



# NEWBORN SCREENING:

*Saving Babies One Foot At A Time*

# Tyler's Tribune

A Quarterly Publication by the Tyler For Life Foundation

## From the President

Welcome to the first ever edition of *Tyler's Tribune*. This publication is written to facilitate communication between newborn screening programs, support groups, and consumers - parents. We welcome articles and input from all aspects of newborn screening - laboratories, follow-up personnel, administrative staff, and families. If you have an article or a letter to the editor that you would like to include in the next issue of *Tyler's Tribune*, please email them to [teri@tylerforlife.com](mailto:teri@tylerforlife.com) or snail mail them to Tyler For Life Foundation, 6340 Holborne Lane, Douglasville, GA 30134. We hope you

enjoy and learn from this publication. Now that the holidays are over and we are all making New Year's Resolutions, try adding Advocate for Newborn Screening to your list. You can do this in simple ways such as sharing your story with the person behind you in the grocery store line or visiting your state's newborn screening laboratory. Many people have become active in advocating for newborn screening by working to educate the public and medical professionals on the benefits of *comprehensive* newborn screening, but we still have a lot of work to do. Many

people still do not know what newborn screening is, nor what more it can be. By sharing your story with your neighbor, an acquaintance, your OB/Gyn, you are putting a face and reality with the issue. It's not just another issue someone reads about in the paper or hears about on the news - it's something that happens to real people close to home. It's this kind of activity that will help our children now with these disorders and the children that will be affected by these disorders in the future.

Again hope you enjoy this newsletter. Take care and God bless.  
Tera Mize, TFL President

## More Hospitals Begin Supplemental Screening

Holy Cross Hospital in Fort Lauderdale, Florida recently started supplemental NBS on their babies after the urging of a member of their medical staff. Pediatrician Dr. John E. Wright has offered the screening to his private patients for over five years. Dr. Wright is a pediatrician with the Holy Cross Medical Group and recommended that

Holy Cross offer the screening to the babies born there. Holy Cross started screening babies last summer. Virtua Health System in New Jersey has also started offering parents the opportunity to have their child screened through comprehensive newborn screening, becoming the first health system in New Jersey

to offer such screening. Virtua Health System delivers some 7,000 babies each year and will offer the screening at no cost to all babies born there. The cost for the screening, about \$20 per baby, is being paid for by contributions from the system's doctors and hospitals. There will not be any charges for the testing to patients.

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# Winter Featured Disorders of the Month

Each month the Tyler For Life Foundation "features" a disorder detectable through newborn screening and a family/individual affected by the disorder. Disorders are randomly chosen and families are then chosen to be featured in this segment. This project was implemented to help raise awareness about the disorder and illustrate the human side of newborn screening. The full stories are available online at [www.tylerforlife.com](http://www.tylerforlife.com).

The January 2001 featured disorder of the month is biotinidase deficiency. William Farmer was born in Georgia where biotinidase deficiency was not included in the state mandated NBS panel. William, who appeared to be a normal, healthy child, began to slowly lose the ability to walk or even sit up. William had to undergo months of doctor's visits and hospitalizations before anyone figured out what was wrong with him.

William had biotinidase deficiency. William is expected to make a full recovery with consistent physical therapy and continual treatment of his biotinidase deficiency - a daily dose of Vitamin Biotin. William's mother, Laurie, has advocated strongly to have biotinidase deficiency mandated in all state NBS panels. The March of Dimes included this disease as one of the 8 disorders they recommend as being the minimum screened for in every state.

The parents of Jonathon Spencer Oliphint noticed delays in his development when he was 4 months old, and continued to notice them as he grew older. Doctors repeatedly told his parents not to be concerned. At 3 years old, Jonathon began to stare off in space and be oblivious to the world for periods of time. After many medical tests were run, Jonathon was found to have a urea cycle disorder called Argininosuccinic

Aciduria (ASA). ASA is treated with a low-protein diet. Jonathon is the February 2001 featured story.

