



*Save Babies Through Screening's*

# Newborn Screening NEWS

Raising the Awareness of Newborn Screening and Related Disorders

www.savebabies.org

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## SBTS Presidency Changes Hands

After 4 years of devotion to newborn screening through Tyler for Life Foundation, now Save Babies Through Screening, President Tera Mize decided to step back from the foundation she and husband Dallas founded and to become re-acquainted with her personal life. Always the NBS advocate, Tera has not left the mission, just the administrative responsibilities of the organization. She has been a persistent,



**Tera Mize & Robin Haygood  
The Founder & The Future**

dedicated “newborn screamer” and will continue as such, contributing her knowledge and passion to the cause.

Having brought the foundation to a new phase of growth, Tera sees this as the right time for another to assume the presidency. Accepting that challenge, at the request of the Board of Directors, is Robin Haygood, whose commitment to newborn screening is well-known. After she and husband Vince lost their son Ben to undetected

MCADD in Mississippi, they pressured their state until “Ben’s Law” was adopted. Under this legislation, all expectant mothers must be informed of optional supplemental newborn screening and how to obtain it. This and other NBS advocacy efforts have prepared Robin for her role as President of Save Babies Through Screening.

From grass-roots beginnings to a position of influence, TFL/SBTS has experienced steady growth, gathering support and volunteers nationwide. Tera’s legacy is a strong foundation on which to continue building and a determination to carry out the mission that babies’ lives be spared through life-saving newborn screening.

## Remembering Kenneth “Pappy” Dunahoo

With the passing of Kenneth “Pappy” Dunahoo on November 8, 2002, newborn screening lost a champion. Despite the diagnosis of a terminal illness in 1999 and the notice that he had six months to live, Ken persevered with great courage and sheer force of will, encouraged by his family. “Pappy” to the little ones--and to some of the big ones--he did not dwell on his physical pain but thought always of children. He was inspired by his own grandchildren, Josias Wilson, affected with GA1, and Mercy Wilson, unaffected.

Ken saw every meeting with people as an opportunity to campaign for comprehensive newborn screening, and telemarketers didn’t stand a chance!

“Do you have children?” he’d cut in. “Have they been screened comprehensively?” And CNBS instruction would follow.

Ken’s generosity of heart is

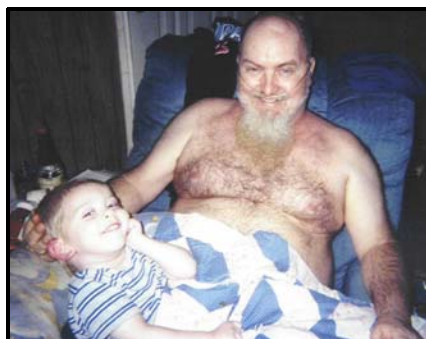
reflected in his answers to survey questions. “If you had a big win in the lottery, how long would you wait to tell people?” the survey asked. “A long time to tell, a short time to help,” was Ken’s quick reply.

“If you could eat lunch with a famous person, who would it be?” the survey wanted to know. The pointed response: “Alive – God. Dead – Harry Chapin.” We can visualize Ken wanting to meet with God while alive and using his telemarketer tactics to ask God’s help with CNBS and

some special attention for little Josias. We’re not so sure what he’d say to Harry Chapin, but it might have something to do with a heavenly concert to drum up support for the cause.

Ken was married to his one true love, Marcia Dunahoo, who serves as Secretary for SBTS, among other advocacy roles. Their daughter, Tiffany, also a CNBS advocate, is mom to Josias and Mercy.

SBTS will dearly miss this lost friend and hero. We remember with fondness Kenneth Edward Dunahoo (July 9, 1952 – November 8, 2002).



**Kenneth “Pappy” Dunahoo  
with his Grandson  
Josias Wilson (GA1)**

**To All of the Volunteers of SBTS  
and Those Who Support our Mission:**

It is with thoughts of babies yet to be born that I humbly accept the title of President of Save Babies Through Screening. With the help of so many capable volunteers and the guidance and vision of Tera Mize, Dallas Mize, and the Board of Directors, SBTS has made tremendous strides for the cause of Comprehensive Newborn Screening since 1998. I anticipate that we will all continue to work diligently to move this issue forward.

