



Save Babies Through Screening Foundation, Inc.

Newborn Screening NEWS

Raising the Awareness of Newborn Screening and Related Disorders

www.savebabies.org

Fall 2003 Volume 3, Issue 3

“Step Up for Jenna”

When little Jenna Clark, 9-month old daughter of Tammy and Roger Clark of Ontario, Canada, died suddenly of undetected MCAD Deficiency on November 22, 2002, the family was devastated. Her death has led them to advocate in Canada for supplemental newborn screening, the screening that would have saved Jenna's life.

Picking up the momentum to raise awareness, Tammy's cousin, JoEllen Felkl of Vermont, organized a walkathon in memory of Jenna to call attention to newborn screening and to generate

funds for distributing newborn screening education materials in her state. In the months prior to the event, which they named “Step Up



Left to right: Roger Clark (Jenna's dad), JoEllen Felkl, Dawn LaPrise, and volunteers Ruth and Paul LaPrise

for Jenna”, JoEllen and her sister-in-law, Dawn LaPrise, handled all the details, which the walkathon encompassed. This included logistics, advertising, participants, sponsors, T-shirts, pledges, and thank you notes. Dawn donated their personal expenses, such as telephone calls and incidentals, which were necessary to the

planning. Save Babies Through Screening Foundation provided support materials, such as pamphlets.

The only thing the two women did not arrange was the perfect weather on June 21, 2003. Individuals and families, smiling in the sunshine, appeared on foot or on bicycles to honor Jenna's memory and to promote newborn screening.

Shortly after the walkathon, JoEllen wrote, “We had a GREAT weekend. The weather was awesome. It appears we will be sending a check to SBTS Foundation in excess of \$5,500.”

These funds will provide for the distribution of newborn screening materials in Vermont, fulfilling JoEllen and Dawn's walkathon goals as they stepped up for Jenna.

Dad's Employer Helps Improve the Future for Similar Children in Virginia Community and in the Nation

Before his life was shattered by undetected Isovaleric Acidemia (IVA), Stephen Monaco was a happy, lively, personable 3-year old. He, his two older brothers, and their parents enjoyed all that a normal family experiences, unaware that crisis lay in wait.

The family's life changed dramatically after Stephen suffered sudden severe brain damage within hours of what appeared to be a common vomiting illness. Medical specialists, rehabilitation, and treatments consume the family's energy and resources. Stephen's parents, Tom and Jana Monaco,

now advocate for the newborn screening that would have prevented the tragedy that struck their son.

Tom's employer, Amyx Defense Logistics, Inc., is helping to improve the future for similar children in the Monacos' community, and in the nation, by supporting the mission of Save Babies Through Screening Foundation.

About Amyx Defense Logistics, Inc.

Amyx Defense Logistics, Inc. is dedicated to providing practical, responsive business and technology solutions for the Department of Defense and other government

agencies. ADL is rapidly gaining a reputation as the preferred small business provider in the D.C./ Metro area for program management, Knowledge Management and innovative, web-based, technology solutions. ADL is also a certified Microsoft Partner.

Honest evaluation, innovative research and solutions, practical recommendations, and effective best practices demonstrate ADL's commitment to the customer. ADL believes that service to the government can make a difference. It is evident that both ADL customers and ADL employees are the company's top concern.

Mississippi Expands Newborn Screening

State Paves the Way in Public Health Arena as a National Leader in Comprehensive NBS
by Robin Haygood

On June 1, 2003, the Mississippi State Department of Health began screening Mississippi babies for 40 genetic disorders, making Mississippi the first state in the nation to provide such an extensive newborn screening program.

"Comprehensive newborn screening will prove to be a great benefit for the children of Mississippi," said Mississippi State Health Officer Brian Amy, MD. "The Health Department's mission is to promote and protect the public's health and what better way can we do that, than by detecting problems early."

