



NEWBORN SCREENING:

Saving Babies One Foot At A Time

Tyler's Tribune

A Quarterly Publication by the Tyler For Life Foundation

From the President

It's been 3 years now since my husband and I founded the Tyler For Life Foundation . . . three years since Tyler's death. I feel as close to him today as the day he passed away. I can't believe it's been so long, or so short. Depends on how you look at it.

Being a newborn screening advocate is not easy. In addition to our volunteerism for this great cause, many of us have jobs, children with special needs, spouses to nurture, other children with homework & soccer games, and homes to clean. Some also suffer through bereavement issues with the loss of their children. And the list goes on. Although we all have different circumstances, we are bound together by heart. Our hearts lie in a cause that we feel is worth fighting for.

Recently there has been some friction between involved professionals and affected families. This was bound to happen. We all knew it would. You see, parents take this issue personally because this issue is about their kids. And they would fight tooth and nail for the well-being of their children, especially when they feel that someone is opposing what they believe benefits

their children. However, it was reported that the events became quite ugly involving hate mail and harassment. This news is quite upsetting to me.

We strongly urge families to be respectful in their actions at all times. Disrespect creates larger gaps between professionals and families, which creates more problems for newborn screening.

Parents and professionals should collaborate to develop a plan to further newborn screening. These two forums must stay in constant communication with one another, as it is needed to ensure that both are efficiently and effectively working together. Newborn screening is a joint responsibility of families, medical professionals and the government. There is a delicate balance to maintain when working together, but we can, as we are all driven by heart for this cause.

The efforts of families are clearly making a difference, and our voices are being heard. Together, we have all done some wonderful things. I'd like to see those efforts channeled by positive energy, because it's positive energy that

accomplishes and gives us (families) the credibility we so deserve.

Many states are moving to expand and enhance their newborn screening programs. Movement in the states of Mississippi, Georgia, New Jersey and Missouri is enlightening. It is proof that what we are doing matters and that we are making a difference.

Traveling this road has been slow, but the progress is happening. I yearn for a day when children are screened routinely for the disorders we are fighting for today.

In a recent interview from a reporter, I was asked what I would do once screening for the disorders I am currently fighting for is common practice. With a slight smile, I, of course, looked at this reporter and said "There will never be an end. As long as technology continues to move forward, there will always be new disorders to fight for."

The road is long and challenging, but we are here for the long haul. To coin a phrase from one of our Alliance Groups, ***we are all in this together.***

-Tera Mize
President/Co-Founder
Galactosemia Parent

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Dallas and Tera Mize

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Foundation
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Children
Sickle Cell Foundation of GA

EDITOR

Terilyn DePaolo

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Your Help Is Desperately Needed

Your help is needed in a letter writing campaign to federal legislators to help get appropriations for the Newborn Screening title of the Children's Health Act of 2000.

The Children's Health Act of 2000 (H.R. 4365; Title XXVI - Screening For Heritable Disorders, Sec. 2601 Program to Improve the Ability of States to Provide Newborn and Child Screening for Heritable Disorders) bill includes legislation on newborn screening. The bill is now law. It passed both the House of Representatives and the Senate, and it was signed into law by President Bill Clinton on October 17, 2000. However, no appropriations - no funds - has been allotted for it. Your help in writing to your local federal Senators and Representatives is very much needed to ensure that this legislation gets the money it so deserves.

34 Cents
&
5 Minutes Of Your Time
Could Help Save A Child's Life
Please Help Children Affected By
Newborn Screening Disorders
By Writing A Letter To Your Legislators.

Not only does this legislation affect newborn screening, but if proper funding is appropriated to Maternal and Child Health (MCH), then this can potentially lead to a grant source for metabolic formulas and medications needed to treat children affected with disorders detectable through newborn screening.

Letters are most effective when handwritten and sent via regular mail (not email), as Senators and Representatives are e-bombed every day, which makes e-mail less effective.

You can find out who your federal legislators are at <http://www.house.gov/writerep/wyrfaqs.htm> for the House of Representatives and <http://www.senate.gov/contacting/index.cfm> for the Senate. Once you know the name of your legislators, please send the letters to:

To Senators:

The Honorable _____
U.S. Senate
Washington, D.C. 20510

To Representatives:

The Honorable _____
U.S. House of Representatives
Washington, D.C. 20515

If you are stumped for what to say and/or are pushed for time, please see the sample letter below. This letter can be easily modified to reflect your relationship to (family member, friend, neighbor, etc.) a child affected by an inherited disorder. It can also be easily changed to reflect if the child has paid the ultimate sacrifice of his or her life needlessly from a disorder detectable through newborn screening. Please encourage everyone you can to write in to help get the much needed appropriations to help newborn screening.

