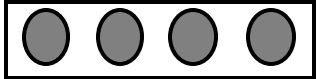


ONBAS^T News

News and Information on
Newborn Screening and Related Disorders

A Quarterly Publication by *Save Babies Through Screening* Volume 2, Issue 1



We Have A New Name!!

Trees and plants must have good care and maintenance to grow properly. Part of good care is routine pruning. Pruning is normally done to train or direct the growth of plants into a particular form or a specified space. Pruning plays an important role in improving overall health and beautifulness of a plant or tree. Pruning trims and cuts away parts of the plant allowing the plant to focus on growing in the proper form and direction.

In an effort to "grow" more in the right direction, the Tyler For Life Foundation has adopted a "doing business as" (DBA) name. The Tyler For Life Foundation is now known as *Save Babies Through Screening*. It was the feelings of the foundation's board of directors that a DBA that better stated who and what we were would better connect with people of all disciples. In particular, we are hoping to better connect with the four million families expecting babies this year.

The Tyler For Life Foundation will always be our parent company, and the boy who started it all, Tyler Wayne Mize, will never be forgotten. *Save Babies Through Screening* is a product of the enormous growth TFL has seen over the last few years and is a step towards encompassing all children that have lost their lives to newborn screening disorders. Although, TFL has always represented all children affected by newborn screening disorders, it was perceived by many as a memorial

organization to Tyler Mize only. We hope that the new name will over ride this false perception and help the organization to continue to grow and reach new levels. The name *Save Babies Through Screening* reflects exactly what NBS advocates are here to do - save babies.

We know that many of you have questions about what this change will mean to you. The main change will be remembering to refer to us as *Save Babies Through Screening*. Secondly, how you contact us has changed. The toll free telephone line and mailing address have stayed the same. However, all email and website addresses have changed. The new website is located at www.savebabies.org. You will need to update your bookmarks and web links to accommodate this change. The old website addresses (tylerforlife.com and tylerforlife.org) will automatically forward to the new site for a while. An email directory of all the new email addresses is located on the new website at www.savebabies.org/directory.htm.

Although we know that it will take a little time for all those who have known us as the Tyler For Life Foundation to catch on to calling us *Save Babies Through Screening*, we feel it will be well worth it in the end.

From all of us here behind the scenes, we are ready to *Save Babies Through Screening* and we hope you are too.

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Dallas and Tera Mize

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Newborn Screening Saves Babies One Foot At A Time[®]

Letter To The Editor

Another Child Is Lost

On March 29, 2001, I gave birth to a beautiful full-term, healthy girl. My pregnancy and delivery were normal. Nora was a very content and happy baby, developing normally. On August 9, 2001, I left her



Nora Hannelle
Waananen

Mar. 29, 2001 - Aug. 9, 2001

for the first time to attend work related training. My husband was also working and my sister was watching our children (we also have a two-year-old boy, Tommy). After training, I called home and told my sister that I was on my way. My sister told me that Nora appeared to be a little bit sleepy and was not her happy self. We were both concerned so she called the doctor. My commute home seemed like an eternity. My husband called and said that he was in the hospital with Nora. Once at the hospital, Nora quickly slipped into a coma and by the time I got there, she had already died. We were devastated!

Luckily we had a connection to the Mayo clinic, and shortly after Nora's death we found out that she had died of Long-Chain Hydroxyacyl-CoA Dehydrogenase Deficiency (LCHAD). We had never even heard of such a thing. Adding to the devastation, we found out that a simple newborn screening test not only would have saved Nora's life, but her prognosis would have been excellent. We were especially angry to find out that a simple newborn screening test could have been used to detect this early on.

We live in California and are very interested in helping to make this screening test available to everyone. We also have a 27-month-old son, whom we had checked yesterday and are now waiting for results from the Mayo clinic. We would love to do our share in helping with this cause.

Sincerely,
Sirpa and Jay Waananen
California

A Legal Perspective on Newborn Screening

By Chuck Hehmeyer

Thank you for asking me to share with your readers my thoughts about legal issues surrounding newborn screening (NBS). As you may know, I handle many cases across the U.S. involving mistreatment of children with metabolic disorders – including failure to screen and negligent screening.

NBS in the United States has been a great success on one hand, yet a great public health failure on the other. It's wonderful to see most kids with PKU and congenital hypothyroidism (CH) growing up healthy today. But it's sad that children with so many other disorders that benefit from early intervention (like Maple Syrup Urine Disease [MSUD], Medium Chain Acyl-CoA Dehydrogenase Deficiency [MCAD], Glutaric Acidemia Type I [GA-I], Galactosemia, etc.) often are not screened.

Quiz question: *How many states in our country screen today for MSUD?* (The answer is at the end of this article.)

I represent a beautiful little girl in Texas with classic MSUD who sat in a coma in the ICU of a major hospital from day seven of life until day 21 while lab studies were "pending." It is a miracle she is even alive. Of course she is now profoundly delayed. Her doctors were confused by her presentation (mistaking it for sepsis). NBS should and could have prevented the heartache of this little girl, her family and her doctors. But Texas doesn't screen for MSUD. Why?