Before June 1, 2003, Mississippi law required all newborns to be screened for only five genetic disorders, with an additional 30 offered upon parental request. The Ben Haygood Comprehensive Newborn Screening Program Act—also known as House Bill 717 in the 2002 legislative session—authorized the Mississippi State Board of Health to determine and specify disorders to be included in the comprehensive newborn screening program. With input from the Mississippi Chapter of the Academy of Pediatrics and the Mississippi Genetics Advisory Committee, the 35 new tests were added.

Mississippi Governor, Ronnie Musgrove, believes that this groundbreaking genetic screening will contribute to a healthier Mississippi. "I am thrilled that Mississippi is taking the lead in protecting the health of its little ones," said Musgrove. "Our children are the future. These tests provide critical information for parents that can help determine their newborn's long-term health."

Vince and Robin Haygood of Tupelo, Mississippi, lost their son, Ben, as the result of a genetic

disorder detectable through comprehensive newborn screening. "He was a loving, generous and seemingly healthy two-year-old in our lives, a life that ended too soon. Newborn screening that is now available would have detected MCAD in Ben," said Robin Haygood. "We could have pursued treatment that would have saved his life. It is a good feeling to know that no more will I look in our newspaper's obituary column and wonder if that child's life could have been saved by appropriate comprehensive newborn screening."

Nancy Helman, RN, the Chair of the March of Dimes Program Services Committee said, "This is an effort that has been supported nationally as an attempt to have an expanded newborn screening program. We are pleased to be partners with such wonderful groups, organizations, and people as to see this come to fruition. This will allow for the babies who are born in the state of Mississippi to obtain quick and appropriate referral for problems that could easily have saved little Ben Haygood. We look forward to a better future for the state of Mississippi."

Pediatric Screening now processes the state's newborn screenings. Mississippi's hospitals collect about five drops of blood from the heel of the newborn from 24 to 48 hours after birth and ship the specimen by overnight courier. Results are generally available within 5 to 7 days. The Mississippi State Department of Health follows up on all abnormal and inconclusive test results. The fee charged by the Mississippi State Department of Health is \$70 per newborn screen. The fee covers the cost of the tests for all 40 disorders and funds the state's follow-up program. For more information, contact the Mississippi State Department of Health at 1-800-489-7670 or online at www.health.ms.gov.

Feedback: American Baby's Baby Faire Dallas, Texas, May 17-18, 2003

Laura Clow, Theresa Murry, and a few helpers ran a booth for SBTS Foundation. Here are two observations from the experience.

Laura: There were tons and tons of people passing through. It was really productive. People we reached included a pediatric nurse who had a booth at the same fair and a pediatrician who now wants to offer supplemental newborn screening to his patients in Greenville, TX. A lady, who sells stork signs for people's lawns when they have a baby, took our pamphlets to include in her packets of baby samples which she distributes with her signs.

Lots of the people who visited the booth had already heard about supplemental newborn screening in childbirth education classes or from their pediatricians. That is new this year.

I talked with a woman from the national March of Dimes who agreed with me that the MOD's position on screening for only nine disorders is not enough.

Discovery Health (the TV show) was there. They heard about newborn screening when they were at American Baby's Baby Faire in Miami in April and visited Patty Blenet's booth. I encouraged them to do a story on newborn screening.

We held a donation raffle to raise some money.

Theresa: It went great. Laura had it all set up so nicely. She had two baskets full of baby items as a give-away for a donation, and she also offered newborn screening test kits. We passed out hundreds of pamphlets and information on the screening process.

I also found out that there is a pediatrician's office in Dallas that supports the newborn screening test and advises patients of its availability before the baby is born. I was very impressed to see that the word is getting out. It really put some zing in my spirit!

The only downfall was those parents who would sort of blow it off because they thought their baby couldn't be tested because they were no longer a newborn. But most would listen, anyway, and it was nice feeling that I was contributing.

Ed. note: Laura Clow is mom to Brickman, MCADD, and two siblings who are carriers. Theresa Murry's daughter Michelle died in 1998, at the age of 20, from undetected MCADD.