Time is of the essence for sending your letters in. Please take a few minutes out of your day to send a letter TODAY!!!,

* * * * * **SAMPLE LETTER** * * * * *

Dear Senator (or Representative)

As the parent of a child affected by an inherited metabolic disorder, I urge you to include specific funding in this year's Labor-HHS-Education appropriations bill for Title XXVI of the Children's Health Act of 2000 (HR 4365).

My son's/daughter's care and treatment has cost our family, our insurance provider, our employer and the nation hundreds of thousands of dollars in treatment that could have been reduced or eliminated had universal, comprehensive newborn screening been in place when he/she was born. Newborn screening would have identified my child's disorder and permitted me to seek early preventative treatment. It also would have spared us the huge emotional and financial toll my child and I now pay.

Please help the many families and children who stand to gain from the implementation of national, universal newborn screening which can be made available through the appropriations of specific funding in this year's Labor-HHS-Education appropriations bill for Title XXVI of the Children's Health Act of 2000 (HR 4365).

Sincerely,

Your Name
Address



Ben Haygood Bill Passes In Mississippi

The signing ceremony for the Ben Haygood bill, House Bill # 986, was held on Monday, April 16, 2001, at the capitol in Jackson, Mississippi. In attendance at the ceremony was the Haygood family, the Boover Family and TFL co-Founders, Dallas and Tera Mize.

The bill mandated that attending physicians for newborns must inform parents of additional screenings that are available beyond those required by Mississippi state law. It also requires that the State Department of Health develop informational materials about comprehensive newborn screening to distribute to medical professionals and the public.

Mississippi currently mandates

screening for only four disorders - Phenylketonuria (PKU), Hypothyroidism (congenital), Galactosemia, and Sickle Cell Disease (SCD).

Congratulations to the family of Ben Haygood for their efforts to get this legislation passed.

Ben, a seemingly healthy child, died from a bout with a stomach virus at age 2 1/2 due to undetected Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD). MCAD, labeled the silent killer, affects approximately every 1 in 10,000 children born in the US each year. MCAD and similar disorders are estimated to be the cause of 5% of all Sudden Infant Death Syndrome (SIDS) cases.



Ben Vincent Haygood
February 19, 1998 - August 8, 2000

Volunteer Needs

We are saving babies! Come share the passion! The success of TFL's efforts in NBS is owed solely to the work of our volunteers. The Tyler for Life Foundation needs volunteers for the following activities:

Database Builder

Person with Excel capability to compile a database of support groups, including national and local chapters, for all disorders detectable through newborn screening. Contact Cindy at hoeks97@cs.com.

Unity Quilt Project Coordinators

People to help with display arrangements in various locations in the United States. Contact Marcia at marcia@tylerforlife.com or call toll-free (866) 710-8202.

For additional descriptions of jobs waiting to be filled, please visit our volunteer web pages at <http://members.tripod.com/~tyler4life> You can also contact the Volunteer Coordinator, Janine Clay, at volunteer@tylerforlife.com who will fit you to an activity which suits your time

and talent.

Many thanks to all those who already volunteer their time and efforts to help keep TFL going. The Tyler For Life Foundation is operated solely by volunteers and has no paid staff.



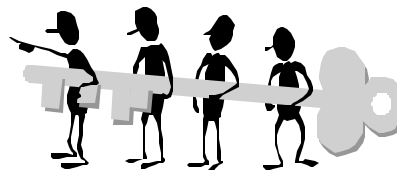
Volunteers at TFL Softball
Tournament Fundraiser last Summer.

Alliance Panel of Support Groups

The Tyler For Life Foundation is excited to announce the establishment of the Alliance Panel of Support Groups. The Alliance Panel is a coalition of national groups who have formally joined together with the Tyler For Life Foundation and have vowed to work together to enhance the lives of individuals affected by newborn screening.

To date the CARES Foundation, FOD Family Support Group, MSUD

Family Support Group, National Coalition for PKU & Allied Disorders, National Urea Cycle Disorder Foundation, Organic Acidemia Association, Parents of Galactosemic Children, and Sickle Cell Foundation of Georgia have all joined this collaborative effort to work together for the mutual goal of giving our babies a fair start in life.



TFL and allied groups feel that together we will strengthen our visibility and better make our presence known.

The first item on the agenda of the

Alliance Panel is to bring about media attention and awareness to newborn screening disorders.

What Does Your State Screen For?