Most of us know that Robert Guthrie pioneered NBS in the U.S. But frustrated by early American Academy of Pediatrics opposition to PKU screening (it's true, the AAP opposed PKU screening in the 1960's), Dr. Guthrie and PKU parents went straight to the state legislatures. Their compelling presentations resulted in legislated PKU screening in all 50 states, saving scores of kids over the

next 35 years from a lifetime of disability. Unfortunately, this prompted legislatures to delegate NBS oversight to state departments of health, resulting in state employees deciding the future progress and development of NBS. Since then, doctors have almost completely abdicated to public health officials' responsibility for thinking about metabolic screening.

This situation is unique to NBS and really a historical quirk due to Dr. Guthrie's decision to go directly to the legislatures. Doctors, rather than government, continue primary oversight of other medical screens like pap smears, mammographs, prostate exams, glaucoma testing, newborn and child hearing exams, etc.

While we now have uniform screening in the U.S. for Phenylketonuria (PKU) and Congenital Hypothyroidism (CH), NBS varies dramatically from state to state for the 30 or so other metabolic disorders that (1) benefit from early intervention and (2) are difficult or impossible to diagnose before a child is harmed.

Let's call it what it is: newborn roulette. Today we know that Tandem Mass Spectrometry reliably and inexpensively identifies more than 20 disorders (including MSUD) using the same blood spots Dr. Guthrie pioneered -- which are obtained from every U.S. newborn. But few states use this technology. State departments of health have proven to be poor managers of NBS systems for familiar reasons. State health officials resist innovation and protect state screening jobs -- at any cost -- from competition from private labs that do the screening more accurately and less expensively. Even when states themselves invest in tandem mass spectrometers, they engage in what amounts to on-the-job

training for the first few years (suffering unnecessary false negatives) rather than just awarding state screening contracts to experienced private labs like NeoGen in Pittsburgh.

So what can we do? Obviously parents and support groups make great advocates. I encourage all parents to lobby state legislatures, departments of health and even the media to expand screening to all disorders that benefit from early intervention. Additionally, parents of children harmed by delayed diagnosis of a controllable metabolic disorder should know that it may be possible to redress this wrong in the legal system.

The first question parents usually ask is whether we can sue the state for not screening or even to force the state to begin comprehensive screening. The answer is almost universally no. State entities are immune from suit, particularly for what the courts view as discretionary legislative and/or executive action. We live in a democracy, and lobbying and voting are the appropriate remedies for perceived mistakes in policy making by government officials. [State laboratories can be sued in some states for mistakes in the screening and reporting process itself (e.g., Ohio: yes, California: no), but, the courts will never permit lawsuits to answer what they view to be executive/legislative policy questions like what metabolic disorders to screen for.]

Although, we cannot sue states themselves for failing to offer comprehensive NBS, in some states we can sue HMOs and hospitals for failing to screen. I have filed three such suits, two in Pennsylvania and one in Texas. There is an interesting split in the U.S. Some states permit suits alleging that the whole medical profession lags behind in adopting new technology. Some don't. States

like Pennsylvania, Washington and Texas permit suits against medical professionals for not adopting clearly appropriate technology – even if none of the other healthcare providers in the state offer the technology. The argument is: Hospitals and HMOs cannot insulate themselves from liability for failing to keep up with important developments simply by uniformly failing to use them. Other states (e.g., Ohio) allow medical professionals to set their own standard of care exclusively, no matter how unreasonable. These states say, essentially, if all the hospitals do it, it's okay legally -- no matter what. (No other group but doctors gets this special treatment, by the way.)

We've made the most headway on newborn screening by suing doctors (pediatricians, neonatologists, ER and NICU doctors, etc.) for delay in diagnosis of a sick child with a metabolic disorder. When doctors realize that they wouldn't be in this position if the child had been screened, they put the heat on. In Pennsylvania we now have over 95% voluntary participation in supplemental newborn screening using tandem mass spectrometry.

The answer to the quiz question: As of July 2000, only 20 U.S. states screen for MSUD -- less than half. Pediatrics, August 2000, volume 106, No. 2 (supp.) p. 393. If the little girl in Texas with MSUD had been born in Georgia or Alaska, she would go to normal school today. But she wasn't, and she's not. Ivory tower public health officials have no problem justifying this. But

they could never explain how this makes sense to the family of that little girl. I doubt they could explain it to twelve ordinary people on a jury.