I know the fever to make universal CNBS a standard of care in the U.S. still burns very strongly within me. My apparently healthy son, Ben, died suddenly at age 2 ½ from complications of MCADD because he was not given comprehensive NBS. Every day I live with the crushing reality that if Ben were born in a state that screened for MCADD, or a hospital that provided supplemental NBS, or to a doctor that had been aware of supplemental NBS and told me about it, Ben would be alive.

In 2001, our family worked to have "Ben's Law" passed in the state of Mississippi. This law required that parents must be informed of the newborn screening tests that are available in addition to what the state mandates. It also required the State Department of Health to publish and distribute materials to the public regarding how to access supplemental NBS.

In 2002, we lobbied the state legislators to pass the "Ben Haygood Comprehensive Newborn Screening Program". This newest law requires the State Department of Health to expand its current panel of newborn screenings from 5 disorders to the more than 30 disorders currently detectable through existing newborn screening programs.

Unfortunately, there are too many stories like Ben's. Because of these babies and the families that are left to live with the devastating consequences of newborns not being screened appropriately, we volunteers must accept the challenge to make

resounding changes in the way newborn screening is conducted in this country. Some volunteers have had success with legislation in their state, but it is a slow, tedious process. The babies born with disorders detectable by comprehensive newborn screening don't always have that precious time.

In the meantime, I would like to request that all of our volunteers and supporters advocate often for comprehensive newborn screening in the way that best suits your talents. There are numerous pathways that we can use to communicate the need to provide all babies with appropriate screening. I don't believe any one way of advocating newborn screening is the only way to help save and protect our babies. I know of advocates who have spoken at their churches, participated in local Baby Fairs, conducted a walk-a-thon, participated in the Handout America Campaign, and reached out to their local media to share the story of a child affected by a disorder detectable by CNBS. These are but a few examples of many ways we advocates can work together to reach the same goal.

There is still so much work to do. The mission of SBTS is to provide information about CNBS in order to prevent death or disabilities from treatable disorders. I look forward to working with all of you as we continue to carry on this mission, continue to advocate for the children yet to be born, and continue to work toward our ultimate goal-universal CNBS.

It's going to happen.

Sincerely,  
Robin Haygood

**"Knowledge shouldn't be a luxury, it should be a right."**

*Terilyn DePaolo, on advising parents that supplemental newborn screening is available and can be very important.*

**American Baby Fair  
in Atlanta, Georgia**

*As reported by Tera Mize*

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Baby fairs are an excellent avenue to give out newborn screening information. At the American Baby Fair in Atlanta, GA, on September 14-15, 2002, Sam Grossman of Neo Gen Screening joined me in running a table for SBTS. Neo Gen sponsored the table and provided 200 test kits for expectant families. In addition, we gave out 1,500 newborn screening pamphlets to visitors stopping by the table.

Parents were very receptive to the information. Apparently the ER television show that featured a child who wasn't screened for everything and went into metabolic crisis had aired prior to the baby fair as several families referred to this episode. It really opened the door for the NBS information to connect with them.

We met a family whose daughter was screened supplementally and found to have Glutaric Acidemia Type I. The child is doing well at this time and has not suffered metabolic crisis to date. The family had decided to have their umbilical cord blood stored through CBR (Cord Blood Registry) and was given a free SNBS kit with their purchase. Their doctor apparently tried to discourage them from getting the additional screening, but they pushed it because it was free.

This is just another illustration that screening can work, and we have to get this information out to families TODAY!

## Birth Announcements

### Bo Vincent Haygood



#### Comprehensively Screened Unaffected

**Born:** June 18th, 2002 at 2:05 PM

**Size:** 9 lb. 14 oz., 20 ½ in.

**Where:** Tupelo, Mississippi

Mississippi is known for Ben's Law, named for Bo's big brother who was lost to undiagnosed MCAD.