Caden & Carsen Richards

A Tale of Two Sons

When Caden Richards (GAI) got sick on Christmas Eve, 2002, no one knew that it would be the beginning of a long ordeal before he began to get better. Not only did Caden have to spend all of Christmas Eve and most of Christmas day in the hospital, but upon their arrival at the local emergency room his mom, Krystena Richards, couldn't convince the medical team to follow Caden's protocol letter. Caden had to be taken to another ER a good distance away. Thankfully, Caden is a tough little guy because he's been spending a lot of time in and out of emergency rooms in recent months.

Lack of prompt treatment during this Christmas episode did not have an impact on Caden's physical outcome, but it did have an impact on his emotional well-being. Caden was unnecessarily frightened by having to leave the hospital where he knew he needed to be. He even begged Mom to take him back into the hospital that wouldn't follow the protocol letter.

But in this case Mom knew best. With the kindhearted help of ambulance drivers, who overheard their plight and offered assistance, Caden was transported to a more receptive hospital. While Caden's current treatment of Carnitor, Riboflavin and Q10 has helped him tremendously and he's on the road to recovery, nothing seems to help with the pain that Caden suffers in his legs.

"Caden is about to start taking Glycine as part of his treatment. We are trying to find something that will help his leg pains," says Krystena.

Caden, who celebrated his fifth birthday on July 13, has also been experiencing difficulty with the summer heat. His leg pains have increased; his energy level is low; and he's suffering

irritability and mental confusion, especially when he's outside. Caden has begun to cry in the night, unable to tell his parents what's wrong.

"He just says that he feels bad," says Mom, who is now looking forward to fall with mixed feelings – because with fall comes the "virus season".

In the presence of all this turmoil there is still joy to be found

in the Richards' home. A part of that joy arrived on June 9, 2003, at 4:44 P. M. in the form of a bouncing bundle named Carsen Phillip Alan Richards, the newest member of the Richards clan.

Because big brother Caden was diagnosed with GAI, Carsen was screened at birth using MS/MS technology. The first newborn screening card indicated a problem. However, Carsen was showing no signs of GAI and was doing very well except for an abundance of spitting up causing the need to switch him to a Lactose Free formula. Carsen hasn't had any problems since starting the new formula.

"He is the best baby. Carsen never cries, eats well, has great muscle tone, and the re-test was normal," brags Krystena.

However, for safety's sake, his parents arranged for additional, in-depth tests. "I am naturally a bit unconvinced [that Carsen is not affected] since Caden's real problems didn't exaggerate until he was about 8 or 9 months old, and his labs have been normal at times and abnormal at others. For now, we are just enjoying being new parents all over again."

But this enjoyment was short lived. Before we were able to bring you this story we received word from

Krystena that test results confirmed that her baby does have GAI.

"Carsen is affected and we are devastated. He seems to be doing so well. It all started with a phone call about the skin biopsy results..."

And so it begins...

The rush to see the metabolic team, waking Carsen every 2 ½ to 3 hours to be fed, the supplementation of Carnitor and Riboflavin, the pre-ordered IV should Carsen look the slightest bit sick, and the universal call that goes hand-in-hand with a metabolic disorder:

"But he doesn't look sick – he seems so healthy."

Carsen is one of the few lucky enough to be diagnosed before crisis sets in, placing the odds in his favor. Even with these odds the family waits... waits for more information from the doctors, waits to see how well Carsen will do with his disorder, waits for the first 'virus season', waits hopefully that all will be well with their smallest angel...

Need Someone to Speak Out for NBS?

May we offer Robert Burke? You may have heard of him. As father to Bryce, a child who has MCAD Deficiency, Bob has been outspoken in the media. Now he is available to travel and speak in your community. Bob shares his son's story, gives out test kits, makes arrangements for children to be tested after the speech, and contacts the press beforehand. His speaking engagements have been held primarily in churches, and after a recent presentation, he had 200 children tested.