Article Written By:

Chuck Hehmeyer

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Email: chuckhehmeyer@aol.com

Charles (Chuck) P. Hehmeyer is a lawyer that has focused his entire practice to representing children with metabolic disorders in suits against HMOs, hospitals and doctors for failing to screen or failing to diagnose children with inborn errors in a timely manner. Mr. Hehmeyer is the only known US lawyer who specializes in this area. His most well known case was Summer 2000 when he defended an Amish family

(wrongly) accused of murdering their baby daughter. The family had their seven sons taken away. He became involved in the case because he thought the little girl might have had a metabolic disorder. It turned out she had a bleeding disorder because the lay midwife who delivered her did not give her a vitamin K

injection at birth. The family ultimately was exonerated and their sons were returned. Mr. Hehmeyer has filed eight cases involving children who died or were injured because they were not screened. Cases include GA-I and Propionic Acidemia cases in Pennsylvania; GA-I and MSUD cases in Texas; a Galactosemia case in Georgia; an MSUD case in Michigan (born in Ohio); an MCAD case in Pennsylvania (born in New York); and an MSUD case in Texas. Other metabolic cases are currently under review.



Attorney Chuck Hehmeyer gives a powerful speech on newborn screening (NBS) at the National Coalition for PKU and Allied Disorders conference in May 2001.

World Congress & Exposition on Disabilities Held In Atlanta

The second annual World Congress & Exposition on Disabilities (WCD) was held in Atlanta, Georgia, September 28-30, 2001. It is an annual international conference and trade event. The WCD is intended to educate, inform and provide a useful exchange of ideas for persons with disabilities and special healthcare needs and those involved in their care and development. More than 7,500 individuals attended this year's conference. Pediatricians, parents, special education teachers, advocates and many more attended the educational workshops and visited the more than one hundred displays in the exhibit hall.

The National Coalition for PKU and Allied Disorders was one of the exhibitors at this year's WCD. The National Coalition allowed the Fatty-acid Oxidation Support Group, Genetic Alliance, International Society for Glutaric Acidemia, Mercy Medical Airlift, Organic Acidemia Association, and Save Babies Through Screening (Tyler For Life Foundation) to be represented at their booth as well. Cay Welch from the International Society for Glutaric Acidemia, Marcia Dunahoo from Save Babies Through Screening and Tera Mize also from the SBTS were available at the display to greet conference attendees and to answer questions about newborn screening and related disorders.

Newsletters, fact sheets, and educational brochures were available from all the participating organizations at the booth. Supplemental newborn screening kits were provided by Baylor Medical Center for the display and were distributed to interested persons. In all over 250 supplemental newborn screening kits were handed out. The display sparked many discussions about newborn screening and the

disorders detectable through it.

Some visitors received a double dose of newborn screening information as Sigma Tau Pharmaceuticals also provided information on NBS and some of the detectable disorders. They also provided supplemental newborn screening kits from NeoGen Screening to visitors of their booth. The Sigma Tau display was located just around the corner from the National Coalition booth.

Educational workshops were held the entire weekend. Several workshops were held on newborn screening related disorders including sessions on genetic disorders, genetic counseling, metabolic disorders, mitochondrial disorders and sickle cell disease.

A 2-part newborn screening workshop was held as well. Speakers at the newborn screening session included Dr. Piero Rinaldo from Mayo Medical Laboratories and Dr. Donald Chace from NeoGen Screening. Topics in the newborn screening sessions included results of current post mortem screening, the need for more disorders to be screened for, ethical issues related to legislative mandates for screening, and outcomes of affected children when detected by screening. Dr. Rinaldo and Dr. Chace presented strong cases for expediting implementation of comprehensive newborn screening.

An open forum question and answer session concluded the conference with a panel of experts lead by Mr. Joe Valenzano, President of Exceptional Parent Magazine (www.eparent.com).

The World Congress & Exposition on Disabilities will be held next year in Orlando, Florida. You can find out more about the WCD by visiting their website at www.wcdexpo.com or by calling toll free 1-877-923-3976.

NBS Public Service Announcements (PSA's)

Public service announcements (PSA's) are educational messages that are designed to focus public attention on serious issues. PSA's are broadcast almost daily on issues such as forest fires, drug abuse, teenage pregnancy and the benefits of reading to your children. PSA's have helped educate millions of people and have helped changed attitudes and behaviors about many important issues. PSA's are useful tools that can also be a great avenue for mass education about newborn screening.

Save Babies Through Screening is working to produce newborn screening PSA's for several different media outlets, including television, radio, print, outdoor (buses, subways, billboards), and the internet. To the right you will see the latest PSA for print ad put together by Save Babies Through Screening. This ad will be used nationally in magazines and newspapers.

With many cuts in public health budgets across the country, SBTS has shifted its focus for 2002 to supplemental screening. It appears that many states will have to push back starting dates for expanded screening because of funding so SBTS has decided that the majority of our efforts this year will be raising the awareness of supplemental screening. Supplemental screening will allow for an immediate safety net to the four million babies born in the US each year. Only approximately 10% of US babies currently receive full-spectrum, comprehensive screening.

Volunteers are being asked to contact their local newspapers and have them run NBS PSA's. The PSA's are available for immediate download at www.savebabies.org/PSA.org. For more information, contact Wendy Nawn at wendy@savebabies.org or (610) 251-9876.

If You Could Protect Your Baby, *Would You?*



(We Thought So.)