Josias (Joey) Wilson, who has Glutaric Acidemia Type I (GA-I), is the March 2001 featured disorder of the month. GA-I is detectable through expanded newborn screening using tandem mass spectrometry. Because Joey was not screened through expanded newborn screening, even though he was born only minutes from one of the 2 laboratories that offered the screening in the US at that time, his GA-I went undiagnosed until he was 7 months old. By this time Joey had suffered irreversible brain damage leaving him unable to ever walk, talk or even swallow. He is fed through a tube in his stomach and his prognosis is very dim. Dr. Holmes Morton of Pennsylvania treats many Glutaric Acidemia children and has a high success rate when they are screened at birth.

## Those Who Are Not Forgotten

**Storm Tyler Hall**  
5/27/99 - 5/28/99  
VLCAD  
Albuquerque, New Mexico

**Eric Michael Bradford**  
8/22/90 - 8/26/90  
MCAD  
Indianapolis, Indiana

**Candice Lingle**  
Feb. 21, 1991 - Nov. 8, 1993  
MCAD  
Tyler, Texas



By Mikaela Hall

**Tiger Jordan Hall**  
9/23/96 - 9/25/96  
VLCAD  
Albuquerque, New Mexico

**Ashley Marie Bray**  
10/2/00 - 10/11/00  
LCHAD  
Madera, California

**Trace Garrett Southard**  
May 2, 2000 - Aug. 26, 2000  
UNCLASSIFIED FOD  
Macclenny, Florida

**Amy Elizabeth Barnes**  
02/20/95 - 19/27/95  
LCHAD  
San Mateo, California

**Jennifer Lee Patrick**  
7/21/86 - 11/16/86  
CARNITINE DEFICIENCY  
San Diego, California

**Skyler Wendell Bryson**  
Nov. 25, 1989 - Aug. 25, 1990  
LCHAD  
Kaysville, Utah

**Ben Vincent Haygood**  
Feb. 19, 1998 - August 8, 2000  
MCAD  
Belden, Mississippi

**Noah Jon Cooper**  
10/10/97 - 06/30/98  
LCHAD  
Jacksonville, Florida

**Jordan Michaud**  
2/19/97 - 3/21/98  
UNCLASSIFIED FOD  
Plainville, Connecticut

**Luke Timothy Aalberts**  
June 7, 1994 - May 1, 1995  
MCAD  
Holland, Michigan

**Katherine Melendres**  
March 6, 2000 - May 3, 2000  
CPT II or TRANSLOCASE  
Fontana, California

**Tyler Wayne Mize**  
5/1/98 - 5/10/98  
GALACTOSEMIA  
Atlanta, Georgia

**Jiovanni Andrew Sandate**  
3/20/00 - 3/29/00  
CPS  
Denver, Colorado

**Sarah Ann Hall**  
June 25, 1998 - July 30, 2000  
MCAD  
Paris, Missouri

**Michael Paul Barilla**  
Feb. 2, 1990 - Nov. 25, 1990  
MCAD  
Cleveland, Ohio

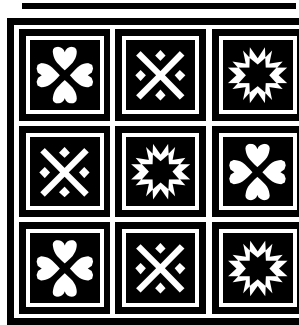
# NBS Unity Quilt : *A Celebration of Rarity*

The Tyler For Life Foundation is coordinating a NBS Unity Quilt that will be displayed all across the country starting next September. The NBS Unity Quilt will allow families to celebrate and share the lives of their children who were born with disorders detectable through newborn screening, including both the children spared and lost.

The mission of the NBS Unity Quilt is to create a visual testimony of the most compelling symbol of newborn screening - the children touched by it. Participation is open to families with children or individuals with disorders currently detectable through newborn screening.

