and hope for the same for Austin.

I am proud to present this cheque to you for the Support Group in memory of Alyssa Jenna-Ann Boucher (undiagnosed MCAD) and in honor of Austin (MCAD) and Jaiden, a carrier. Unfortunately, our Canadian money is not worth much right now, but we raised $330 Canadian dollars ~ which is a little over $201 in US dollars! Again, thank you for everything!

Dorene and Ron Bellaire (Nana and Grandpa) canadanana49@aol.com
Jennifer, Bill, Austin, and Jaiden Boucher (family of Alyssa)

***Dorene and Ron, I can’t thank you enough for your donation and your neighborhood’s generosity and thoughtfulness ~ gifts like that will help us get back on track with our printed newsletters! DLG

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Letters to the Editor

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National Coalition for PKU & Allied Disorders Conference

October 3-5, 2002 Orlando, FL

A wonderful time was had by all! We started off our Orlando experience with a poolside ‘Welcome to the Conference’ get-together on Wednesday, Oct 2nd. It was great to finally meet many of you that I have spoken to over the phone and emailed for years! Hopefully next Conference we’ll have even more than the 35 who attended this year.

After the bus ride to the Orange County Convention Center Thursday morning, we not only listened to all our tremendous speakers [Dr Charles Roe, Dr Mark Korson, Lynne Wolfe (Pediatric Nurse Practitioner), Cris Trahms (Registered Dietician), and Dr Susan Winter], but we had a chance to chat with them and ask whatever questions we needed to ask. They were all very responsive and informative. You can find their presentations on our website. At the end of the day, all of the support groups attending the Metabolic Conference came together in one of the larger rooms so we could share a ribbon ceremony with ALL the Families to SHOW that ‘We Are All In This Together.’ We then saw a touching slideshow (to the Gloria Estefan music ‘I See Your Smile’) of many of our FOD children and children from the Organic Acidemia and Tyrosinemia Groups. It was a wonderful day full of great information and connecting with Families.

On Friday and Saturday, families also had the opportunity to attend several NBS seminars, as well as many of the seminars sponsored by the World Congress on Disabilities. They offered hundreds of talks on various topics, as well as exhibit booths. Many of the Families also took advantage of having Disney nearby ~ they definitely wanted to make this Conference a fun Family experience! I also had the pleasure of seeing some of our Sigma-Tau (makers of Carnitor®) friends, Ken Mehrling, Justina Lambert, and Lesli King (picture in Pharmaceutical section) ~ if not for their solid support over the years we would not have been able to provide our issues to Families and Professionals. THANK YOU again for supporting our mission!

We do not have any information as far as our next Conference, but it may be late Spring/early summer of 2004. So start saving now ~ that way you can SEE and HEAR everyone firsthand and you won’t have to wait for my report!
Joe was born on the 22nd of Jan 2000 after an uneventful pregnancy and caesarean section birth. He was a big baby, weighing 3.950kg and was perfectly healthy. We started having a few problems with reflux but were told that that happened quite often and would get better over time, as it was only occasional trouble. We didn't think any more about it. He gained weight well, always being above average on both weight and height. **We had a perfect little boy** who started standing with help, sat up etc, **but things started to go wrong when he was about 8-9 months old.**

The paediatrician became concerned that he stopped raising his arms above his head and developed a slight nystagmus. Within a month we had an appointment with a neurologist in Gran Canaria (the nearest children's hospital). He was submitted to test after test, and finally a diagnosis of Spinal Muscular Atrophy (SMA) was reached pending the DNA test. This came back negative, and we felt like the whole thing had been a waste of time, that we had taken 2 steps forward and 3 back! Meanwhile Joe had stopped sitting up unaided and became withdrawn. We were convinced it was because of all the trauma of the tests and his stay in the hospital.

One month later we went to the UK for Christmas…unfortunately 2 days after we arrived, Joe became ill with what turned out to be Bronchiolitis and had to be admitted to hospital all through Christmas and the New Year. One of the doctors there referred us to a neurologist in the Dubowitz Centre-London, after hearing the problems we were having. I'm actually from London although have lived in Spain for the last 13 years, so they said there wouldn't be a problem.

February arrived and I went to the UK with Joe for the appointment, stupidly **hoping the Professor would have a quick solution to Joe's problem.** More tests, most biochemical things came back normal, MRIs revealed little, all muscle, skin biopsies showed denervation, **but nothing concrete. Even the Prof admitted to being a little baffled!** He had an idea that it was one of two disorders and started Joe on carnitine and subsequently on riboflavin in case it turned out to be one of the two. I was convinced I'd seen improvements in Joe's sight (he now squinted if we took him into bright light), and general mood (from being grumpy and clingy, whining constantly, he became self content and happier). His movements became better after a longer period of time on the supplements although he still has hardly any trunk control and therefore can't sit unaided.

**Joe and I spent a year in the UK with my husband in Lanzarote attempting to get a diagnosis.** The probability seemed more and more remote. Finally in Jan '02 he had a g-tube fitted and another muscle and nerve biopsy done. This was when **we decided to stop putting Joe through any more tests.** If a diagnosis couldn't be obtained with all the tests that had been done, we would live without one. I couldn't justify putting our little boy through any more.

Then, **out of the blue,** in August, after chasing up the hospital for the results, **we got the diagnosis of SCAD!** I couldn't believe it ~ I burst into tears, not because it was good news but because it was news! Meanwhile Joe had been in hospital for 6 weeks firstly because of a chest infection, and subsequently to have his g-tube replaced because the first one had been fitted badly and had twisted his stomach over!