Bob is very willing to speak in different areas, but he needs your help. Please contact him at bburke@savebabies.org or (817) 501-8390 to arrange for a presentation in your community.

Caden & Carsen Richards



State Program Updates

California conducted an optional supplemental NBS program for more than 25 additional disorders from January, 2002, until June, 2003. During the 18 months of the pilot 320,000 infants in targeted areas of the state were screened supplementally. Among these, 41 infants were diagnosed with an inherited metabolic disorder, 11 of which were identified as MCADD. When the pilot expired on June 13, 2003, no funds had been allocated for adding these disorders to the existing NBS program. Residents of California have been urging the state to adopt the expanded newborn screening which was successful as a pilot program. For more information about the California project, please contact Kathleen Fergus by email kathferg@pacbell.net or phone 415-665-6767.

Source: Kathleen Fergus, MS, CGC

Georgia began screening for Biotinidase Deficiency as part of its NBS panel on May 12, 2003, and within a few weeks had detected its first case.

Source: Sharon C. Quary, MS, GA Newborn Screening Follow-up Program

Iowa approved the addition of certain MS/MS disorders to its newborn metabolic screening panel on July 9, 2003. Routine screening and reporting were scheduled to begin August 1, 2003.

Source: Tonya Norvell Diehn, M.S., State Coordinator for Genetic Services

North Dakota increased the NBS fee from \$18 to \$30, effective April 1, 2003, to allow for the addition of Biotinidase Deficiency, Hemoglobinopathies/Sickle Cell Anemia, and MCADD. Blood samples are sent to the Iowa Hygienic Laboratory which conducts the testing for North Dakota.

Source: Karen Obey, Newborn Screening Coordinator

Oregon, since starting MS/MS in October, 2002, has detected more than two dozen cases of metabolic disorders, approximately 1:2400 births, in Oregon and Idaho, combined. (*Note: Idaho NBS is served by the Oregon State Newborn Screening Laboratory.*) Also, Oregon routinely does newborn screening on second specimens to see whether any of the MS/MS diseases can be better identified on the second screen.

Source: Judi Tuerck, RN, MS, Oregon Health and Sciences University

Washington state could begin implementing the addition of five disorders to its NBS panel in January, 2004, if the state Board of Health, at its October meeting, approves the recommendations of the NBS Advisory Committee. The five disorders are Biotinidase Deficiency, Galactosemia, Homocystinuria, MCADD, and MSUD. The state legislature has already approved an increase in the NBS fee to accommodate the expanded screening. Also approved is additional funding for the state's share of Medicaid's costs. Medicaid pays for 43% of births in the state. If the Board of Health accepts the recommendations to expand NBS, full implementation would be accomplished no later than June, 2004.

Source: Michael Glass, State of Washington Department of Health

United Way

If your workplace has a United Way workplace campaign, don't forget us! You can help save babies by donating to Save Babies Through Screening Foundation through the convenience of a payroll deduction.

Each United Way is independent. To donate, some United Ways require a code and some do not. If your United Way does not require a code, simply write on their donor designation form our name and address - Save Babies Through Screening Foundation, 4 Manor View Circle, Malvern, PA 19355.

If your United Way does require a code, ask your employer what is involved in getting a code, or simply contact us and tell us whom to ask about what is involved in getting a code. We'll be happy to complete any paperwork needed. Because each United Way has a different giving process, your help is needed to get started.

To those already giving through the United Way, Save Babies Through Screening Foundation extends a heartfelt thank you for your giving. Your donations help us continue the foundation's awareness and education programs to save the lives of babies.

With Gratitude and Recognition

Time, talent, and funds...these are critical components of the foundation's programs. We are grateful to all who donate from the heart and from the pocket. It is the generosity of those who give of themselves, in one form or another, that enables us to continue our mission. Sincere thanks to all, with special note of these contributions received between January and June, 2003.