To read more see:

*NBS and Baby Bo*

### Caroline Elizabeth Monaco



#### Prenatally Diagnosed Isovaleric Acidemia (IVA)

**Born:** Sept. 20th, 2002 at 8:18 AM

**Size:** 7 lb. 15 oz., 21 ¼ in.

**Where:** Falls Church, Virginia

Caroline was prenatally tested for

IVA because her big brother,

Stephen, has IVA.

To read more see

*NBS and Baby Caroline.*

## NBS and Baby Bo

As we announce SBTS's new president and welcome Robin Haygood, the Haygoods announce the newest addition to their family, Bo Vincent Haygood.

We *know* Bo is unaffected by MCADD thanks to a Mississippi law named for his older brother, Ben, whose precious life was stolen away because of undiagnosed MCADD. Ben's Law was enacted to make it mandatory that all expectant parents within the state be told of the testing available for their newborns. That testing would have saved Ben.

Bo will never get a chance to know his older brother personally, but he will learn the impact of Ben's life on all who knew him or have heard his story. Because of Ben and the hard work of the Haygoods, thousands of babies in Mississippi will benefit from and be saved by Ben's Law.

When the hospital provided Robin with information on newborn screening before Bo was born, it was a moment of huge significance for her. All of us at SBTS are touched by that moment as we welcome Bo into our lives and look to Robin for guidance as our new president.

## NBS and Baby Caroline

This is Caroline's very first picture. This little doll was born Sept 20, 2002, at 8:18 AM, weighing 7 lbs. 15 ounces and 21 ¼ inches long. Caroline was diagnosed prenatally with IVA (Isovaleric Acidemia). "She is doing much better than anticipated with eating and controlling the disorder. You could never tell she has a problem," says proud Daddy, Thomas Monaco.

Caroline was very fortunate to be diagnosed prenatally so that when she made her way into this world all the necessary precautions could be taken to prevent her from suffering a metabolic crisis, like her big brother Stephen.

Stephen suffers devastating and irreversible damage because his parents weren't told about a simple, inexpensive test that would have detected his disorder. As sad as Stephen's outcome is, in his own special way, this little prince protected Miss Caroline from suffering his plight – given the choice isn't that what any brother would do for his little sister? Protect her at all costs? Stephen is

a hero. But it doesn't stop there. According to their happy Mom, Jana Monaco, Caroline and Stephen were included in the Children's Annual Creating Solutions Day in December 2002. One of the topics was expanded newborn screening and an audio/visual PowerPoint presentation was done about them because of the two different scenarios.

So as we welcome this healthy little bundle of joy named Caroline there is no question that early detection is imperative. Universal, comprehensive newborn screening would dramatically reduce the potential number of heroes that are sacrificed every time a newborn isn't comprehensively screened.

With all that the Monacos do to help raise awareness, and the magnitude of this issue, the least we can do for them, and our readers, is to tell you about the Monaco Treasures, Prince Stephen and the newly arrived Miss Caroline.

**Save Babies Through  
Screening appreciates  
the kindness and  
generosity of all who  
support our mission.**

**Donations were made in  
honor of:**

**Stephen Monaco  
Caden Richards  
Joey Wilson**

## State Program Updates

**NEW YORK** added Congenital Adrenal Hyperplasia (CAH), Cystic Fibrosis (CF), and Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD) to its newborn screening panel in the fall of 2002.

**MICHIGAN** installed tandem mass spectrometry (MS/MS) equipment at the state laboratory in Lansing in the spring of 2002. A pilot program for Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD) is currently underway, with MCADD to be added to the mandated screening panel in April, 2003. This will increase the number of disorders tested to 8, with the potential of adding more because of the capabilities of MS/MS.

**IDAHO** participates in the regional newborn screening program provided by the Oregon State Newborn Screening Laboratory. Effective October 1, 2002, all Idaho samples are screened by the Oregon lab using tandem mass spectrometry (MS/MS) for a number of disorders beyond state mandate.