So here we are…nothing has changed with our day-to-day life since we've had the diagnosis, except **contacting other parents in this group.** **It's comforting to know that what the doctors are telling us is the same as other doctors.** A diagnosis doesn't always mean things will change, but it helps to know what you are fighting. We found out 2 months ago that I'm pregnant, and we have decided to risk it and go ahead and have the baby. At least this time **it won't take them nearly 18 months to get a diagnosis!**

Mandy Myram
Joe Cabrera-Myram (SCAD)
mandykike@hotmail.com
Canary Islands, Spain
Family Stories - *Kaitlyn’s Story, MCAD*

My name is Wendy Stiteler. I am the grandmother of Kaitlyn Wright. I wrote to you/the Group four years ago about Kaitlyn, who was diagnosed with MCAD. I have been getting the newsletters all this time and keep saying I should write back, but after I read all those letters from parents that have had children die, it saddened me.

Kaitlyn was born in Ellwood City, PA on November 9, 1997. Five days after she was born, we got a call from Dr Finegold at Children’s Hospital in Pittsburgh telling us to get her there as soon as possible. We had no idea what this was all about. They wouldn’t tell us what was wrong ~ just to bring her in.

At the hospital, we were met by the Dr and he tried to explain to us why we were there and what was wrong with Kaitlyn. We couldn’t believe what he was telling us because she looked so healthy to us. He told us that in PA they send the newborn screen card to Philadelphia and do a series of blood tests on it and then they call the hospital if they have positive results.

After he told us what to do and what to watch for, they did a test on my daughter and her boyfriend and said they were both carriers. I had never heard of this but they said some cases are linked (misdiagnosed as) to SIDS. We were so scared that for weeks we took turns staying up at night to make sure she was okay. We took her to Pittsburgh every 3 months for 2 years for a checkup.

We had a few scary times when she had a cold and was running a high fever. They gave her glucose and watched her for awhile and then we were able to take her home. We have been one of the lucky ones because of the testing they do in our state. I don’t understand why it’s not done worldwide ~ it is so important!

It has been almost 5 years since she was born and we go once a year for a checkup at Children’s. We’ve had a hard time finding a pediatrician who knew anything about MCAD or even wanted to learn about it. Fortunately, Dr Finegold found a Dr for us in a town near us that works with Children’s Hospital in Pittsburgh.

Today, Kaitlyn is a beautiful little girl and most people that see her wouldn’t know anything was medically wrong with her. I know she will have this all her life, but I know in my heart she will be just fine.

Keep up the good work you all do and God bless all the parents and grandparents who have to face this. Here is a picture of our baby girl, Kaitlyn Marie Wright.

Grandma Wendy Stiteler
Portersville, PA

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**Pampered Chef Fundraiser**

I would like to undertake a fundraiser for the FOD Support Group. I have been an Independent Pampered Chef Consultant in Vermont for one year now. Pampered Chef offers a product fundraiser that has a limited amount of products that range in price of $4.50 to $14.00. Forty percent of sales will be donated to the FOD Support Group. This will NOT be tax deductible. The FOD Support Group does NOT have tax-exempt status so you will not be able to deduct this from your taxes. Deb has provided a great support system for us and I would like to try and return the favor.

Here is how it will work. Email me directly if you are interested. If you would like to participate I will mail you the product fundraiser order form. You will then need to collect a minimum of five orders or $100.00 in sales. Mail the order form back to me with payment in FULL (if people write checks have them make them out to Sheri Merrill). I will then send in the order to Pampered Chef and it will be mailed to you directly and you will separate the orders and deliver them. I will mail you the receipts to be handed out with the customers’ orders. Once I send in the order I will send a check to the FOD Support Group for the funds raised. I will also send a letter stating who raised the funds for the Group. I think this is a great opportunity to give back to the FOD Support Group. If anyone is interested please e-mail me at Shermerril@juno.com. If you would like to see the Pampered Chef products you can visit their web site at www.Pamperedchef.com. Thank you and I hope to here from you soon.

P.S. Pampered Chef products make great gifts too!

Sheri Merrill
Kristen 5, MCAD and Jamie 3, Carrier
My name is Misty Smale and I am 26-years-old. From what I was told when I was 13, my story is unique, in that I was an older child when my disorder was diagnosed. At the age of 13, I got sick. Not just the flu or a stomachache...I pretty much died. Let me take you back to what I can remember...I remember feeling really bad, vomiting, weak, and very tired. The last thing I remember was laying on the couch in my Santee, CA apartment where I lived with my younger sister and mother. I was ill and couldn't hold anything in my stomach. I remember vomiting on the floor, then turning over and going to sleep.

Next thing I know, people are saying my name, but I can't open my eyes or tell them I hear them. I was cold and couldn't move. At this time I had no idea I had been asleep for 4 days. I had no idea how much time had passed or what had happened to me. I could hear my father, who lived in Ohio, my best friend from California, my mother, aunts and uncles. I was too tired to think about what had happened. But I did know I didn't feel bad anymore. I just wished I could move. I heard people saying my name again telling me I needed to sit up, but I couldn't, and I felt them pull me up and lay me down on something that felt like a block of ice. For the first time I looked around...doctors? Why was I seeing doctors, where was I? They asked me if I could sit up again and I shook my head no. The ice was gone...I guess I passed out. I don't know. But then when I woke up no one was there. I raised my arms to see tubes coming out of my hands in just about every direction...a black box on my finger, tape on my nose, and my head was throbbing something terrible.