The Quilt can be a heartfelt tool in the fight for proper NBS. The Quilt will be displayed across the United States in medical schools, hospitals, newborn screening laboratories, businesses and corporate offices, and numerous other related forums.

The quilt will be displayed each year during the month of September, which has been declared as Newborn Screening Awareness Month. The first unveiling of the quilt will be on September 1,



Participation is open to anyone with a disorder detectable through NBS.

2001. Once the September month is over, the quilt will begin its way across the country on display at various locations. A full display schedule will be released at a later date.

For more information about the NBS Unity Quilt project, you can contact the project director by email

at [unityquilt@tylerforlife.com](mailto:unityquilt@tylerforlife.com) or by phone at 1-888-454-3383.

Information is also available on our website at [www.tylerforlife.com](http://www.tylerforlife.com).

## Children's Health Act of 2000

On October 17, 2000, President Bill Clinton signed into law the Children's Health Act of 2000. This bipartisan legislation authorizes expanded research for a variety of childhood health problems, including disorders detectable through newborn screening. Title XXVII, Section 2802 of the law specifically talks about the review of treatment for PKU and other metabolic disorders, including formula and other

items necessary for optimal outcome of treatment. Currently, research is being done on these disorders to decide if the federal government should amend current law to include coverage for formula for metabolic disorders.

Furthermore, Title XXVI, Section 1109 of the legislation outlines a plan to improve newborn and child screening for heritable disorders, and establishes monies for

states to establish, expand, or improve newborn screening systems. A federal advisory committee will also be established as outlined in Title XXVI, Section 1111 of the law. To date, no appropriations have been made for the legislation. A full copy of the bill is available online at <http://thomas.loc.gov> and searching by bill number HR 4365. You can also contact your local legislator's (federal) office for more information.

## 1st Annual TFL Softball Tournament

The First Annual Tyler For Life Foundation Softball Tournament and Fun Day Fundraiser was held September 30, 2000 at Fairplay Park in Winston, Georgia.

The tournament was a great success and raised much needed funds for the foundation.

Many thanks to all the volunteers, sponsors and the teams that played in the tournament.

A super thank you to Amanda Crosby for coordinating the event and to "Star" the clown who flew in from Memphis, TN for the event.

Also, a special thank you to World Championship Wrestling (WCW) Superstar Marcus "Buff" Bagwell for his personal appearance



and autograph signing at the tournament.

Again, many thanks to all who helped make this tournament a success.

The tournament is planned as an annual event with the next one being scheduled for Summer 2001.

# Newborn Screening Q&A

## What Is The NBS Test?

This test is called the newborn screening test but often is referred to as the "PKU" or "NBS" test. It tests babies for serious hereditary disorders. Most states currently screen for between 3 and 8 disorders. A relatively new method of screening using tandem mass spectrometry allows for screening of more than 30 additional disorders.

## How Is The Blood Test Performed?

The test is performed by pricking your baby's heel and putting a few drops of blood on a special filter paper. The paper is allowed to dry and then sent to the laboratory where several different tests will be performed. The results of these tests will be sent to your hospital and/or doctor. If your child's test shows an abnormal result, you will be notified immediately and given directions on what to do. Follow the directions of your doctor very carefully. Usually additional tests will be necessary to determine if your child has the disorder. It is important the NBS be performed on your child between the age of 24 hours & 48 hours old.

## Does My Baby Have To Have A Newborn Screening Test Done?

Yes. Each state has different laws surrounding newborn screening in their state. However, most require that at birth every baby must have a blood test done between 24-48 hours of age or before going home from the hospital. Some states also require that if your baby is discharged from the hospital before 48 hours of age, your baby will be required to have a repeat test. The repeat test can be done by the hospital, the doctor, or the health department. Some

providers can even arrange to come to your home to perform the test.