*These additional disorders are:*

- Tyrosinemia (types I and II)
- Homocystinuria
- Citrullinemia
- Argininosuccinate lyase deficiency
- Isovaleric acidemia (IVA)
- 3-methylcrotonyl-CoA carboxylase deficiency
- 3-methylglutaconyl-CoA hydratase deficiency
- 3-hydroxy-3-methylglutaryl-CoA lyase deficiency
- Propionic acidemia (PA)
- Methylmalonic acidemia (MMA)
- VLCADD
- LCHADD
- MCADD
- SCADD
- Glutaric aciduria, Type I
- Glutaric aciduria, Type II
- Carnitine acylcarnitine translocase deficiency (CT)
- Carnitine palmitoyl transferase II deficiency (CPT II)

## Update on Iowa NBS

In November Iowa joined nine other states in adding a \$3.00 surcharge per baby to its newborn screening fee. The surcharge receipts are applied to a fund which is used to assist families in paying the high cost of formula for PKU patients. Where insurance pays for newborn screening, this approach bills insurers the added fee, thus gaining some financial support for the expense of formula which often is not provided through insurance.

*Source: Des Moines Register, Oct. 21, 2002*

## Volunteer Voices

“The process [of government expansion of NBS] is long, and babies are born in the meantime that could have one of these deadly diseases. I hope our actions move as swiftly as possible, and we adopt the technology to save future babies. I have to believe that we’ll do the right thing here; we have to. After all, we know these diseases are treatable, so how can we say no to offering a baby life.”

Peggy Harris, grandmother of Malik & Anya Lewis (IVA and SCD)

*Ed. Note: Peggy serves on the Newborn Screening Advisory Committee in Washington state.*

## Volunteer on a Quest: Julie Greichunos

When it comes to advocating for newborn screening in Michigan, there is no hesitation from volunteer Julie Greichunos. Initially stunned by the sudden death of her one-year-old granddaughter, Madison, from MCAD Deficiency in March of 2002, she quickly mustered the courage to press Michigan to expand newborn screening. Julie wants her state to provide for its newborns the life-saving screening that would have saved her grandchild’s life. Arming herself for a multi-pronged approach, Julie advanced on the media, the state, parents, and the medical profession.

A re-cap of her advocacy in the past few months includes interviews by two television stations in September, each of which ran 4-minute stories, with one of them airing as the top story on the 11 P.M. news broadcast. These two news groups cover nearly half the population of Michigan. “Good exposure,” Julie says, modestly.

When asked to participate on the state’s Newborn Screening Subcommittee, Julie eagerly agreed. By late October this committee had managed to acquire the first MS/MS testing unit which has been installed at the state lab in Lansing, MI. The next step was to run a blind study with the state of Wisconsin. Currently, testing for MCADD is being piloted, with April 1, 2003, targeted as the date to officially add MCADD to Michigan’s NBS panel.

Julie explained, “We have legislation to amend the public health code which would include MCADD. The first rough draft of the bill was sent to me and I

rejected it. All it said was that they were adding MCADD. I sent back to the state attorney 1 1/2 pages of disorders that should be added--the same number of disorders that could be screened by an outsourced company for \$25.00. Also, I included 6 policies that I had drawn up to cover education for physicians, nurses, etc. that I thought need to be a part of the legislation. They were shocked and said that they didn’t know what any of these disorders are. Two days later the state attorneys got a packet of information on those disorders. They need to be educated as well. It is not fair to other families with other genetic metabolic disorders to only have the addition of MCADD. We will keep working.”

In November Julie addressed parents and the general public at the Star Chefs Auction, a huge fundraising event for the March of Dimes. Telling her family’s story and speaking about MCADD, Julie brought tears to the eyes of the audience.

As of this writing, she has been invited to speak to resident doctors at Michigan State University and is preparing her presentation on metabolic disorders and the need for comprehensive newborn screening.

“I have had a lot of luck going about my quest for change,” Julie says. We at SBTS think her determination and drive are at the heart of this “luck”, and we honor her unwavering advocacy.

## **A Sense of Urgency: A Family's Perspective**

*by Sharia Leslie-Brown*

Since being thrown into the newborn screening advocacy arena at the sudden and unexpected death of my grandson, Ben Haygood, just over two years ago, it seems that I have noted a sense of urgency in families to expand newborn screening NOW. I do not detect that urgency in those who have not been personally affected. There is a reason for that. It simply lies in the phrase "personally affected". When one has had the experience, one "knows".