Although every state in the US has a newborn screening program, the disorders screened for in each state's test varies from state to state. The state in which your child is born will determine what disorders your child is screened for. For instance if your child was born in the state of California, he would be screened for 4 disorders. Yet, if he were born in Massachusetts, he would be screened for 28 disorders. Many families are demanding that all states be uniform in the disorders they screen for and are fighting for uniformity among the programs. They hope that one day the lives of their children won't depend on something as arbitrary as lines on a map.

	Total #		Amino Acid Disorders						Organic Acid Disorders										
	MAND	OPT	HOMO	HYPER	MSUD	NKH	PKU	TYRO	2MCD	HMG	3KETO	3MCC	3MCH	5OXO	GA-I	ICD	IVA	MMA	MAC
Alabama	5						•												
Alaska	6	1			•		•												
Arizona	7		•		•		•												
Arkansas	4				C		•							C		C	C		
California	4						•												
Colorado	7						•												
Connecticut	8	1	•		•		•												
Delaware	4						•												
D.C.	7		•		•		•												
Florida	5						•												
Georgia	8		•		•		•	•											
Hawaii	7				•		•												
Idaho	5				•		•												
Illinois	6						•												
Indiana	8		•		•		•												
Iowa	6						•												
Kansas	4						•												
Kentucky	4						•												
Louisiana	4						•												
Maine	9	17	•		•		•	B	B	B	B	B		B		B	B		
Maryland	8		•		•		•	•											
Massachusetts	10	18	•		•		•	B	B	B	B	B		B		B	B		
Michigan	7				•		•												
Minnesota	5	17					•	B	B	B	B	B		B		B	B		
Mississippi	5						•												
Missouri	4				D		•							D		D	D		
Montana	3	2					•												
Nebraska	5						•												
Nevada	6				•		•												
New Hampshire	5	1	•		•		•												
New Jersey	4		D		D		•	D											
New Mexico	6						•												
New York	9		•		•		•												
North Carolina	4	30	B	B	B	B	•	B	B	B	B	B	B	B	B	B	B	B	B
North Dakota	4						•												
Ohio	7		•		•		•												
Oklahoma	4						•												
Oregon	6				•		•												
Pennsylvania	6				•		•												
Rhode Island	8		•		•		•												
South Carolina	6						•												
South Dakota	3	1					•												
Tennessee	5						•												
Texas	5		C		C		•												
Utah	3						•												
Vermont	7		•		•		•												
Virginia	7		•		•		•												
Washington	4						•												
West Virginia	3	1					•												
Wisconsin	7	15			A		•			B	B	B		B		B	B		
Wyoming	6				C		•												
TOTAL SCREENING FOR			15	1	23	1	51	5	3	2	4	4	1	1	4	1	4	4	1
			HOMO	HYPER	MSUD	NH	PKU	TYRO	2MCD	HMG	3KETO	3MCC	3MCH	5OXO	GA-I	ICD	IVA	MMA	MAC
Laboratories Offering Screening to the Public																			
Baylor	27			•	•	•	•	•	•	•		•		•	•	•	•	•	•
NeoGen	27				•		•			•	•	•	•		•		•	•	

REFERENCES: A = selected population only; B = pilot program; C = planning underway (recommendation from NBSAC and/or drafted or

Fatty-Acid Oxidation Disorders (FOD)										Other Disorders							Urea Cycle Disorders				MS/MS			
A	24DCR	CPT-I&II	CA TRANS	GA-II	LCHAD	MCAD	SCAD	TRI	VLCAD	BD	CAH	CF	G6PH	GALT	CH	HIV	HEMO	TOXO	ARGT	ASA	CITR	HHH	Status	
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											A							
						E				.	C	E		.	.		.							E
3						C								.	.		.							C
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3		B		B	B	.	B		B				B	B	B	B
										.	E			.	.		.							E
3		B		B	B	.	B		B	.	.	B				B	B	B	B
																E
3		B		B	B	B	B		B				B	B	B	B
																
D						D				D	D	D	D	.	.		.							C
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						C										C
																
														.	.		A							
					D	D	D		D	D	D			.	.		.			D	D	D		D
																
						C				.	.	C								C
3	B	B	B	B	B	B	B		B			B	B	B	B	B
												
						C					C	C		.	.		.							C
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3	B	B		B	B	B	B		B							B
										.	E							
4	2	4	1	4	4	9	4	0	4	23	25	6	1	49	51	1	47	1	1	3	3	3	MS/MS	
A	24DCR	CPT-I&II	CA TRANS	GA-II	LCHAD	MCAD	SCAD	TRI	VLCAD	BD	CAH	CF	G6PH	GALT	CH	HIV	HEMO	TOXO	ARGT	ASA	CITR	HHH	Status	
			
		

d legislation already); D = mandated: not yet implemented; E = considering/formally discussing

September is NBS Awareness Month

September is Newborn Screening Awareness Month. Help celebrate it and show your support by wearing your NBS lapel pins every day in September.