## Why Is The Test Done?

The test is done to find out if your baby has inherited a disease or condition for which early treatment can prevent death or mental retardation. For example, mental retardation can be avoided for babies who have some of these disorders simply by changing the baby's milk within a few days after being born. It is very important that your baby is tested as soon as possible. Parents who have no family history of problems and/or who have already had healthy children can still have children with these disorders. In fact, most children with these disorders come from families with no previous history of the condition. It is important that all babies be screened for these diseases so that they can be identified and started on treatment early.

## What Is The Chance My Baby Will Have One Of These Disorders?

Most of the disorders screened for in the newborn screening are rare by themselves, but altogether the incidence of the disorders detected through expanded newborn screening is 1 of every 1,500. This means that 1 of every 1,500 babies born has a disorder detectable through a newborn screening test.

## How Many Disorders Can Be Screened For In NBS?

Currently used technologies can allow more than 40 disorders to be detected in newborn screening using the same specimen.

## What Disorders Are Normally Screened For In Our State's

### "Regular" Newborn Screening Test?

The disorders screened for are different in

every state. Most states currently screen for 3-8 of the following disorders:

- Biotinidase Deficiency
- Congenital Adrenal Hyperplasia (CAH)
- Galactosemia
- Homocystinuria
- Hypothyroidism
- Maple Syrup Urine Disease (MSUD)
- Phenylketonuria (PKU)
- Sickle Cell Disease & Hemoglobinopathies
- Tyrosinemia

See page 5 to see what your state screens for.

## How Can I Get My Baby Tested For All Of The Disorders If My State Only Screens For A Few?

Most states and hospitals do not offer expanded screening. If expanded screening is not available through your state or your hospital, you can obtain a screening kit by contacting either of the following laboratories:

- **Baylor Medical Center**  
1-800-4BAYLOR  
[www.baylorhealth.com/newbornscreening](http://www.baylorhealth.com/newbornscreening)
- **NeoGen Screening**  
1-866-4NEOGEN  
[www.neogenscreening.com](http://www.neogenscreening.com)

It is best to discuss the screening with your pediatrician and obtain a screening kit prior to delivery.

## How Much Does It Cost To Have My Child Tested Through Expanded Newborn Screening?

Cost of expanded newborn screening using tandem mass spectrometry is approximately \$25. Screening kits should be obtained prior to delivery and taken to the hospital with you.

Learn more at [www.tylerforlife.com](http://www.tylerforlife.com) or by calling 1-888-454-3383.

# National Coalition Launches Website

The National Coalition for PKU and Allied Disorders launched its website in August 2000. The long awaited website provides useful information for disorders treated by a low protein diet, on the Robert Guthrie Scholarship program, and on newborn screening.

The National Coalition was formed in 1998 and is a nonprofit organization comprised of individuals,

metabolic support groups and professionals directly involved with issues related to inborn errors of metabolism requiring low protein diet including, Phenylketonuria, Maple Syrup Urine Disease, Homocystinuria, Organic Acidemias, Urea Cycle Disorders, and Tyrosinemia.

The National Coalition seeks to improve identification, treatment and management of PKU and Allied

Disorders, and improve the lives of people with these disorders through advocacy, education, support, promotion and support of research, and services.

The website can be found at [www.pku-allieddisorders.org](http://www.pku-allieddisorders.org). You can also reach the Coalition at 1-877-996-2723. The Coalition is planning their first ever conference on May 4 & 5 in Columbus, Ohio.