Volunteer Efforts:

JoEllen Felkl and Dawn LaPrise ~ "Step Up for Jenna" Walkathon in Vermont

Linda Glendening ~ NBS Unity Quilt Management

Tammy Clark ~ NBS Advocacy in Canada

Shelly Grabow ~ Special project assistance NBS Advocacy in Florida

Nancy Tier ~ NBS Advocacy in Florida

Jane Wilson
Shipping NBS materials

Baby Fair Exhibits:

Patricia Blenet
Viviane Blenet
Jeffery Drouillard
Laura Clow
Debra Gara
Donna Miele
Theresa Murry
Debbie Ottinger
Roberta Yeagle

Technical/Business

Services:
Mark Wawrzenski and Annemarie Starker of Shooters Post and Transfer ~ Donating editing services

Nawn & Company, CPA's, LTD & Richard Switzer, Esq. ~ Donating copying & printing services

Jamme Romanoff
Providing data support

Brian Beck
Providing computer services

Lori Diefenderfer
Providing accounting services

Roxanne Diefenderfer
Assisting with Mother's Day Fundraising Drive

Corporate Sponsorship:

Silver Sponsor - \$5000
Amyx Defense Logistics

Sponsors:

\$1000 and above
Neo Gen Screening
Robert and Joan Dircks Foundation

Patrons:

\$500 and above
Stephanie and Andrew Plaisted
Tupelo Public School
District Advocates for Gifted Education

Supporters:

\$250 and above
Terilyn DePaolo
Tera and Dallas Mize

Donations in memory of:

Kenneth James Butts
Jenna Clark
Zachary Wyatt Davis
Cristal Marie Gara
Caleb Patrick Grabow
Ben Haygood
Tyler Mize
Andrew Dylan Plaisted
Kristin Mary Sadler
Dick Selland
Nora Waananen
June A. Waite

Donations in honor of:

Grace Burke
Jordan Cartwright
Matt Davco
Terilyn DePaolo
Nathan Garipey
Robin Haygood
Nikki Hrichak
Brandy Landry
Stephen Monaco
Alex Nawn
Justice Quent
Brett Revinski

Born with PKU: Margaret Doll's Story

When the PKU test was mandated in Minnesota in 1965, it arrived too late to benefit Margaret Doll. Born with PKU in 1958, Margaret had a part in the inspiration that led her uncle, Robert Guthrie, to develop the test that would have altered her life in a different year. Recently, SBTS heard from Margaret's mother, Mary Lou Doll. The following article shares her family's experience as participants in newborn screening history and shows us how far we've come since Robert Guthrie, the Founder of Newborn Screening, changed forever the way we would welcome our babies into the world.

When Margaret Doll was born in 1958, the "diaper test" which was done in some doctors' offices and well-baby clinics was not offered in hers. This test wasn't effective until a child was several months old. It was not always perfect, and it was given too late to prevent early brain damage.

When Margaret was 9 months old, her general practitioner diagnosed petit mal seizures and referred the family to a pediatrician friend. This doctor felt she was mentally retarded to some degree and recommended that she be taken to the University of Minnesota for an EEG when she was a little older. No hurry, he stated.

Margaret's parents phoned her uncle, Robert Guthrie, in Buffalo, who was working on developing a way to prevent mental retardation. His original inspiration was his son John, who was mentally retarded but not because of PKU. Soon Dr. Guthrie would have more inspiration from family. He referred them to the university where the diaper test confirmed that Margaret, then 13 months of age, had PKU. The test was too late to prevent brain damage.

Margaret's mother, Mary Lou Doll, says that Robert was shocked to learn that the child had PKU. He had graduated from the University of Minnesota and had made trips to the PKU clinic there to gather frozen urine specimens as part of his research—research that had suddenly become yet

more personal than before.

Margaret was started on the PKU diet immediately, and her motor skills improved quickly, although she didn't sit up until about 18 months, nor walk until 27 months. It took three years of medication for the petit mal seizures to stop. After seven years Margaret was removed from the PKU diet because it was commonly held by the medical establishment that the brain was fully developed by that time. Food would no longer matter.