Lapel pins are available for a suggested donation of \$3 each. An order form can be downloaded on the TFL website at www.tylerforlife.com, or

you can get more information by contacting the project director at tiffany@tylerforlife.com

Last year more than 26,000 pins were distributed. We hope to see even more participate in the campaign this year and bring even more awareness to newborn screening.

Many events are scheduled in celebration of Newborn Screening Awareness month including the unveiling

of the NBS Unity Quilt. The quilt will be unveiled at Virtua West Jersey Hospital. This location was chosen because of Virtua's proactivity in 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. In addition, the cost for the screening, about \$20 per baby, is being paid for by contributions from the system's doctors and hospitals.

In keeping with the tradition of Newborn Screening Awareness Month, The Tyler For Life Foundation is again issuing a challenge to all advocates for September. The challenge is to initiate at least two NBS related articles (local paper, magazine, TV news, etc.) in the month of September. 100 articles is the goal so contact those

Calendar of Events

July 7

Sigma Tau Pharmaceuticals

Family Picnic & Luau

Phone: (301) 670-2197

Smokey Glen Farms, Maryland

1:00 pm - 5:00 pm

August 9-12

Maryland Alliance for PKU Family Camp

Camp Fairlee Manor (Ages 8 & up)

Chestertown, Maryland

Cost: \$120.00 per child for week

\$60.00 per child for weekend only

Contact: Rob Kerrat (410) 795-2091 or

Sean Harrigan at (410) 549-1721

Email: SPHarrigan@msn.com

September 4

NBS Unity Quilt Unveiling Ceremony

Contact: Marcia Dunahoo

Toll Free: (866) 710-8202

Virtua West Jersey Hospital

Voorhees, New Jersey

National Coalition for PKU & Allied Disorders Conference

The National Coalition for PKU and Allied Disorders (NCPAD) held its Metabolic Conference on May 4th and 5th with great success. The response to the meeting was enormous. Over 325 people attended the conference, representing over 19 different disorders, 30 states and 9 countries.

Break-out sessions for organic acid disorders, fatty-acid oxidation disorders, Homocystinuria, MSUD, PKU, Tyrosinemia and Urea Cycle disorders were held on Friday. There



was also a reception and newborn screening session held on Friday night. On Saturday all the participants gathered in one forum for a session that applied to all the disorders.

All the break out sessions and the Saturday session were great. It was wonderful to see the panel discussion where affected families could candidly ask questions and speak to the specialists of their disorder. The newborn screening session on Friday night was also particularly touching as Attorney Chuck Hehmeyer shared personal

stories of affected children with the audience. Many were moved to tears by Mr. Hehmeyer's speech and he received a standing ovation.

The National Coalition plans to hold similar conferences every other year so for the many that have expressed that they wished they could have attended, there will be future opportunities to do so. Many thanks to the National Coalition for their hard work in putting together such a great event.



Writing Letters To Legislators

The efforts of families are clearly making a difference in newborn screening and our voices are being heard. Many families are taking the initiative to write legislators regarding newborn screening. With that in mind, there are several points to remember when writing a letter to these people.

- Include a photo of your child.
- Identify your child by name.
- Include your personal story.
- Write legibly. Handwritten letters are good, but they must be readable.
- Identify yourself as a consumer, family member, or an advocate.
- Include a return address on the letter.
- Focus on one issue, bill or topic.
- Identify a bill by name and/or number.
- Personalize the letter to show depth of concern.
- Be positive and respectful. One of the largest mistakes a family can make in dealing with professionals is to appear to be attacking the

- person.
- State the reason for writing, explaining how the specific bill can affect a specific individual, family or entire group.
- Be clear, stating exactly what is wanted from the legislator.
- Ask for a written response that states their position on the issue.
- Thank them for his/her time on the issue.
- Keep the letter to one page.
- Show that you are familiar and knowledgeable on the subject.
- Call other organizations for help, if necessary, with the letter.
- Send a copy of the letter (cc:) to the appropriate organizations involved in the issue.
- Send a "thank you" when a response is received.

One of the biggest points that consumer "pros" push is that letters are most effective when handwritten and sent via regular mail (not email) Most consumers who are accustomed to writing their legislators and have had

good response have found that regular mail is the best way to send these letters as Senators and Representatives are e-bombed every day and e-mail is not as effective.

Another good point is to be up front. The first sentence of your letter should state exactly what you want.