My mom came in with my father and they told me how scared they were. My mother told me that I got sick and started shouting at her and the paramedics and fire department came to take me to the hospital. She said I had given one of them a black eye fighting them off. She thought I had taken some drugs or something. From what she said it sounded like they didn't know what happened to me yet. I had never taken any drugs. Heck, I didn't even know what they were. My father had flown to California because I had gone into a coma. He brought me the blanket my mother had made for my older sister who lived with him. That was her gift because she couldn't come. That meant the world to me.

I guess I was in some kind of shock not knowing what had happened to me. The next thing I remembered was being on my way to my own room in the Children's Hospital. When we got there, the nurses had to lift me because I had no strength to move myself. I was so embarrassed. I still had an IV in one hand and one in my chest. I had to learn to walk and use the bathroom all over again. When I felt my head, there was something hard there. My mom told me that there was a tube going into my head. She said I had 'waste' on my brain and that's how they drained it off. I had to keep it clean.

I'm not sure how long I was in the hospital...a few weeks I guess. I know I went home a week before my 14th birthday. I tried to go to school but after a few hours I got dizzy and had to go home. I had so many doctors' appointments.

All this happened because I had a disorder known as medium chain acyl-coA Dehydrogenase deficiency (MCAD). Unlike most cases when younger children are diagnosed, my system waited until I put myself on a starvation diet. I wanted to be thin like everyone else in southern California. That's what happened to me 13 years ago.

Today I wish I could say I'm healthy, but the truth is I have no idea. I haven't seen a doctor in years for various reasons. When I was pregnant with my first child in 1995 (a boy, Taylor), I had the chance to take care of myself. Then two years later in July 1997, I had my little girl, Jessica...4 months later she died. I asked the coroner if she had what I had. They said no. But I'll always wonder. When she died they labeled it SIDS. I'll never know.

So that's my story. I've tried to get healthcare for myself but the state of Ohio told me medicaid will not cover carnitine because you can buy it over-the-counter. So I'm stuck I guess and asking anyone for any information on what I can do. I have a 7-year-old son, Taylor, who seems unaffected, but I still have him checked. I don't care what their tests say ~ if it didn't happen to me until I was 13, I want to make sure he will always be okay.

Misty Smale
moonriser25@hotmail.com

[Please note that information was given to Misty on resources for getting services and for possibly getting a post-mortem diagnosis for her daughter, as well as the articles on the difference between the FDA-approved drug Carnitor® and the health food store brand of carnitine. I'm sure she would appreciate any further suggestions and support so please email her directly. DLG]
Medical Update

Carbohydrate Metabolism and Blood Sugar Monitoring

Lynne A. Wolfe, MS, PNP, BC
LAWPNP@aol.com

Blood Sugar Regulation

Glucose is the major carbohydrate used as fuel in our body to supply energy. It can easily be measured because some circulates in our blood stream, and can be easily checked with finger sticks. Average blood sugar levels are 100 mg/dl (70-120 mg/dl) or 5 mmol/L. The risk of developing Diabetes is increased when FASTING blood sugars stay consistently > 125mg/dl or 7 mmol/L. The risk of developing a Hypoglycemic Coma occurs when blood sugars are consistently < 45 mg/dl or 2.5 mmol/L. Under normal circumstances glucose is the preferred fuel of brain cells, and also muscle cells in early exercise.

Blood glucose levels are regulated by several hormones – Insulin, Glucagon, Epinephrine, Cortisol, and Growth hormone. Insulin promotes Glycogen synthesis, fat storage in the form of Triglycerides, and cellular uptake of blood glucose. Too much Insulin can lead to hypoglycemia (low blood glucose). Insulin acts in two phases. The first phase is secretion within 10 minutes of eating. The second phase is secretion about 2 hours after eating. Glucagon, Epinephrine, Cortisol, and Growth hormone all cause Glycogen breakdown and stimulate conversion of Amino acids to glucose. Persistent elevations of these hormones can lead to hyperglycemia (high blood sugar.) Glucagon breaks down Liver Glycogen stores to release glucose into the blood stream and it prevents the normal storage of extra glucose into Glycogen and Triglycerides. Glucagon has no effect on Muscle Glycogen. Epinephrine is very important during times of stress, including acute illnesses/infections, trauma etc. It causes increased glucose levels in the blood stream to ensure adequate glucose reaches brain cells. It stimulates the breakdown of muscle glycogen to raise blood glucose.

The FED State

When we are healthy and eating regular meals our body uses what it needs for energy immediately, then stores energy for later use. Stored energy comes from conversion of glucose into Glycogen and Triglycerides. Glycogen stores are in the Liver and Muscle. Glycogen can supply up to 1900 kcal. That will only last about 16 hours in an adult. Fats are stored in Adipose tissue. Depending on how much Adipose tissue we have, it can supply up 130,000 kcal. Glycogen stores and Fat stores increase with age. Proteins are also stored to be later broken down into their Amino acids, which can be converted into glucose if needed.

The FASTED State

Defined as no food intake for 6-12 hours, depending on your age. After 12 hours of no food intake, it is called a Prolonged Fast or Starvation. At the end of 6-12 hours 80% of glucose from food, will have been absorbed by tissues. The brain uses 50% of that glucose. After 12 hours, the body will get up to 75% of its energy from the breakdown of Glycogen stores. More glucose gets released from fat and muscle breakdown. Early in Fasting periods, free fatty acids and ketones begin to circulate in the blood. These can be used for energy by many tissues, including brain cells.