Newborn screening may save your baby's life.

Although your baby received a newborn screening test, it may not have been enough. Most babies only receive partial screenings that do not tell your doctor everything.

Make Sure Your Baby Is Screened Comprehensively.

What if your baby couldn't properly use the fat his body stored? He would look normal. He would act normal. No one would ever know . . . until he got a some type of common childhood illness, like the flu, fever or a virus, and didn't feel like eating much. The doctor says don't worry, just give him plenty of fluids. But, what if that wasn't enough? What if after a few hours of not eating much, your child just stopped breathing? All because no one knew he couldn't use his body's own fat to keep his body going when he wasn't eating a lot. What if after your son died you found out that the only thing that your child needed was an IV of sugar water when he wasn't eating well?

What if I told you that exactly this happened to the little boy pictured above?

This child's name is Ben. And it did happen to him.

Comprehensive screening would have told Ben's parents and doctors of his silent, underlying condition. It would have told them that treatment was to take him to the hospital immediately for an IV when he wasn't eating well.

Children like Ben are dying all across our nation.

Ben's parents don't want this to happen to your child.

Studies Show that Comprehensive Newborn Screening may prevent up to 5% of all SIDS deaths. 1 of every 1,500 babies born has a disorder detectable though comprehensive newborn screening.

Knowing can make all the difference.

Ask Your Doctor for Supplemental, Comprehensive Newborn Screening.

For more information call us toll free at 1-888-454-3383 or visit us online at www.savebabies.org.

State Screening Program Updates

Although every state in the US has a newborn screening program, the disorders screened in each state's tests vary from state to state. Many states are moving to expand the number of disorders they screen for and implement enhancements in the existing NBS systems.

Iowa

The state of Iowa began screening all infants for the full spectrum of fatty-acid oxidation, organic acid, and amino acid disorders (urea cycle included) on October 1, 2001. Although the state hasn't specifically outlined the exact disorders it is screening for through tandem mass spectrometry (MS/MS), they are reporting all abnormal results that they find. Specific disorders will be outlined at a later date.

Georgia

The state of Georgia has begun a public and private partnership involving the March of Dimes, the Division of Public Health (DHR) and the Centers of Disease Control and Prevention (CDC) to expand newborn screening in Georgia. The Georgia March of Dimes will purchase four tandem mass spectrometry (MS/MS) machines over a four-year period, and

the Georgia DHR will provide the ongoing maintenance and staff to implement the MS/MS screenings. Actual screening is not expected to begin until at least January 2004. However, with budget cuts called for by the Governor, there are fears that the date could be pushed back even later.

Mississippi

On October 1, 2001, the Ben Haygood Law, which mandated that attending physicians for newborns must inform parents of additional screenings that are available beyond those required by Mississippi state law, went into effect. The law required that the State Department of Health develop informational materials about comprehensive newborn screening and to distribute this information to medical professionals and the public.

Missouri

On June 13, 2001, the Missouri Governor signed into law a newborn screening expansion bill. The new law requires the Department of Health to expand the newborn screening requirements by including screening for various potentially treatable disorders, including cystic fibrosis, galactosemia, and congenital adrenal hyperplasia. The bill requires

this expansion be done by January 1, 2002. The expansion, however, is subject to appropriations.

New Jersey

Screening for Biotinidase Deficiency, Congenital Adrenal Hyperplasia (CAH), and Cystic Fibrosis (CF) was scheduled to begin on July 1, 2001. Furthermore, screening for Fatty-acid Oxidation Disorders (such as MCAD, SCAD, and VLCAD), Maple Syrup Urine Disease, Citrullinemia and Arginosuccinic Acidemia is scheduled to begin by January 1, 2002. The New Jersey Newborn Screening Advisory Committee (NBSAC) is considering adding even more disorders, such as organic acidemias.

New York

New York is scheduled to start screening for Congenital Adrenal Hyperplasia (CAH), Cystic Fibrosis (CF), and Medium Chain Acyl-CoA Dehydrogenase deficiency (MCAD) in 2002. An exact start date had not been reported at the time of this publication.

How Many Disorders Does Your State Screen For?

as of September 2001

Alabama	5	Illinois	6	Montana	5	Rhode Island	8
Alaska	7	Indiana	8	Nebraska	5	South Carolina	6
Arizona	7	Iowa	6	Nevada	6	South Dakota	4
Arkansas	4	Kansas	4	New Hampshire	6	Tennessee	5
California	4	Kentucky	4	New Jersey	4	Texas	5
Colorado	7	Louisiana	4	New Mexico	6	Utah	3
Connecticut	9	Maine	26	New York	9	Vermont	7
Delaware	4	Maryland	8	North Carolina	34	Virginia	7
D.C.	7	Massachusetts	28	North Dakota	4	Washington	4
Florida	5	Michigan	7	Ohio	7	West Virginia	4
Georgia	8	Minnesota	22	Oklahoma	4	Wisconsin	26
Hawaii	7	Mississippi	5	Oregon	6	Wyoming	6
Idaho	5	Missouri	4	Pennsylvania	6		

For the most up-to-date information, visit www.savebabies.org/stateTOC.htm

Footnote . . .