Margaret Doll, PKU

Between the ages of 19 to 20 years, Margaret's behavior changed dramatically. She became violent, destructive, and self-abusive. Hallucinations caused her to scream over things her parents couldn't understand. The PKU diet was resumed. Mary Lou says they should never have abandoned the diet.

She is amazed by how well Margaret adjusted to the rigors of the PKU diet and says it is apparent that her daughter feels better. Beginning with no meat, cheese, eggs, milk, or the like, the diet is enhanced with a powdered supplement, mixed with water. She remains on minimum dosages of psychotic drugs for behavior control.

Reflecting on the past, Mary Lou says, "Despite the promise of Bob's test, we elected not to gamble on more children. We had seen several families in the PKU clinic in the early years who had two or even three children affected. We opted instead to do foster care and eventually adopted three brothers for Margaret."

Today Margaret is calm and

contented, living successfully in a four-person group home eight miles from her mother, close enough to go home for visits. She is considered severely to profoundly retarded, but she speaks in complete sentences and exhibits complicated thought patterns. "Socially, however, she can be taken to church, simple concerts, restaurants, to people's homes for visits, and even rides a 2-wheel bike well!" Mary Lou tells us.

"Margaret enjoys music and food. Especially loves French fries and pop! She is a happy young woman, and we're very proud of her! She can pare potatoes, load and unload the dishwasher, and open cans and packages. Though she can't read, she's always interested in what a package says. Margaret goes to a cabin with us for a week every summer—loves the paddle-wheel boat, fishing off the dock, and playing in the lake.

"She attends a Developmental Achievement Center (DAC) five days a week where they do simple crafts, sing, and go to coffee shops. She loves coffee! She can also bowl about 60 to 70 but has developed neuropathy and wears braces on both legs. She throws one foot very badly so walks best with a walker or a cane. Margaret doesn't complain, but long distance walking is not an option."

Last fall Margaret's image was used by Sutherland Media Productions in the Howard Hughes Medical Institute Holiday Lecture Series on biomedical research. Also, her picture at the age of three years is on page 155 of Jean Holt Koch's book, "The PKU Story—Robert Guthrie". The author is the wife of Dr. Richard Koch, world-renowned expert on PKU.

Looking at the advances in newborn screening since Robert Guthrie's achievements, Mary Lou concludes the telling of her daughter's story by saying, "I pray that your sons and daughters have had miraculous things in their lives or that the screening has prevented further tragedies."

Visit us online @ www.savebabies.org

Third Annual Mother's Day Fundraising Drive

Save Babies Through Screening Foundation extends our deepest thanks to all people who donated for the annual Mother's Day Fundraising Drive this year. Volunteers distributed over 1,500 flyers and newborn screening pamphlets to the Foundation's mailing list and to individuals at work, church, neighborhoods and other places where people know people. More than \$5,000 was raised this year. Thank you all for making the annual fundraiser a success!



4 ½ year old volunteer Alex Nawn, MCADD, stuffed envelopes for the Mother's Day Fundraising Drive.

Letters

I just wanted to send you a quick email to thank you for posting such useful information on your website. I was having difficulty obtaining a list of diseases checked by any of the supplemental screening tests done on newborns and your set was the only one I found that was so complete.

Thank you for posting that information for concerned mothers such as myself.

CT, via email

It's not a baby disease – death of a 45-year-old woman

A 45-year-old woman died from MCADD, per the September/October 1999 issue of Genetics in Medicine, Vol. 1 No. 6 p. 293, Medium-chain acyl-coA dehydrogenase deficiency: Sudden and unexpected death of a 45-year-old woman. The woman had surgery for colon cancer. After the surgery, she received the standard treatment of IV saline for 72 hours. She needed IV dextrose. She complained of nausea before dying. MCADD can be asymptomatic; that means there are people who have it and don't know it. "Newborn" screening is ideal; however, comprehensive newborn screening can be done, and perhaps should be done, at any age for most disorders.