# What Does Your State Screen For In NBS?

	PKU	CH	GALT	MSUD	HOMO	BIO	SCD	CAH	TYRO	CF	MCAD	TOXO	G6PD	# MS/MS	TOTAL
Alabama	•	•	•				•	•							5
Alaska	•	•	•	•		•		•							6
Arizona	•	•	•	•	•	•	•								7
Arkansas	•	•	•				•								4
California	•	•	•				•								4
Colorado	•	•	•			•	•			•					6
Connecticut	•	•	•	•	•	•	•	•							8
Delaware	•	•	•				•								4
D.C.	•	•	•	•	•		•						•	1	7
Florida	•	•	•				•	•							5
Georgia	•	•	•	•	•		•	•	•						8
Hawaii	•	•	•	•		•	•	•							7
Idaho	•	•	•	•		•									5
Illinois	•	•	•			•	•	•							6
Indiana	•	•	•	•	•		•								6
Iowa	•	•	•				•	•							5
Kansas	•	•	•				•								4
Kentucky	•	•	•				•								4
Louisiana	•	•				•	•								4
Maine	•	•	•	•	•	•		•			•				8
Maryland	•	•	•	•	•	•	•		•						8
Massachusetts	•	•	•	•	•	•	•	•		b	•	•		19b	29
Michigan	•	•	•	•		•	•	•							7
Minnesota	•	•	•				•	•							5
Mississippi	•	•	•				•								4
Missouri	•	•	•				•								4
Montana	•	•	•												3
Nebraska	•	•	•			•	•								5
Nevada	•	•	•	•		•	•								6
New Hampshire	•	•	•	•	•										5
New Jersey	•	•	•				•								4
New Mexico	•	•	•			•	•	•							6
New York	•	•	•	•	•	•	•								8
North Carolina	•	•	•				•	•			•			33	39
North Dakota	•	•	•					•							4
Ohio	•	•	•		•		•								5
Oklahoma	•	•	•				•								4
Oregon	•	•	•	•		•	•								6
Pennsylvania	•	•		•			•								4
Rhode Island	•	•	•	•	•	•	•	•							8
South Carolina	•	•	•				•	•							5
South Dakota	•	•	•												3
Tennessee	•	•	•				•	e							4
Texas	•	•	•				•	•							5
Utah	•	•	•												3
Vermont	•	•	•	•	•	•	•								7
Virginia	•	•	•	•	•	•	•								7
Washington	•	•					•	•							4
West Virginia	•	•	•				a								3
Wisconsin	•	•	•			•	•	•		•	•			13	21
Wyoming	•	•	•	c		•	•			•					6
Baylor	•			•	•				•				•		28
NeoGen	•	•	•	•	•	•	•	•		•	•		•	28	39

**DISORDER ABBREVIATIONS:** PKU—Phenylketonuria; CH—Congenital Hypothyroidism; GALT—Galactosemia; MSUD—Maple Syrup Urine Disease; HOMO—Homocystinuria; BTD—Biotinidase Deficiency; SCD—Sickle Cell Disease & Hemoglobinopathies; CAH—Congenital Adrenal Hyperplasia; TYRO—Tyrosinemia; CF—Cystic Fibrosis; MCAD—Medium Chain Acyl CoA Dehydrogenase Deficiency; TOXO—Congenital Toxoplasmosis; G6PD—Glucose-6-phosphate Dehydrogenase Deficiency; MS/MS—Tandem Mass Spectrometry Screening Method

**REFERENCES:** a = selected population only; b = pilot program; c = planning underway; d = mandated; not yet implemented; e = considering

# Calendar of Events—Winter & Spring 2001



February 15-20

**American Association for the Advancement of Science**

*Annual Meeting and Science Innovation Exposition*

Phone: (202) 326-6450

Web: [www.aaas.org](http://www.aaas.org)

Hilton San Francisco & Towers

San Francisco, CA

Hotel: (800) 445-8667

March 1-4

**American College of Medical Genetics**

*Annual Clinical Genetics Meeting*

Phone: 856.423.7222, ext. 235

Web: [www.faseb.org/genetics/acmg](http://www.faseb.org/genetics/acmg)

Hyatt Regency Miami

Miami, FL

Hotel: (800) 233-1234

May 4 & 5

**National Coalition for PKU & Allied Disorders**

*1st Biennial NCPAD Conference*

Phone: (877) 996-2723

Web: [www.pku-allieddisorders.org](http://www.pku-allieddisorders.org)