My experience in newborn screening advocacy began about 5:00 PM on August 7, 2000, but I was clueless. The phone rang, and my daughter reported, "Mama, Ben's not feeling well. He's vomiting a little... not bad. He does not have diarrhea or a fever. He says he doesn't hurt anywhere, and he's up playing with the girls a lot. I don't know if he's picked up a stomach virus, or maybe he just has a nervous stomach from returning to the daycare after being at home all summer." Being an experienced mother of three, a grandmother of six, and a teacher of numerous children over the years, I quickly reassured her that I felt that it was probably one of her two surmises... that if he wasn't having other symptoms, he'd be OK. She reassured me that plans had been made to take him to see his pediatrician the next day even if other symptoms had not surfaced by then.

I hung up the phone feeling no undue concern for Ben...sympathy, but no fear. After all, what would a doctor tell us if we took in a child with just mild vomiting that had only manifested over

a period of four to five hours? I had spent years of watching children have vomiting episodes that easily cleared within twenty-four hours with the precautions taken with Ben that night...observation for other symptoms and hydration. I knew the dedication of Ben's parents and that he'd get needed care. Too, my working days were and are filled with detecting developmental delays in children from birth to three, and little Ben-Ben was on target and above in all developmental domains. Besides, Ben had always had well-baby check-ups, his screenings had all come back negative, and he had come through typical childhood illnesses thus far without incident.

The next day never came for Ben. A new calling was born for his family just about a month later when we got his postmortem diagnosis of MCADD and learned that Ben's disorder could have been detected with tandem mass (MS/MS) spectrometry screening at birth, or at anytime before his fatal crisis, and that the disorder was very treatable. With screening and detection of his MCADD, Ben's prognosis would have been excellent.

A sense of urgency comes from seeing first hand that the ONLY way to know what to do to save children like Ben is for them to get adequate newborn screening, thereby giving parents and doctors much needed information in how to deal with specific

life-threatening health issues that are usually typical childhood rites for most children. Often there are no red flags to clue parents, medical providers, or care givers that there is a silent, underlying deadly disorder. Fully screening babies in a timely manner and handling the specimens in a timely manner will offer the chance for these children to have the life they deserve...that means all babies NOW. It is time for us to utilize the means we have to save these children from death or disabilities, and to stop the delay in expanding screening while many haggle over bureaucratic ideals.

From one family's perspective, let it be known that had we been informed, we would have gladly paid for a \$25 screening at Ben's birth. Let it be known that we would have gladly taken on the responsibility of finding follow-up care. Did Ben have to needlessly die while the system tries to make all things perfect for all? I think not! I reiterate, start utilizing the means we have to save our children. Then, by all means, continue to work on perfecting the system of making it the best it can be for all. To do less sets up a very biased system against those of us who would have taken the measures to save our child. To do less is to allow officials to withhold information that is life saving for our children and to make decisions about how we will spend our personal dollars. Let's stop allowing the needless deaths and disabilities that are occurring NOW!

## **Too Busy to Run a Booth at a Baby Fair?**

*by Wendy Nawn*

You may like to do a smaller, simpler version of a baby fair by participating in our Tell the Shoppers Program. This is a one-day event designed to make an impact in your community.

Tell the Shoppers is a new program created by Roberta Yeagle, grandmom to Charlene, 10, who has glutaric acidemia type 1. Tell the Shoppers means that you set up a table in the lobby of a store (Babies R Us, Wal-Mart, or any store convenient to you). You distribute our newborn screening pamphlets, and you have a raffle to win a gift certificate at that store. An option is to bring a TV/VCR to show a videotape and grab the shoppers' attention. Calling reporters to cover your event increases exposure to NBS.

To participate, contact any store's manager, and ask permission to set up a table in the store lobby. Let us know of anything that you may need. If you are not comfortable contacting the store manager, then please provide us with the store's name and phone number, and we will be happy to set something up for you.

Many thanks to Roberta Yeagle for creating this awareness-raiser and fundraiser!