"Babies are born every day, and it doesn't matter to them what the uncertain state of the nation's affairs may be. These babies will be born with these disorders, whether they are screened or not. We can choose to protect them, or we cannot. I choose to protect them."

-Wendy Nawn, mother to Alex, who has MCAD and was screened at birth through supplemental screening.

The Ins & Outs of Supplemental Screening

If your state does not screen for the full spectrum of disorders, you should consider getting supplemental newborn screening. This screening is in addition to the screening required by your state. Supplemental screening will ensure that your child receives the full screening that is currently available. You can find out how many disorders your state screens for on page 6 of this newsletter.

Cost for supplemental screening is approximately \$25-\$100 depending on which laboratory you get the screening from. Most families pay for this testing out of pocket, but some insurance companies may cover the cost of supplemental screening. You should check with your insurance company to find out whether or not they cover it.

Where to Get Supplemental Screening Test Kits

You can get a free supplemental newborn screening testing kit by contacting the following laboratories:

Facilities offering comprehensive screening for ALL disorders:

- **NeoGen Screening**
Phone: 1-866-463-6436
www.neogenscreening.com
- **NewScreen**
Phone: 1-800-747-3319
www.newscreentest.com

Facilities offering screening for some disorders only:**

- **Baylor University Medical Center**
Phone: 1-800-422-9567
www.baylorhealth.com/newbornscreening
- **Mayo Medical Laboratories**
Phone: 1-800-533-1710
www.mayo.edu/mml

NOTE: Babies that are born in the states of Massachusetts, Wisconsin & Maine should receive full screening in their state's routine newborn screening test.

How to Get Supplemental Newborn Screening

- Call one of the laboratories listed above to receive a free test kit.
- Give the kit to your doctor and let him or her know you would like to have an extra blood sample drawn at the time of your baby's routine newborn screening.
- Include payment for the test when the specimen is returned to the laboratory.

If there is anything abnormal with your child's test, the laboratory will telephone your doctor immediately. Your doctor will contact you with directions on what to do. Normal results are mailed back to the physician within 2-3 weeks. If you do not receive results from your child's physician, you should telephone the office to follow-up on the results of the test. This step is true for both supplemental screening through private laboratories and the state required newborn screening test. Follow-up on your child's test results (both tests) to ensure your child doesn't fall through the cracks.

Older children can also be screened through supplemental newborn screening. Contact the laboratories listed above for specific directions.

It is best to discuss supplemental screening with your pediatrician prior to your child's birth. Because supplemental screening was not available everywhere until recently, your doctor may not know about supplemental screening. You may have to educate your doctor on supplemental screening and provide him or her information on it.

Key Facts You May Not Have Known About Newborn Screening

- Approximately 1 out of every 1,500 babies born has a disorder detectable through newborn screening.
- Less than 10% of babies born in the US currently get comprehensive screening for all detectable disorders.
- Six babies are born every day in the US alone that have disorders detectable through newborn screening, but go undetected because they aren't screened.
- Newborn screening can detect more than 35 disorders.
- Studies have linked disorders detectable through newborn screening to be the cause of 5% of Sudden Infant Death Syndrome (SIDS) cases.
- Most disorders detectable through newborn screening are treated by diet restrictions.
- More than 15-30% of children in the first year of life with undiagnosed MCAD will die in their first crisis. This number then gradually increases as more than 50% will die in their first crisis if the first crisis happens after 2-3 years of age.
- The newborn screening test is commonly called the "PKU test" as PKU was the first disorder found to be detectable through the newborn screening test.
- Newborn screening first began in the United States in the 1960's.

Have a Heart Fundraiser *Short Stature Study*



Save Babies Through Screening is again offer window clings this February to show your support of NBS.

The clings are in the shape of a red heart and carry the text "I gave my heart to a baby!" The clings are removable and attach to glass, such as windows and windshields.

Help support NBS activities by participating in this fundraiser. Clings are available for a suggested donation of \$5 each (includes shipping and handling).

To get clings, send your name, mailing address, phone number, and quantity of clings along with check or money order made payable to:

Save Babies Through Screening
5335 N. Helton Road
Winston, GA 3018

With your help in this fundraising drive, we can continue to help *save babies one foot at a time.*

The Children's Hospital of Denver is conducting a study involving patients with Methylmalonic Acidemia (MMA) and Propionic Acidemia (PA) who are short. Several patients with MMA and PA have been found to have growth hormone deficiency thus investigation is being done to see if the growth hormone deficiency is responsible for the short stature in these patients.

The study is open to patients with either MMA or PA between the ages of 2-18 years old and whose height is below the 5% percentile for their age.

Persons interested in participating in the study should contact their local metabolic doctor and advise him or her of the study and your willingness to participate. Then the metabolic doctor should contact the metabolic division at the Children's Hospital in Denver at (303) 861-6847.