Hypoglycemia

Blood sugars consistently < 45 mg/dl or 2.5 mmol/L defines hypoglycemia. Symptoms include: feeling hungry, sweating, trembling, and fast heart rate. These symptoms reflect the action of Epinephrine, as it tries to ensure that brain cells get adequate blood glucose. Remember, that under normal circumstances glucose is the preferred fuel of brain cells. If the action of Epinephrine and Glucagon cannot maintain a normal glucose supply to the brain cells we see confusion, loss of consciousness, and coma. Most Emergency Protocols, therefore require IV glucose be given if blood sugars are < 60 mg/dl to avoid the risk of severe hypoglycemia that can lead to coma or death.

Hyperglycemia

Hyperglycemia defined as blood sugars consistently > 125mg/dl or 7 mmol/L. It is only valid after a 6-12 hour fast, of a healthy child. Because of the normal stimulation of both Glucagon and Epinephrine, during periods of stress (which include fever, acute illnesses like a GI infection or cold, trauma), a slightly higher than normal blood glucose is considered normal and protective to the brain and other tissues.

Prevention/Treatment of Hypoglycemia in Fatty Acid Oxidation Disorders

The normal body response to prevent severe hypoglycemia, is the release of fats that are broken down into ketones. In Fatty Acid Oxidation disorders the ability of the body to make ketones is limited NOT eliminated. The risk of developing severe hypoglycemia, and not having enough Glycogen stores is increased in infants and young children, in periods of Fasting longer than 6 hours, during acute illnesses especially those with fever, and only in certain Fatty Acid Oxidation disorders. MCAD and hypoglycemic VLCAD are the two Fatty Acid Oxidation disorders really at risk for severe hypoglycemia. Most children with SCAD will not experience severe hypoglycemia and the Carnitine Uptake disorders are also not usually associated with hypoglycemia. Also, once a child has been diagnosed and is under treatment for their FOD, they are less likely to develop severe hypoglycemia ~ especially if they are drinking Cornstarch at bedtime.

Continued on Page 7 | Page 6
Nonetheless, since severe hypoglycemia can be life threatening, most Metabolic Specialists do set up Emergency Protocols for the recognition and prevention of a severe hypoglycemia. The precautions usually include: 1) preventing periods of fasting > 6 hours (infants usually 4 hours), 2) adjusting the Carbohydrate Sources in the Diet during periods of increased stress or illness, and, 3) use of Raw Cornstarch shakes.

During periods of “Low” stress, Carbohydrates in the diet should include complex carbohydrates with fiber, such as High fiber cereals, Whole grain breads, Brown rice, Bulgar wheat, Vegetables, Legumes, Apples, Oranges, Apricots, and low fat Dairy products. During periods of “high” stress, Carbohydrates in the diet should include more simple sugars and foods that breakdown easily into glucose, such as Sports drinks, Soft drinks, White rice, low fiber breads and cereals, Crackers, cooked potatoes, Fruit juices, Fruit Roll-ups, Jello, Jams, Jelly, and Bananas.

The use of Raw Cornstarch was first introduced in the 1980s as a therapy for Glycogen Storage diseases. It was given because it is a complex carbohydrate, high in fiber that takes 6-8 hours to fully breakdown. It therefore, could be given at bedtime, to prevent drops in blood sugar during the overnight fast. It could also be given 4 times a day during periods of illness to prevent severe hypoglycemia. Because of that Research we know several important things. First, Argo brand cornstarch appears to have the highest amount of Amylose, gets metabolized the slowest, and therefore has the longest action. We also know that Cornstarch shakes must be mixed in cool or room temperature fluids – cooking breaks the starch down and therefore stops the benefit of giving it. We know that compared to other starches, such as, Potato, Rice, Arrowroot, and Tapioca – Cornstarch has no flavor, although it does change the consistency of fluids which can be an issue for some children. Cornstarch has the best absorption of all the other starches as well. Additionally, Cornstarch has altered absorption when mixed in high sugar drinks, especially those high in Vitamin C, such as Orange juice or Lemonade. So it is recommended that Cornstarch be mixed in Sugar-free liquids. The one limitation to the use of Cornstarch, is that the enzyme, Amylase, is required to break it down. Normally Amylase function does not begin until after 8 months of age, sometimes as late as 2 years of age. That is one reason we usually recommend Infants get fed every 4 hours around the clock – we can’t use Cornstarch to prevent hypoglycemia during the overnight fast in them.

Glucagon should not be used to treat hypoglycemia in children with FODs, since their Glycogen stores are usually significantly depleted in the face of limited ketones as a secondary source of energy.

**Question & Answer**

**Question:** Do you have information about the skin biopsy done for FOD diagnosis? How large is the area of biopsy, any sutures/steri strips? How long does it hurt afterwards? What is the average waiting time for results?

**Answer:** Skin biopsies taken for enzyme analysis require an amazingly small piece of tissue, 2-3mm. This can be accomplished with a Punch biopsy tool or scalpel. Usually the skin is numbed. Some Providers use some EMLA cream topically first. It should optimally be in place 30-60 minutes. (I personally write prescriptions for families and have the patch put on prior to arrival in Clinic. Then the child isn't hanging around getting more nervous.) Some providers use a very small needle to put in some numbing medicine, like Lidocaine, right before the procedure. For enzyme analysis, it doesn't matter where the tissue comes from so long as it is cleaned well, and not a pressure point that won't heal well and may hurt more. On infants and small children, I like the upper, outside of the buttocks. It's easy to hold them to get at this spot. They can't see it or pick at it after it is done. Older kids will hold still, even if they aren't happy. Under the arm is commonly used because even though the scar is very small, it will be completely hidden. Under the arm is also very important, if the tissue is to be looked at under the microscope for any reason. The wound is very small and doesn't usually require stitches ~ sometimes steri-strips are used. Some type of dressing will be on top, a bandaid, gauze or Tegaderm - it doesn't really matter. It heals fast. It doesn't hurt very long either. I think most kids just hate being held still, and are most upset by that, rather than the procedure itself which is usually very quick.