Frustrated with your state's NBS status?

Draw attention to newborn screening by holding a walkathon. Save Babies Through Screening Foundation now has a distribution program for newborn screening educational materials that go directly to pregnant women in specific geographic areas, such as your county or your state. But funding is needed to get the materials distributed there. A walkathon is a healthy, inviting way to raise funds needed to get newborn screening educational materials distributed in your community or your state...and it's fun! For more information, email fundraising@savebabies.org or call Save Babies Through Screening Foundation toll-free at 888-454-3383.

When it comes to optional newborn screening, parents should have to opt out rather than opt in. Just as with telemarketers. They can do their thing unless you say no. NBS should be given the same consideration.

Federal Government Employees

You can now help support the programs of Save Babies Through Screening Foundation by donating through the Combined Federal Campaign. To have donations deducted directly from your paycheck, ask your payroll office if they allow employees to participate in the Combined Federal Campaign. If they do, use code # 1520 or use the Children's Charities of America membership list and locate Save Babies Through Screening Foundation's code. Please give!

SBTS Foundation Welcomes New Board Members

* * * * *

Save Babies Through Screening extends a warm welcome to new board members:

*

Sandee Beatty
Bob Burke
JoEllen Felkl

*

Lawsuits have been filed against hospitals throughout the country regarding lack of supplemental newborn screening. Several have been settled with the hospitals for undisclosed sums. The children at stake have died or suffered permanent irreversible brain damage. These deaths and injuries were preventable.

No Surprise

We're not surprised. After newborn screening programs are expanded, we keep seeing a common thread of "disorder frequency was higher than expected." That's because they're looking.

A few years ago it was said that SCADD was so rare that there were only a few cases of it in the world. Yet California's pilot program found SCADD to be the most common disorder during the duration of their pilot. They identified 16 cases of SCADD in 16 months. They looked in only half the state. What would they find if they look in the other half?

Unfortunately, no one is looking anywhere in California at the time of this writing. Their pilot program ended June 13, 2003, and California's newborn screening program reverted to only its mandated 4 disorders.

When Chris and Wendy Nawn's son Alex was born 5 years ago and diagnosed with MCADD, they were told that MCADD is primarily a Northern European, Caucasian disorder. Yet 7 of the 11 MCADD cases identified in California's pilot program are

Hispanic. Several identified in South Dakota have been American Indian. Things are found when we are looking.

Currently, 23 newborn screening programs are not looking for CAH, 30 newborn screening programs are not looking for Biotinidase deficiency, and 51 newborn screening programs are not looking for cystic fibrosis. To look for Biotinidase deficiency and cystic fibrosis, it's not necessary to have the equipment in every laboratory. Because Biotinidase deficiency and cystic fibrosis have a generous detection window of weeks to months, the existing blood sample can be forwarded to another laboratory that has the capability to screen it. Laboratories do so all the time - but not in newborn screening.

We must look for the disorders which threaten the lives of our babies. If we don't, these disorders will find us first, and that surprise can come too late for our children and their physicians.

SPREAD THE WORD

If you don't tell them, nobody will.

Students Raise Awareness of NBS

by Robin Haygood

5th and 6th grade students from Jenny Decker's class at Lawndale Elementary School in the Tupelo Public School District, Tupelo, Mississippi, worked to research, share knowledge, and collect donations for the Save Babies Through Screening Foundation. These students participated in the 6th annual SHOP (Students Helping Others Planetwide) event. During SHOP, students select a charity of their choice, learn more about that charity, and show how that charity benefits the public. This is the second consecutive year Mrs. Decker's class has chosen to support SBTS Foundation.