Grassroots Fundraising Is Instrumental

Although SBTS is seeking grants from corporate sponsors and businesses, the grassroots fundraising efforts of volunteers are instrumental to see that we can continue our efforts in newborn screening.

Please join our volunteers in our ongoing fundraising campaign to raise funding for advocacy, education and research projects. These projects are instrumental in helping to protect children born with disorders detectable through newborn screening. All types of fundraising are welcome. Here are a few ideas:

- Walkathons
- Bike Rides
- Family Fun Days
- Wine Tastings
- Treasure Hunts
- Animal or Car Shows
- Birthday Parties
- Potlucks Dinners or Picnics
- Luncheons or Dinners
- Auctions
- Bake Sales
- Variety Shows
- Sports Tournaments (golf, softball, bowling, soccer, etc.)
- Garage or Yard Sales
- Car Washes
- Campouts
- Krispy Kreme Donut Sells
- Raffles
- Tupperware or Pampered Chef Parties

For more information about hosting a fundraising event, contact fundraising@savebabies.org.

WANTED: Items For Online Charity Auction

An online auction is being held to benefit Save Babies Through Screening. The auction will be held on the Ebay website. We are currently requesting donations of items for the charity auction. All proceeds from the auction will benefit SBTS and our efforts in newborn screening. Items that have already been donated and are up for bid are available for viewing from the SBTS website at www.savebabies.org/auction.htm.

Items such as toys, books, collectibles, software, quilts, handmade items (such as baskets), etc. would be most appreciated. This is a great way to clean your closets & garages and help our organization continue to save babies one foot at a time. All contributions of items are tax

deductible.

Please send items for the auction, along with a photo of each item, to:

Laura Clow
109 Lilac Lane
Mabank, TX 75147

For more information on how to participate, please contact Laura Clow at auction@savebabies.org. In addition, you may want to visit the Ebay website at www.ebay.com for other ideas of items that are often offered for auction.

Many thanks to Laura Clow for volunteering to organize this auction and to all who have already donated and purchased items.

Footnote . . .

"While we continue to talk and talk and talk, children are dying."

-Robin Hayhood, mother of Ben, who died from undiagnosed MCAD at 2½

A Common Mission

By Janine Clay

Peggy Harris and Jennifer Heberer live on opposite sides of the United States, but they have a common mission--to save the lives of babies through expanded/comprehensive newborn screening. Both women volunteer as State Coordinators in a national effort to monitor the status of newborn screening and to promote expanded screening in their states: Peggy in the state of Washington and Jennifer in Maine. Each is a member of her state's Newborn Screening Advisory Committee. Both have a deep personal commitment because of affected children in their own families.

Malik Lewis, age 3 1/2, and his sister D'Anyia, age 2, both have sickle cell disease, and Malik also has Isovaleric Acidemia. They are Peggy's grandchildren. Jennifer's daughter, Ella, nearly 3 years of age, has Tyrosinemia Type I. All of their disorders are detectable through newborn screening. These beautiful children provide the inspiration and motivation for two people, separated by 3000 miles, to pursue their common goal.

There are 45 other State Coordinators, some working in teams and others working as individuals, throughout the U. S. Some have children who suffer with metabolic disorders, while others just want to help save babies. Would you like to join them? We need State Coordinators in Alabama, Arkansas, Illinois, Iowa, Kansas, Louisiana, Massachusetts, Nevada, New Hampshire, New York, North Dakota, Oklahoma, Pennsylvania, Rhode Island, South Dakota, Vermont, West Virginia, and Washington, D.C. If you have the passion to save babies through newborn screening and would like to volunteer as a State Coordinator, please contact Jacque Bradford, Program Director, by emailing jacque@savebabies.org or call 1-888-454-3383. Peggy and Jennifer will applaud your decision!

NBS Unity Quilt Panel makes a trip to Washington DC

By Heather Brown

The Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD) quilt panel honoring, Ben Haygood, was on display during the National Society of Genetic Counselor's 20th Annual Education Conference held in Washington, DC from November 4-7, 2001. Nearly 1,000 genetic counselors were in attendance to learn about recent developments in medical genetics, anticipated advances in comprehensive genetic testing, and new complexities in counseling issues.

The quilt and Ben's story made a lasting impression and were an ideal prelude to the short course about the counseling and management of metabolic disorders, which followed the regular program. The purpose of the short course was to provide a comprehensive review of a variety of inborn errors of metabolism. Emphasis was placed on understanding the status of current biochemical and molecular testing options, treatment and medical management, and counseling strategies aimed at assisting families in coping with the medical implications and psychological impact of metabolic disease.

Genetic Counselors left the conference equipped with the scientific knowledge and personal perspective needed to integrate this new information into their clinical practice.