Results can take a while, several months sometimes. Bottom line is that the small piece of skin cells needs to grow large enough to get enough enzymes to test, that takes time, before any tests can even get done. Sometimes, skin cells grow slowly, and there is no way to speed that up. Patience is the word of the day. Waiting for results and answers will be hard.

**Answered by:** Lynne A. Wolfe, MS, PNP, BC
NBS Update

Issues Raised by Newborn Screening for Fatty Acid Oxidation Disorders
Through the Eyes of Genetic Counselors

Dawn Allain, MS and Amy White, MS - Children’s Hospital of Wisconsin, Milwaukee, WI
Kristine Hanson, MS and Erin Vanden Heuvel, MS – University of Wisconsin, Madison, WI

The State of Wisconsin formally began using tandem mass spectrometry to screen for fatty acid oxidation disorders (and organic acid diseases) in April 2000. To give you a glimpse of the impact in the state of Wisconsin, 67,475 babies were screened in 2001. Of these babies screened there were 64 with an abnormal result for the fatty acid oxidation disorders. Of these 64 cases, 8 babies were confirmed to have short chain acyl-coA dehydrogenase (SCAD) deficiency and 1 baby was found to have medium chain acyl-CoA dehydrogenase (MCAD) deficiency.

As genetic counselors involved in the implementation of tandem mass spectrometry for newborn screening, we are learning that along with the benefit of detecting treatable and potentially life threatening diseases, the screening has raised a number of issues and questions for ourselves and for the families of these children.

As with all screening tests, the children must undergo additional laboratory testing to determine if an abnormal result is a true positive. In most cases the additional testing involves the collection of a repeat newborn screening specimen. However, 10 babies in 2001 had to have more extensive laboratory testing that requires waiting up to several weeks for test results that confirm a diagnosis. This is very frustrating and anxiety provoking for families.

The newborn screening program has also alerted us to the fact that there are varying degrees of severity for some of these disorders. According to a presentation by Rhead et al (2001) at the European Meeting of The Society for the Study of Inborn Errors of Metabolism (SSIEM) two states involved in newborn screening with tandem mass spectrometry have identified a total of 17 infants with varying degrees of biochemical SCAD deficiency. Yet, all of these individuals have normal development and no medical complications at two years from the time of diagnosis. In Wisconsin, a number of healthy older siblings of children whom we picked up through the newborn screening program have also subsequently been diagnosed. The fact that all of the infants to date have been clinically normal, despite biochemical variability, has led parents and health care providers to question why we have raised their anxiety over screening for a disorder that appears to have no effect on their child.

In addition to the variability seen within the disease types, there is also variation in the management of these children. For instance here in Wisconsin, we have some children who are treated with dietary restriction and carnitine supplementation, some only with carnitine and others who have no dietary treatment or carnitine supplementation. This leads to the question of what is the appropriate treatment for children who test positive for fatty acid oxidation disorders.

Our recent experience has shown us that newborn screening for FAOD can also detect conditions which were not intended to be included in the screen, and for which very scarce information is available regarding the effects or treatment of the "disorder." This causes confusion for families and creates additional management challenges for clinical staff.

Unfortunately, many of the issues and questions raised by the use of tandem mass spectrometry in newborn screening currently have unresolved answers. This leaves genetic counselors involved in newborn screening programs to balance the variations in medical care with the needs of parents coping with their anxiety raised by these results.

Thank you Dawn and all for sharing the concerns and issues that WI is experiencing (as well as several states). They are very relevant and important concerns and will need to be further explored and hopefully resolved. However, I would like to raise my voice to our Group’s overall concerns and why EVERY STATE should expand testing despite some of the concerns raised in WI and in other states that are already testing. There will continue to be heightened anxiety and confusion for families AND professionals until we are ALL on the same page. Yes, there may be differences in treatment protocol (for various reasons – EACH child/adult’s treatment depends on a multitude of factors and it’s a not a ‘one treatment fits all’ type of disorders) and yes, there may be differing presentations of a disorder (even within the SAME family), but that doesn’t mean these disorders shouldn’t be detected at birth. Who knows when that asymptomatic child with a so-called ‘mild’ form of an FOD will experience an episode that could change his/her life forever? Sometimes when families are told that it MAY be a ‘mild’ form they get too complacent and think that they don’t have to do ANY kind of treatment…BIG mistake! My comments below do not dismiss what Dawn and her colleagues have discovered in WI since instituting expanded screening, but they are from a bereaved parent’s perspective ~ and you can bet I would have MUCH rather dealt with a little anxiety over a false positive screen than deal with what we’ve had to cope with for over 17 years! Our Group’s stand offers some other things to think about ~ and ALL for the sake of our present and future children!
FOD Stand on Expanded NBS

Along with my statement on our site’s NBS page, I wanted to expand on WHY I have taken this stand. And YES, I am far from 'politically correct' when it comes to saving babies ~ so I’ll warn you that some may be offended or put off by my comments and opinions. But I can live with that ~ I don't have time to worry about others not liking my point of view ~ saving lives is a higher priority for me.