The event took place November 21-22, 2002, at the Gloster Creek Village shopping center. More than 20 booths were set up, which represented various charities, including LeBonheur Children's Hospital, The Salvation Army, The Humane Society, SBTS Foundation, and many others. The SBTS booth was designed by the students and featured a map of the United States which displayed the number of disorders that are screened in a state-by-state format. When visitors stopped by their booth, the students talked about NBS, handed out educational materials, and shared stories about families whose lives had been changed forever because of the lack of appropriate NBS. These students raised \$756.30 in donations. SBTS Foundation thanks Mrs. Decker and her students for all their hard work.

Please detach and enclose with your donation.

Your Donations Make a Difference!

Won't you help *Save Babies*?

Donation Amount \$ _____

If paying by credit card:

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This gift is in Memory of Honor of

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*If your donation is in *memory of* or *honor of*, please include the full name of the designated person. SBTS will send a certificate if you provide a name and address for mailing.

See address on reverse

TEST YOUR CHILD



Michelle Murry

May 21, 1977 - March 16, 1998

"But my child is beyond the baby stage." Michelle Murry, age 20, had an invisible metabolic problem. She died from it shortly after climbing a mountain.

Her death was preventable.

Test your child.

Show your appreciation of Save Babies Through Screening Foundation by making a donation. Credit cards accepted.

By email: email@savebabies.org

By phone: toll free (888) 454-3383

By mail: 4 Manor View Circle
Malvern, PA 19355

Please Contact the John Walsh Show

The host of the TV show America's Most Wanted, John Walsh, now has a talk show called the John Walsh Show. We need you to contact them. Go to <http://www.johnwalsh.tv/html/tellstory.html> and click on Medical Issues; or, if you have been falsely accused of child abuse, as have a number of our readers, click on Falsely Accused. Email your story.

"The only thing that could possibly make it worse, is if it happens for no reason – if you don't create meaning to that suffering in some way. Your story is hugely compelling. It's something that people need to hear."

- Dr. Phil McGraw,
on surviving a child's death.

Quilt Panel Displayed at Professional Conferences

by Robin Haygood

The Ben Haygood quilt panel was recently displayed at two professional conferences in Mississippi. On March 3-5, 2003, Ben's quilt was displayed at the "Growing Up Healthy in Mississippi in 2003" conference in Philadelphia, Mississippi. This conference attracted various healthcare providers from throughout the state. The quilt gave a visual testimony to Ben's life and was the opener for many conversations at the Save Babies Through Screening information booth.

On March 19-20, 2003, the Haygood quilt panel was exhibited at the Mississippi Early Intervention Conference entitled "Innovation and Best Practice for Tomorrow" in Hattiesburg, Mississippi. About 350 child care professionals, teachers, education

administrators, therapists, nurses, social workers, and other health professionals from Mississippi and the surrounding southern states attended the conference.

Ben's Nanna, Sharia Brown, lovingly created his quilt panel. Families are encouraged to submit panels to celebrate the lives of their children. Participation is open to anyone who has a disorder currently detectable through newborn screening. For more information about the NBS Unity Quilt project or if you are interested in hosting a display, contact Linda Glendening, at quilt@savebabies.org or call 1-888-454-3383. Guidelines for uniformity of quilt panel construction are also on the website at www.savebabies.org/awarenessprojects/quilt.htm and can be printed for reference.

Cartwheels and Back-Flips!

Cartwheels and back-flips are happening in a couple of states with recently improved screening panels.

In Georgia they're doing cartwheels because they confirmed their very first case of Biotinidase Deficiency detected by newborn screening. Screening began May 12, 2003, just in time to detect this child.

In Oregon they're doing back-flips because they just picked up a baby with Arginase Deficiency on the routine second specimen. Oregon expanded its screening panel on October 1, 2002.

Congratulations to Georgia and Oregon on their potentially life-saving finds!

Formerly Tyler For Life Foundation

Save Babies Through Screening Foundation, Inc.

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4 Manor View Circle · Malvern, PA 19355

1-888-454-3383 ·

www.savebabies.org

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