Quilt Panel Displayed at Pediatrics Conference

By Amy Seirer

A panel from the Newborn Screening Unity Quilt was displayed

at the American Academy of Pediatrics conference in San Francisco, October 20-22, 2001. The panel, featuring Ben Haygood's story—a little boy who was lost to MCAD, was displayed in the NewScreen: Expanded Newborn Screening booth to promote awareness about the importance of comprehensive newborn screening. The quilt panel was successful in giving a face to the so-called rare disorders that are not included in many state-mandated screening programs. "For many doctors, reading Ben's story gave them a new perspective about newborn screening," says Neeta Patel, a representative from NewScreen who attended the show. "Doctors were touched by his story."

The conference attracted nearly 6,000 attendees and also featured an expanded newborn screening talk by Dr. Ed McCabe, professor and executive chair at the UCLA Department of Pediatrics. Dr. McCabe mentioned "Ben's Bill," Mississippi legislation spearheaded by Vince and Robin Haygood that requires patient education about comprehensive newborn screening.

NewScreen offers a simple screening for more than 50 metabolic disorders and is available to all babies born in the U.S., regardless of what state they are born in.

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NBS Related Events

February 2002

February 13-14, 2002

National Institute of Health (NIH) - Secretary's Advisory Committee on Genetic Testing (SACGT) Meeting
Web: <http://www4.od.nih.gov/oba/sacgt/sacgtmtg.htm>
Bethesda, Maryland

February 14-19, 2002

American Association for the Advancement of Science (AAAS) - Annual Meeting and Science Innovation Exposition
More Info: (202) 842-1065
Web: www.aaasmeeting.org
Boston, Massachusetts

May 2002

May 1 - 30, 2002

Tyler For Life Foundation - Annual Mother's Day Fundraising Drive
Contact: fundraising@savebabies.org

May 13-14, 2002

National Institute of Health (NIH) - Secretary's Advisory Committee on Genetic Testing (SACGT) Meeting
Web: <http://www4.od.nih.gov/oba/sacgt/sacgtmtg.htm>
Bethesda, Maryland

June 2002

June 6-9, 2002

United Mitochondrial Disease Foundation - Joint Medical/Patient Symposium
More Info: (412) 793-8077
E-mail: info@umdf.org
Web: www.umdf.org
Dallas, Texas

June 7-9, 2002

National Urea Cycle Disorder Foundation (NUCDF) - Annual Family Conference
More Info: (800) 38NUCDF
Web: www.nucdf.org
Orlando, Florida

June 9-11, 2002

Association of Public Health Laboratories - Annual Meeting
Web: www.aphl.org
Albuquerque, New Mexico

June 26- 29, 2002

International Society for Neonatal Screening - 5th Meeting
"Neonatal screening from the spot to diagnosis and treatment"
Web: www.isns-neoscreening.org
Genova, Italy

July 2002

July 22-24, 2002

National Healthy Mothers Healthy Babies Coalition - Biennial Partnership Conference
More Info: (813)974-6682
Web: www.hmhb.org
Clearwater Beach, Florida
NOTE: *Tyler For Life Foundation President, Tera Mize, will be speaking at a newborn screening session of this event. Other speakers for this NBS session are Calvin & Tricia Luker and Pierre Rinaldo, MD.*

August 2002

August 15-16, 2002

National Institute of Health (NIH) - Secretary's Advisory Committee on Genetic Testing (SACGT) Meeting
Web: <http://www4.od.nih.gov/oba/sacgt/sacgtmtg.htm>
Bethesda, Maryland

September 2002

September is Newborn Screening Awareness Month and Sickle Cell Awareness Month

NBS Unity Quilt Awards Ceremony
Phone: 1-888-454-3383
Web: NBS Unity Quilt
further information yet to be released

September 17-22, 2002

Sickle Cell Association of America - Annual Meeting
The meeting will be held jointly with the NIH.
Web: www.sicklecelldisease.org
Washington, DC.

October 2002

October is SIDS Awareness Month

November 2002

November 9-13, 2002

American Public Health Association - 130th Annual Meeting & Exposition
Contact: Lynn Schoen
More Info: (202) 777-2479
Web: www.apha.org
Philadelphia, Pennsylvania

November 21-22, 2002

National Institute of Health (NIH) - Secretary's Advisory Committee on Genetic Testing (SACGT) Meeting
Web: <http://www4.od.nih.gov/oba/sacgt/sacgtmtg.htm>
Bethesda, Maryland

Nurse Practitioner Donates Time To Help Save Babies

By Robin Haygood

Deborah Whitehead, FNP, was recently recognized by the Tyler for Life Foundation (now known as Save Babies Through Screening) for her contributions to expanded newborn screening. Nurse Whitehead's medical practice, The Sherman Family Clinic, is located in Sherman, Mississippi. After the passage of Ben's Law during the Spring of 2001, Nurse Whitehead offered to provide supplemental screening at her clinic without charging for a routine office visit. Then, her office will help provide follow-up by calling the parents after the results are received from the lab. Many thanks to Nurse Whitehead and her commitment to help save babies through screening.



Pictured (from left to right) Robin Haygood, Lori Haygood, Sharia Leslie-Brown, and Nurse Whitehead

A Special Thank-you to Our 2001 Donors

Thank you for your generous support. Your contributions are what allows us to continue to help save babies.