For more info, contact Roberta Yeagle at (856) 358-2445 or alykat35@aol.com; or Wendy Nawn at (610) 251-9876 or wendy@savebabies.org; or call SBTS at our toll-free number (888) 454-3383. Tell the shoppers...save a baby!

**Visit us online @  
www.savebabies.org**

## Charlene Meets Al and Ann!

Debbie Ottinger took her daughter to New York City in September to draw some attention to NBS. In the company of other family members, and armed with posters, they joined the crowd outside the Today show. Here is Debbie's account of their experience.

Stopping along the way to pick up Charlene's cousins, Jackie and Susie, Aunt Maureen, and Nana, we drove from Delaware to New York City on the evening of September 2, 2002. Charlene was in her glory! She made Nana sit in the back with her to hold her head up. (Mind you, for the first hour of the trip, before Nana was in the car, Charlene did a wonderful job keeping her head up. As we pulled into Nana's driveway, the head went down!)

Oh, what a long night it was! Charlene and Jackie kept us up until around 1 A.M., giggling, and then the

alarm sounded at 5 A.M. to start our day! It was a beautiful brisk morning with the wonderful energy of NYC all around us as we walked to Rockefeller Plaza at 6:30. People read our signs along the way, and as we entered the plaza, a security officer directed us to our own "special" spot. We were placed in front, right next to the door where the celebrities come out.



Charlene with Ann Curry

Almost immediately the cameramen began asking questions. We told them Char's story [GA 1], and why we were there. As people on the other side of the plaza read our signs, they asked the employees of the station to come over and get pamphlets for them. We handed out over 100 pamphlets.

One cameraman, in particular, was very interested and asked lots of questions. We gave him information, and he spread the word. He

was very kind to Charlene, talking to her, offering her hot chocolate.

Almost before we knew it, we were talking to Ann Curry and Al Roker, who are as nice in person as they are on the air. Ann gave kisses to Char, which was so special, and Al did the introduction to the weather with Char. We gave them NBS information and told them Char's story. They listened.

The cameramen took a great shot of all of our signs. We accomplished, if nothing else, some more recognition for NBS. Even if only one person paid attention, it was well worth the trip.

On the way back we had to stop to shop, of course. I mean, really, who could visit that wonderful city and not buy at least an "I Love NY" shirt!



Charlene with Al Roker

### Have a Few Minutes? Call CBS about our PSA!

Here is how to use a few minutes of your time, and come away gratified. SBTS has a 30-second public service announcement for TV, with actor Michael O'Leary as spokesperson for newborn screening. You've heard about the PSA; will you help to get it aired locally? Here's how:

1. Call your local CBS television station and ask to speak to the Public Service or Community Relations Director.
2. Tell them you volunteer for a nonprofit organization that advocates saving infants through newborn screening.
3. Tell them that one of the actors on CBS's "Guiding Light" did a public service announcement taping.
4. Ask them to air the tape around "Guiding Light's" air time as frequently as possible. Be sure to get the address of where to send the tape and the name of the person who is to receive the tape.
5. Contact SBTS at 1-888-454-3383 and tell us where to send the tape. Or email [wendy@savebabies.org](mailto:wendy@savebabies.org) with the mailing information.

Your use of a few minutes could be the gift that saves a baby's life!

### Pleading with Oprah

When Theresa Murry stepped to the microphone to speak with Oprah and the audience following a November broadcast, she was understandably nervous. This was an important moment, a rare opportunity to catch the ear of an influential television celebrity who holds the power to reach millions of viewers. Oprah listened as Theresa explained what comprehensive newborn screening is and how it can save lives if parents are informed of it. She urged Oprah to do a program on CNBS. Oprah's staff wrote down the information, and Theresa lingered in the studio afterwards to be sure the message was noted.

Theresa's 30-second encounter was all SBTS volunteers needed to launch a massive email/letter-writing campaign to plead with Oprah to schedule a show on CNBS. At the time this article was written, it was too soon to know if the campaign succeeded. We hope that, as of this newsletter's publication date, our readers will be saying, "Yep, saw that on the Oprah show."