I've quietly advocated (mostly in print) utilizing a Regional Testing Lab format for many years, since the early 90s. However, over this last year, and especially over the last several weeks, I have become more VOCAL about my feelings on getting expanded NBS MOVING and out of the let's talk, let's wait and see, let's not screen until this or that, let's not screen for disorders that may not have a so-called 'effective treatment’ (of course you can’t DEVELOP EFFECTIVE TREATMENTS until the babies are IDENTIFIED ~ and you DO that through SCREENING!) or let's not screen for disorders that are CURRENTLY considered fatal because having to tell the parents would be difficult!

Well, you know what's even MORE DIFFICULT folks? Having to bury your own child and NOT KNOWING that he/she had a specific disorder (I did that over 17 years ago with my own daughter!) or having to live with the major residual medical complications of NO or LATE DIAGNOSIS ~ and then for some moms, having to live with being SHAMEFULLY and WRONGFULLY LABELED as having Munchausen by Proxy (some accused by professionals/Drs that haven’t even SEEN their children!) all because they have been trying desperately to find a diagnosis (which is already FAR TOO LATE!) for their constantly sick child that has LOTS of Drs visits and hospitalizations ~ THAT is BEYOND DIFFICULT!

It really galls me that many are battling (in state committees, legislatures etc) over which disorders SHOULD or should NOT be tested for (even though they CAN be screened for), and making decisions NOT to include certain disorders because THEY THINK parents wouldn't want to know if it was a disorder that hasn't YET been treated effectively. Again, folks, HOW DARE ANYONE MAKE THAT DECISION FOR ME OR ANY OTHER PARENT! It's somewhat analogous to some HMOs that have LAY people making TREATMENT decisions for the person and telling them that they CAN'T have some MEDICAL procedure!

Even if there wasn't a positive prognosis for a particular disorder you better believe I (and many other families I’ve spoken with) would WANT TO KNOW ANYWAY so I/they could spend what little time there may be with that infant, as well as to be able to grieve WITHOUT having the complicating factors of an UNKNOWN cause (unknown ONLY because someone made that decision FOR us not to screen for that screenable disorder ~ yet I/we would find out on autopsy!).

Let me tell you WHY I advocate a regional system:

I am DISGUSTED at having to respond to MANY calls from grieving and angry families that have just experienced the NEEDLESS death of their young child (especially when they find out these are disorders that CAN be screened for ~ even if their state DOESN'T test for them yet ~ and that most DO have effective treatments) or from ones that are dealing with LONGTERM medical problems of 1, 2 and for some, 3 children, ALL because their child was not tested/diagnosed/treated at birth!

I am DISGUSTED and FRUSTRATED at WAITING for EACH STATE to debate whether to make the decision to screen, then debate over money and which disorders to screen, then buy their own instrumentation, then train personnel to EFFECTIVELY INTERPRET these tests, ...and the List goes on ~ in the meantime I keep getting the above CALLS!

If a Regional format was used, QUALITY CONTROL over say for instance 5-7 Labs would be alot easier than keeping an eye on 50 or 51 DIFFERENT LABS ~ and ALL doing their own thing as far as deciding which disorders to screen for. I advocate that Regional Labs do UNIFORM and UNIVERSAL SCREENING so that EVERY STATE is on the SAME PAGE!

But here's where the problem lies with this issue as well as with MANY human issues ~ money, politics and turf all get in the way of JUST DOING WHAT NEEDS TO BE DONE ~ SAVING LIVES! Right now, we are in a state of INEQUALITY depending on which state you happen to live in ~ and the BABIES and FAMILIES PAY THE PRICE ~ that is NOT right!

Continued on Page 10
FOD Stand on NBS …cont’d

I don't have all the answers (what parent does?!) and I certainly don't have a foolproof plan to set up these Regional Centers [although, in my opinion, there are already 3 major NBS Labs EFFECTIVELY FUNCTIONING like Regional Centers doing supplemental and/or comprehensive screening, as well as Diagnostic Testing when necessary AND researching new developments in screening techniques etc, AND two of the three Labs also have the capability to offer families either new treatment research studies/follow-up or long-term clinical care follow-up/consultation for several of the disorders] ~ but one thing I DO know is that we have to THINK MORE OF THE CHILDREN instead of placating egos and being politically correct and bickering over what I see as ridiculous turf issues WHILE BABIES DIE! And don't tell me there's a 'PROCESS that NEEDS to be followed' ~ THESE BABIES DON'T HAVE TIME FOR PROCESS!

WAIT for EACH state's PROCESS? With ALL the above issues we MAY end up UNFORTUNATELY having to do that, but you better believe I won't stop giving a VOICE TO THE CHILDREN ~ THEY CAN'T AFFORD TO WAIT for EACH state to do their own cost benefit analysis etc just to prove the expanded testing would be worth it! EVERY newborn's life is worth it!

Those of you that have already had a child die or one/several medically impacted because of NO screening or not KNOWING that there IS testing available, I believe you KNOW where I'm coming from. But for others that may think my comments are from being some 'over emotional' mom ~ go ahead and think that ~ damn right I'm emotional and I'll KEEP being emotional until EVERY NEWBORN IN THIS COUNTRY IS SCREENED UNIFORML Y, UNIVERSALLY, and with FAST TURNAROUND IN SENDING SPECIMENS and GETTING RESULTS so EARLY TREATMENT CAN BEGIN and I believe that would MOST EFFECTIVELY be done THROUGH A REGIONAL LAB FORMAT!

I welcome any and all comments.