Embassy Suites

Dublin, OH

May 6-9

**Association of Public Health Laboratories**

*Newborn Screening and Genetic Testing Symposium*

Phone: (202) 822-5227 x220

Web: [www.aphl.org](http://www.aphl.org)

Hilton North Raleigh

Raleigh, NC

Hotel: (919) 872-2323

June 22 & 23

**Parents of Galactosemic Children**  
*National Galactosemia Conference*

Email: [mesameadow@aol.com](mailto:mesameadow@aol.com)

Web: [www.galactosemia.org](http://www.galactosemia.org)

Atlanta Airport Marriott

Atlanta, GA

Hotel: (404) 766-7900

June 29—July 1

**Organic Acidemia Association & National Urea Cycle Disorder Foundation**

*Joint Metabolic Conference*

Phone: (800) 38NUCDF

Web: [www.oaanews.org](http://www.oaanews.org)

Marriott - Medical Center

Houston, TX

Hotel: (713) 796-0080

## TFL President To Speak At AAAS Conference

The American Association for the Advancement of Science will hold its Annual Meeting and Science

Innovation Exposition on February 15-20, 2001.

The meeting will be held at the Hilton San Francisco & Towers in San Francisco, California.

The 2001 exposition will offer more than 150 symposia, plenary and topical lectures, specialized

seminars, poster presentations and an exhibition hall. There will be a symposium on Medicine and Public Health, which will include a newborn screening presentation. The session,



entitled 'Screening for Inborn Diseases: Trouble in the Postgenome Days', will include several speakers

including Edward McCabe of UCLA, Edward J. Lammer of Children's Hospital Oakland, Gregory M. Enns of Stanford University, and TFL President Tera Mize.

Tera will be speaking on 'A Parent's Perspective On Newborn Screening'.

Other topics in the NBS segment will include 'Infant Screening for Metabolic and Genetic Disorders', 'Screening for Metabolic and Genetic Disorders: Today and the Future', and

'Economics of National Policies for Improving Newborn Health'. Steve Kern of the University of Utah organized the session.

For more information on the AAAS's Annual Meeting and Science Innovation Exposition visit the AAAS website at [www.aaas.org](http://www.aaas.org) or call the AAAS Meetings Office at (202) 326-6450.

The AAAS was founded in 1848 and is among the oldest scientific societies in America. The association's mission is the advancement of scientific and technological excellence across all disciplines, and to the public's understanding of science and technology.

# PGC Plans Semi-Annual Conference

Parents of Galactosemic Children is planning to hold their semi-annual conference on June 22 & 23, 2001. The conference, entitled "Galactosemia Today and Tomorrow - Encouragement and Hope", will be held in Atlanta, Georgia. The conference is open to all galactosemic families, individuals and interested medical professionals.

Keynote speakers for the conference include Dr. Louis Elsas from Emory University, Dr. Gerard Berry from Children's Hospital of Philadelphia, dietitian Laurie Bernstein and many others. Both the

Friday and Saturday meetings will have breakout sessions, dealing with issues like newborn screening, ovarian failure, diet, school and much more.

The conference is being held at the Atlanta Airport Marriott. Hotel accommodations will be \$89 per night for PGC registrants. The Atlanta Airport Marriott is conveniently located within 3 minutes of the Atlanta airport and provides courtesy transportation to & from the airport

## Galactosemia Today and Tomorrow "Encouragement and Hope" Conference

June 22 & 23

as well as to & from the local MARTA (public transportation) station. Registration for the conference will begin in January 2001. The "Early Bird" registration is \$47, before May 1, and \$55 after, per person. The registration fee covers the costs of lunch for both days of the conference, and a no-host social on Friday night.

You can find more information on the PGC website at [www.galactosemia.org](http://www.galactosemia.org).

## Newborn Screaming

Over 3.9 million babies are born each year in the US alone. Tragically, 2,700 kids each year in the US alone die or are brain damaged because no one knew they should have a \$25 newborn screening test.