If you haven't seen that comprehensive newborn screening show yet, then, let your voice be heard. Write to Oprah at Harpo Productions, P.O. Box 909715, Chicago, IL 60607 or send an email by going to [www.oprah.com](http://www.oprah.com) and following the "E-mail Us" link in the left menu bar.

## ***Want to Get Motivated? Attend a Conference!*** ***- A personal reflection by Peggy Harris***

I debated some before committing simply because I wondered whether I (as a grandma) would get as much out of the Metabolic Conference in Orlando, FL, as my daughter, Tiana, might. I am so happy I put all those doubts aside and decided to go. This conference last October, sponsored by the National Coalition for PKU & Allied Disorders, was the first I've attended.

Exhausted from the red-eye flight out of Seattle, I was, nevertheless, enthused to attend the welcome reception at the hotel and meet many people whom I had known only through e-mail. I can't say enough about the importance of connecting with others who share such common interests and lives. Many of us stayed up late chatting, and our inner clocks were still crazy from traveling when the bus came very early the next morning to shuttle us to the conference.

Held at the Convention Center in Orlando, the conference included sessions designed according to disorder. I attended the Organic Acidemia sessions and those on universal newborn screening. The over-all day left me feeling energized from all the information offered; I also felt a bit of an awakening in regard to my grandson Malik's care and learned so much about continued care for him. Professionals came from all over (as far as France) to share their expertise on many genetic conditions.

It was pleasing to see one of Malik's nutritionists, Cris Trams, at the conference. Cris is the director of Nutrition Services at the Center on Human Development and Disability and Program Director of the PKU Clinical Program at the University Hospital. Her presentation emphasized that educating children at a very early age about their condition is critical and that one day they will have to take on some of the responsibility for managing their treatment. She stressed the need for parent support for children's accomplishments for tasks and managing their disorder and engaged parents in discussing their children's care. The business-like style of this presentation helped me to remember not to put so much of the "woe" in our lives. It's really important to learn about the care and management of these diseases so they aren't such mysteries but a part of life within the family.

Dr. Guy Touati, who obtained his medical degree in Paris, described his

clinic's approach to nutritional teachings and over-all treatment for some kids. This model showed how to help make the diet nutritious, fun and tasty. After all, we're speaking of France, where there is pride in presentation and enjoyment of fine cuisine. They offer two schools for children: one for younger and one for older children. The curriculum for both includes cooking classes taught by a chef, games relating to protein/amino acid count, and various ways to cook a recipe with added nutrients and calories to make it taste good. There is a huge concentration on teaching children how to manage their diet and enjoy their food. It seems that formula isn't a big part of treatment in France; rather, the emphasis is on dietary restrictions in the foods they can eat. We all wanted to move to France after hearing this presentation!

Piero Rinaldo, M.D., Ph.D., Director of the Biochemical Genetics Laboratory at the Mayo Clinic in Rochester, MN, presented a serious session on Ketosis and Organic Acidemias. He challenged us to be able to communicate the disorder and ketosis to our doctors and caretakers. He gave an overview of Ketone bodies--what they are and how they relate to Organic Acidemias.

A presentation by Susan Winter, M.D., was on treatment of Inborn Errors of Metabolism (IEM's) with particular interest in the use of carnitine for OA's and FAOD's. Dr. Winter has been the Medical Director of Medical Genetics/Metabolism at Children's Hospital, Central California, for 22 years. She presented a slide show that followed patients from early to teen years, in and out of crisis. The discussion was an eye-opener for me. I always thought that because Malik presented early, and treatment was started early, he wasn't as vulnerable to setbacks (maybe wishful thinking). On the contrary, it seems that because Malik presented so severely, he is likely to have setbacks. She suggested that kids can go into crisis (not necessarily major) during adolescent years. This information was offered as awareness for parents so they can adjust treatment methods accordingly.

The day ended with a slide show featuring many of our children, both living and lost, and a ribbon-cutting ceremony.

Moving into a circle to hold a yellow ribbon that repeated the words "WE'RE ALL IN THIS TOGETHER", we concluded by cutting the ribbon, and everyone took home a portion that held this phrase. I was very emotional by this time so the ceremony brought tears to my eyes and thoughts of how much we've all been through. I think this part of the conference will stay with me forever.