Take care...
Deb Lee Gould, MEd, Director
FOD Family Support Group

Pharmaceutical Update

Lesli King

Sigma-Tau Pharmaceuticals, Inc. (makers of Carnitor® ~ www.sigmatau.com)
New Fax: 301-948-2049

Suggested directions for a pharmacist to make riboflavin (B2) into an elixir: Vitamin Elixir

Your pharmacist may be willing to make flavored syrup that can be given to your child. One pharmacist uses the following recipe:

• Crush a 20-day supply of the prescribed vitamins
• Mix crushed vitamins with 100cc 1% methyl cellulose solution
• Add flavored syrup to total volume of 200cc
• A tart flavor (such as Pina Colada) is recommended
• Patient takes one (1) teaspoon (5cc) two times per day to obtain total vitamin dose (discuss dosage with your/your child’s Dr)

Crushing the Vitamins

If your pharmacist is unable to make an elixir for you, than you can crush a day’s supply of the pills by one of the following methods:

1. Mortar and pestle or
2. Blender

Place the pills in the blender with ½ cup water. Blend well. Scrape the sides and the bottom of the blender to prevent the pills from sticking to the blade and sides.

As you know, most children don't take medicine very well. The crushed vitamins often have to be put in something to hide the flavor. Some suggestions follow:

Mix in orange juice, Mix in a carbonated beverage, Mix in a shake (try chocolate Quik, crushed ice, and skim milk), Instant breakfast and skim milk, Mix in applesauce. You may also want to experiment on your own to find something that works for your child. Make sure you check with your doctor or pharmacist.

Sheryl Gerstl
sherylgerstl@yahoo.com
Love Messages

Please remember these families in your thoughts and prayers throughout the year

Joan and Tim Aalberts

Sandy and Howie Aitken

Jeanne and Mark Barilla

Jodi and Wayne Barnes
Amy - Birth Feb 20, 1995 Death Sept 27, 1995
Baby Barnes - Death in-utero Oct 7, 1999

Delane and Althea Becker

Sue and Jim Berneski

Jacque and Mike Bradford

Joseph and Barbara Brown
Amber - Birth June 18, 1989 Death May 17, 1990

Barry and Julie Bryson

Carolien Grootaert - Callens

Tom and Lynn Camino
Stephanie - Birth June 28, 1995 Death Feb 6, 1996

Mark and Karen Carpenter
James - Birth May 7, 1985 Death Dec 6, 1986

Jenny and John Carroll
Sarah - Birth March 4, 1992 Death Sept 1, 1992

Mark and Diane Casey
Matthew - Birth Apr 15, 1974 Death Jan 13, 1975
Lori - Birth Aug 31, 1980 Death July 1, 1984

Valerie & Chris Ciachette
Benjamin - Birth Jan 12, 1987 Death April 18, 1987

Toni and Mark Cline
Kasie - Birth June 6, 1990 Death March 10, 1991

Sandy and Jon Cooper

Martin and Kathy Davis
Mary Katherine - Birth June 27, 1996 Death Nov 7, 1996

David and Amy Deshais

Doug and June Evenhouse
Marie - Birth Dec 15, 1985 Death Nov 19, 1986

Andrea and Phillip Franklin
Brandi - Birth Dec 2, 1986 Death Jan 1988

Lance and Dawn Goldsmith

Deb and Don Gould
Kristen - Birth Oct 6, 1983 Death July 21, 1985

Shelly and William Grabow

Brandis Greichunos
Madison Burchette - Birth March 8, 2001 Death March 24, 2002

Jeanettte and Keith Guillory
Dominique - Birth Jan 21, 1997 Death Jan 23, 1997

Nicoile and Chris Gulinello
Alec - Birth Feb 21, 2001 Death Aug 24, 2001

Michael and Nicole Gumiela
Michael - Born March 28, 1998 Death April 4, 1999

Carol and John Hall
Sarah - Birth June 8, 1998 Death July 30, 2000

Robin and Vince Haygood
Ben - Birth Feb 19, 1998 Death Aug 8, 2000

Ralph and Angie Hedrick
Chelsea - Birth Jan 11, 1995 Death Apr 3, 1996

Nikki and Toby Hiatt
Reece - Birth Aug 1998 Death April 18, 1999

Pauline and Bill Hill
Rosemarie Rees - Birth April 15, 1976 Death Dec 23, 1999
Welcome to new babies!
• Starr was born to Misty and Randy McDonald on January 8, 2002. She is sister to Jeremiah (undiagnosed MCAD) and Tyler. 
• Lisa and Tracy Kretzman welcomed Isabelle (MCAD) into the world on February 8, 2002.
• Rion Tyler (VLCAD) was born to Jessica and Shane Lesnow on August 5, 2002. He weighed in at 6 lbs 7oz and 18½” long. He is the brother of Owen (undiagnosed VLCAD).
• Claudia and Rick Evans, along with Nicholas (unclassified) and Aaron welcomed baby Matthew (unclassified) into the world on July 18, 2002.
• Robin and Vince Haygood and daughters, Leslie and Lori, are happy to announce the arrival of Bo Vincent (brother to Ben, Undiagnosed MCAD) on June 18, 2002. Bo weighed in at 9lbs 14 oz and was 20½” long.
• Brayden Aitken, brother to Kristopher (undiagnosed unclassified) and Tiegan, entered the world on October 10, 2002 at 6 lbs 10oz and 18” long. Parents Sandy and Gary are glad he’s here!
• Doug and Lisa Tennyson (Sammy, undiagnosed CACT) welcomed newly adopted baby, Lucas, into their lives when they brought him home from Guatemala. He was born Oct 2, 2002 ~ 7lbs 4oz and 19” long. Big brother Brad wants to call him Luke!
• As of December 10, 2002, Zachary Wilt (MCAD) has a new baby brother, Aaron (MCAD). Proud parents, Cindy and Kevin Wilt announced that he weighed in at 8lbs 13.1oz and was 22” long!