Families whose children have suffered the consequences of not screening, whether it be mental retardation or early death, have banded together to make a difference in the lives of other children. Because of their efforts, many states are working to implement better screening systems and expanding the number of disorders they screen for. Many hospitals and doctors are also choosing to offer expanded supplementary screening as well.

There are many ways to help advocate for better newborn screening. Here are just a few ideas:

- **Wear Your NBS Lapel Pin**



Many families have joined in 'Newborn Screaming' to get adequate newborn screening.

Pins are available from the TFL website at [www.tylerforlife.com](http://www.tylerforlife.com).

- **Distribute NBS Pamphlets**  
Pamphlets can be ordered from the TFL website at [www.tylerforlife.com](http://www.tylerforlife.com) or by calling 1-888-454-3383.
- **Give Comprehensive Screening Tests As Gifts to Expectant Parents**
  - **Contact Your Local Media**
  - **Participate in Collaborative Efforts to Contact National Media**
  - **Share Your Story to Anyone Who Will Listen**
  - **Participate in Letter Writing Campaigns**
  - **Communicate With other NBS Advocates**

TFL hosts a Newborn Screening Discussion List Serve for concerned individuals to communicate about newborn screening advocacy. Interested persons can join the list serve by sending an email to [NBSAdvocacy-subscribe@listbot.com](mailto:NBSAdvocacy-subscribe@listbot.com). The list serve is open to interested

consumers and professionals.

TFL also offers an Announcement List Serve where a monthly online newsletter, periodical In the News Alerts and Announcements are sent. Interested persons can join the announcement list serve by sending an email to [tylerforlife-subscribe@listbot.com](mailto:tylerforlife-subscribe@listbot.com).

You can obtain an advocacy package containing a listing of recent national press articles, ideas for advocating, personal family stories, and much more by emailing your name, address and phone number to [adpacks@tylerforlife.com](mailto:adpacks@tylerforlife.com). You may also call 1-888-454-3383 to receive a package. A \$5 donation is requested for each package to cover the cost of printing and shipping.

For parents of affected children, percentages and economics mean little. It is very clear that parents want screening, not statistics, and many feel that 'Newborn Screaming' is the only way children will be comprehensively screened.

# Tyler For Life Foundation

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

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## NEWBORN SCREENING:

*Saving Babies One Foot At A Time*

Tyler's Tribune  
Winter 2001



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## Awareness Campaigns Exceed Expectations

The Tyler For Life Foundation has been involved in several newborn screening awareness campaigns that have all exceeded our best expectations.

In September TFL participated with several other groups, including the FOD (Fatty-acid Oxidation Disorder) Family Support Group members, Organic Acidemia Association, and the National Coalition for PKU and Allied Disorders, in an awareness lapel pin campaign. The campaign, which was launched in early August, distributed NBS lapel pins and asked people to wear them every day in September. The groups initially wanted to circulate 20,000 pins combined between the groups. Once September was over the groups had

exceeded this number by 7,000 pins, handing out more than 27,000 pins in all. The pin campaign is planned to be an annual collaborative event running from approximately Memorial Day to the end of September each year.

September was the kick off of another successful campaign for TFL. The Handout America campaign has distributed over 40,000 newborn screening pamphlets in two months. The pamphlets, entitled "A Parent's Guide to Newborn Screening: It's Not Just PKU Anymore", have been distributed all across the United States. The pamphlets are supplied at no cost to volunteers willing to hand them out. They are also

supplied to doctor's offices and hospitals willing to distribute them to their patients. The Handout America campaign will be a continuous campaign for TFL. We hope that it will continue to grow. The pamphlets can be ordered from our website at [www.tylerforlife.com](http://www.tylerforlife.com) under 'Get NBS Pamphlets', or by calling TFL at (888) 454-3383.



**September  
was declared  
Newborn Screening  
Awareness Month.**

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