The following day offered many sessions including Dr. Rinaldo's presentation on universal NBS. He told us how states developed programs independently, clearly unfair to the well-being of newborns. He embarrassed us a bit as he spoke on states that still don't screen for Galactosemia, expressing "how on earth" we can do this. The discussion went on to talk about the national trend to add disorders that are clearly treatable if tests and treatment are offered early enough. He gave parents much credit for driving this change. Dr. Rinaldo is very passionate about universal NBS and was quite open to discussions in the hallway after his presentation.

Questions were asked about the future of recruiting residents to study genetics and IEM's, and about educating all medical staff on these diseases. It was interesting to hear that many specialists are close to retirement age, and there aren't many that are young to this field. Since the awareness is there, it is hoped that these studies will become an attractive pathway for newcomers in the medical field.

The greatest pleasure in attending this conference was meeting other parents and caretakers of children with special needs. Some parents left their children for the first time in order to participate, and this was their first experience entrusting another with their children's care. Many brought their children, and it was so great to meet these youngsters I've been hearing about for the past four years.

Wow, it's been four years since I began communicating with other families through a listserv, and it took that long to get to one of the conferences! I surely encourage anyone that can to make the journey to a conference. It's well worth it, and I'm so thankful for all who urged me, "Go!"

## Newborn Screening Focus of Family Meds Infomercial

Family Meds, Inc., a pharmaceutical retailer in nineteen eastern states of the United States, sponsored an infomercial. The infomercial aired in Mississippi, Alabama, and Tennessee during the months of October and November, 2002, for the purpose of informing the public of the availability of comprehensive newborn screening. The infomercial featured Dr. Mary Ann Sheffield, a pediatrician who practices in Amory, Mississippi; Robin Haygood, the mother of Ben Haygood who died from undiagnosed MCADD in Tupelo, Mississippi; and, Cyndi Bowen, a pharmacist and manager of Family Meds in Fulton, Mississippi. Robin spearheaded a campaign to change laws in Mississippi, which resulted in the passage of the "Ben Haygood Comprehensive Newborn Screening Program." Cyndi is a cousin to

Ben Haygood. Cyndi has been very active in newborn screening advocacy and has been an instrumental part of getting legislation passed in Mississippi.

Dr. Sheffield made opening remarks on the infomercial by asking parents if they were aware that their baby was at risk. She stated that one in twelve hundred children die as a result of metabolic disorders for which screening is available. Next, while a picture of Ben Haygood was shown, Robin explained that her son died as a result of not having a simple \$25 test. Cyndi followed with a statement of Family Meds' concern for families.

Family Meds is to be commended for their efforts via this infomercial to make parents aware of risks to their children and to inform them of newborn screening options.

## Professional Affiliations

To maintain our professionalism, stay current on NBS issues, and align the foundation with other organizations concerned with the well-being of children, Save Babies Through Screening Foundation is affiliated with the *Coalition for Positive Outcomes in Pregnancy; Genetic*

*Alliance; National Birth Defects Prevention Network; National Healthy Mothers, Healthy Babies Coalition; and SIDS Families, Inc.* From them we learn, and with them we share our concerns regarding newborn screening. While our primary missions differ, together we work toward common goals.

## Miami Baby Fair, 2003

SBTS will be exhibiting at the Miami Baby Fair in April, 2003, with experienced volunteer Patty Blenet. This is a grand opportunity for Miami area residents to learn about newborn screening and what it means to Florida's families. If you can help Patty run a booth and distribute NBS information, please let us know. Contact SBTS toll-free at 888-454-3383 or email [wendy@savebabies.org](mailto:wendy@savebabies.org) to volunteer your assistance.

Patty ran our booth at last year's Miami Baby Fair and was pleased by the interest of visitors and the successful sharing of NBS information. She would love to have you join this awareness event. What better way to spend a day or two than to save a baby's life!

Formerly Tyler For Life Foundation

## Save Babies Through Screening

A 501(c)(3) Non-Profit Organization

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