Condolences
Our entire FOD Family Network offers our sincerest condolences to Karen and Steve Imhoff on the death of their 10-year-old son, Michael (TFP), on July 8, 2002 from an unknown virus. We are also saddened to hear of 3 year old Emily Sleezer’s (undiagnosed) death on June 18, 2001. She is the daughter of Lisa and Scott Sleezer. Our thoughts and prayers will always be with you, Karen, Steve, and older sister Sarah Imhoff and Lisa and Scott Sleezer.

Love is something eternal,
the aspect may change,
but not the essence.

~ Vincent van Gogh
Notes

**NBS and Formula Legislation Email Lists** ~ see the National Coalition for PKU & Allied Disorders at www.pku-allieddisorders.org ~ they provide Email Lists that raise awareness for the need to EXPAND Newborn Screening in this country and discuss ways to promote that objective, as well a List to advocate changes in Legislation for coverage of formulae.

?? Genetic Alliance Update ~ as of Jan 1, 2003 the GA has opened up its membership to EVERYONE FREE (families, health professionals, researchers and policymakers) so be sure and check out their website at www.geneticalliance.org or call 800-336-GENE for more information.


**Special Needs Advocate for Parents (SNAP)** ~ problem solve insurance problems 1-888-310-9889, www.snapinfo.org

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**Extra Conference Notebooks**
We still have @ 40 - 9x12 vinyl notebooks that we purchased for the October Metabolic Conference. Each notebook is royal blue with our logo imprinted in gold on the cover, and it also contains a tablet of lined paper and a nice pocket for loose-leaf papers. If you would like one, please write a check made out to the FOD Family Support Group (not tax deductible since we aren’t an official non-profit) for $10.00 in the United States, $15 US for Canada and $20 US for overseas. The price covers the cost of the notebook plus postage, as well as a small ‘donation’ to go toward our printed newsletter costs.

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**FOD Family Questionnaire**
If you do NOT see your name on the Family List, it is because I (Deb) never received the FOD Family Questionnaire that I sent you in the Family Packet when you first registered with us. **If you would like to be listed for networking purposes**, please go to *Online Forms* on our website (www.fodsupport.org) and **print out the Questionnaire**. Then **SIGN it and DATE it** so I have your permission to list you. **Please mail it to me via the regular mail** (see page 1 of this issue for address) so we can list you in the next List Update.
Kids Korner

Dakoda Eades
(unclassified FOD)

Leslie, Lori, & Bo Haygood
(brother Ben, undiagnosed MCAD)

Adam Cornette
(LCHAD)

Lauren Wagoner
(undiagnosed MCAD)
& Mom, Jenni

Austin Boucher (MCAD) &
Alyssa’s (undiagnosed MCAD) pond
Family & Professional Donations

**Family Donations:** St. John’s Episcopal Church, in honor of Rachel Gibson, VLCAD, daughter of Lisa & Bill (grandparents Dixie & George Cernovich are church members), Cindy & Kevin Wilt in honor of Zachary (MCAD), Sheri & Walt Leising in honor of Bryce (undiagnosed metabolic disorder), and Dorene & Ron Billaire and Neighbors in memory of granddaughter, Alyssa (undiagnosed MCAD) and in honor of Austin Boucher (MCAD), ‘Notebook Donations’ ~ Gwen Abele, Wrenn Dees, Maria Tuttle, Pam Sweeney, Kathy Miller, and Sharon Fisher. We also wish to thank the many family members and friends of Karen and Steve Imhoff that contributed to a Memorial Fund in Michael’s (TFP) memory and given as a donation to our Group.

**Professional Donations:** Sigma-Tau Pharmaceuticals, Inc., makers of Carnitor®

We greatly appreciate donations to help with postage and copying fees.

**Checks can be made payable to FOD FAMILY SUPPORT GROUP.**

Because we are not officially a non-profit organization, donations are not tax deductible at this time.

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Reminders

**Families** - Please send **TYPED** stories by **May 1, 2003.** To be listed on the FAMILY LIST, please return the SIGNED Family Questionnaire or hand-write your information as seen on the current Family List and sign and date it. Continue to spread the word about FODs and the need for screening -- it will SAVE LIVES!

**Professionals** - Please let us know about your research and/or clinical work with FOD Families. Send articles by **May 1, 2003.** Also, please return to Deb the Professional Questionnaire even if you are already listed on the printed Professional List.

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Communicate With Us

Please **ADD** me to your mailing list
Family □ Professional □ (please circle one)
Name/Address or Address Correction (circle one)

Please **REMOVE** me from your mailing list:
Name/Address:

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Thank you to Erika Wallace - erikawallacepa@yahoo.com (Mailing Lists), Mary Lingle - Mcartwrite@aol.com (Web Site) and Brian Gould - BulaBri2000@hotmail.com (newsletter) for all your hard work.

Special thanks to Sigma-Tau Pharmaceuticals, Inc. for their continued financial support.

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The views expressed in the FOD Communication Network Newsletter do not necessarily represent the views of our Advisors or all of our members. Before trying anything new with your child or yourself in regard to treatment, please discuss matters with your doctor or specialist.

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‘One can never consent to creep when one feels an impulse to soar.’

~ Helen Keller ~