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Mary Thorson

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Jane and Kirk Wilson

*In kind Contributions
List as of 11-1-2001

Donations were made in memory of:

Andrew Dylan Plaistad
Ben Vincent Haygood
Jacob Shamboo
Lorriane Hill
Preston Cole Williams
Tyler Wayne Mize

Donations were made in honor of:

Alex Nawn
Brett Revinski
Brett Rosen
Caitlyn and Alec Kerr
Haylee Thurman
Joshua and Matthew Hammer
Josias Wilson
Malik Lewis
Melissa Stagni
Nicole Weber
Wendy Thorson
William Farmer

NOTE: If you would like your donation to be made in memory or in honor of someone, please note this along with the person's name on the memo line of your check.

Your Tax Rebates Can Help Save Lives

It's that time of year again . . . *tax time*. Many of us will be seeing extra money in our mailboxes from tax refunds. **Why not donate your refund, or at least a portion of it, to Save Babies Through Screening and help save babies?**

By donating your rebate check to SBTS, you will be funding awareness projects, such as the printing of newborn screening pamphlets and supporting the SBTS website, which has become a clearinghouse of information for parents, medical professionals, and others seeking knowledge of newborn screening and the issues surrounding it. Please donate a portion of your tax rebate check to help us continue to ***Save Babies One Foot At A Time.***

To make a donation, you may send your check or money order payable to:

**Save Babies Through Screening
5335 N. Helton Road
Winston, GA 30187**

Or you may donate online via credit card from our website at www.savebabies.org/contribute.htm.

And for even more tax savings next year, all donations are tax deductible!!!

Volunteer Spotlight

CINDY HOEK

Charlotte, North Carolina

Cindy Hoek got involved in newborn screening volunteerism because she has a friend with a child with MCAD. She found our organization while doing research on the internet about the condition and offered her time any way we needed. Cindy became our database manager and handles all our mailing lists, including the one this newsletter is sent to. Cindy has developed databases of state NBS programs, US follow-up clinics, disorder support groups, and much more. Although many of you may not have corresponded with Cindy directly, she is the person that enables us to correspond at all!!! Thank you Cindy. You're great!!!

About Us

The Tyler For Life Foundation was created in 1998 by a family who lost their infant son, Tyler, to a treatable inherited disorder detectable through newborn screening. Had Tyler been screened properly, he would have likely lived a normal, healthy life. In 2001, the Tyler For Life Foundation adopted the name Save Babies Through Screening in an effort to better connect with the general public.

Since its creation, SBTS has strived to provide information on newborn screening to parents and the medical community. The organization is a non-profit organization operated solely by volunteers.

SBTS provides services such as a toll free information line, a quarterly newsletter, a monthly online newsletter, announcement email list, discussion list servs, informative publications, public awareness campaigns, national public service announcements, advocacy materials, NBS unity quilt, and supporting research.

Every second counts in the life of a child affected by a metabolic disorder. It is our hope that Save Babies Through Screening will help prevent other families from having to endure the pain of losing their child needlessly, maybe even yours.

Volunteers Visit Maryland NBS Laboratory

From TFL Volunteer and Galactosemia Parent, Therese Cozzo

On March 7, 2001, Bill and I (and our son Vincent) visited out state newborn screening lab on behalf of the Tyler For Life Foundation where we distributed newborn screening awareness pins. It was a wonderful experience. I hope you have been able to recruit volunteers for other states. I think the lab employees really appreciated hearing our story and learning about the Tyler For Life Foundation (now known as Save Babies Through Screening). Employees were also happy to be "thanked" for their work.

At our visit we presented a brief overview of the Tyler For Life Foundation and we shared our own story of how effective newborn screening saved our son's life (he has galactosemia).

Prior to our presentation to the NBS lab employees, we met with Linda Corcoran, Program Director for the Maryland NBS Laboratory, Dr. J. M. Joseph, Director of Laboratory Administration, and Dr. Jagdish Patel, Chief, Division of Virology Immunolgy and Hereditary Disorder Program. Most of the laboratory employees were able to attend this presentation. There were approximately two-dozen people in

attendance in all.

After our presentation, our son Vincent handed out the Tyler For Life newborn screening appreciation pins to all of the employees. In addition, we brought in cookies as an added thank you.

We were greeted with warmth and appreciation. It was a wonderful experience. We were also given a tour of the laboratory, which was quite interesting. Maryland is currently screening for eight disorders, but is likely to add more disorders to the list soon. We discussed with Dr. Joseph the need for comprehensive newborn screening and faster turn around time. Dr. Joseph shared with us some of the changes that Maryland might be looking into in the near future to improve turn around time.

Thank you Therese, Bill and Vincent for putting faces behind the bloodspots.



Left to Right: Therese Cozzo, Dr. J. M. Joseph, Vincent Cozzo, Bill Cozzo

Save Babies Through Screening

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