A "pro" consumer advocate recently spoke at the Genetic Alliance conference and said that she and her group got on the Rosie O'Donnell Show by writing one letter. The letter said "Dear Rosie, Can "Person's Name" come to your show and speak about XX disorder and the XX organization." This group has had much success with such short and sweet letters.

Active families are what is making the difference in newborn screening and helping to keep it in the public eye. Along with the pointers above, there is only one other thing to remember when writing letters for newborn screening - every letter counts!!

Those Who Are Not Forgotten Memorial

'Those Who Are Not Forgotten' is a memorial to those lost to lack of newborn screening or mishandled tests. If you or someone you know would like to have a loved one

listed in this column, please email the person's name, date of birth, date of death, disorder name and city & state born in to editor@tylerforlife.com Names will be run in the issue following

original receipt of the name and rerun in the issue in which the person's birthday falls. Many thanks to all who have already submitted names for this segment.

Those Who Are Not Forgotten

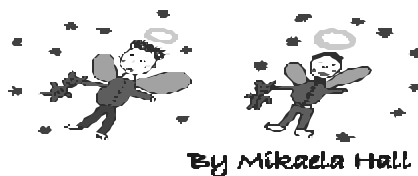
Jacob Ryan Shambo
Citrullinemia
Mattoon, Illinois
Mar 22, 2001 - Mar 28, 2001

Megan Deshais
LCHAD
Bartlett, New Hampshire
Feb 11, 1991 - July 7, 1991

Alyssa Jenna -Ann Boucher
MCAD
Windsor, Ontario Canada
Nov 18, 1999 - July 22, 2000

Luke Timothy Aalberts
MCAD
Holland, MI
Jun 7, 1994 -
May 1, 1995

Hayley Effie -Ann Wood
MI TOCHONDRIAL DI SEASE
Fairfax, VA
Jun 23, 2000 - Jun 26, 2000



Sarah Ann Hall
MCAD
Paris, MO
Jun 25, 1998 - Jul 30, 2000

Jennifer Lee Patrick
CARNITINE DEFICIENCY
San Diego, CA
Jul 21, 1986 - Nov 16, 1986

Eric Michael Bradford
MCAD
Indianapolis, IN
Aug 22, 1990 - Aug 26, 1990

Storm Tyler Hall
VLCAD
Albuquerque, NM
Sep 23, 1996 - Sep 25, 1996

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NEWBORN SCREENING:
Saving Babies One Foot At A Time®

Tyler's Tribune
Summer 2001



Editor: Terilyn DePaolo
Email: editor@tylerforlife.com

Newborn Screening Resources

The Tyler For Life Foundation has several online resources for newborn screening including email list serves and a website.

The TFL Announcement List Serve provides newborn screening announcements, such as alerts to related media articles, an event calendar, a monthly newsletter, and much more. You can join the Announcement List Serve by sending an email to tylerforlife-subscribe@listbot.com. The Announcement List Serve receives an average of approximately 10 emails per month.

Another list serve hosted by the Tyler For Life Foundation is the Newborn Screening Discussion List Serve. This list serve is open to anyone wishing to communicate with others about newborn screening issues. Any member of the list serve can post NBS related messages to the group. You can join this list serve by sending an email to NBSAdvocacy-subscribe@listbot.com. The Discussion List Serve receives an average of approximately 80 emails per month. The TFL website at www.tylerforlife.org allows interested individuals to instantly access information about newborn screening and the disorders detectable through it. The website provides an abundance of easy to understand information.

New Jersey Plans To Expand

At a press conference on Monday, April 16, 2001, the New Jersey Governor, Donald T. DiFrancesco, announced the expansion of the state's newborn screening panel. The Governor signed an executive order for the expansion.

The executive order added 10 more disorders to the New Jersey newborn screening panel. It added Argininosuccinic Aciduria (ASA), Biotinidase Deficiency (BD), Citrullinemia, Congenital Adrenal Hyperplasia (CAH), Cystic Fibrosis (CF), Long-Chain Acyl-CoA Dehydrogenase Deficiency (LCAD), Maple Syrup Urine Disease (MSUD), Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD), Short-Chain Acyl-CoA Dehydrogenase Deficiency (SCAD) and Very-Long-Chain Acyl-CoA Dehydrogenase Deficiency (VLCAD) to the NJ panel.

The New Jersey Newborn Screening Advisory Committee (NBSAC) reconvened June 11 and recommended adding even more disorders to the panel, including several organic acidemia disorders, Tyrosinemia, Homocystinuria, and Arginase Deficiency.

All infants in New Jersey are currently screened for only four disorders - Phenylketonuria (PKU), Hypothyroidism (congenital), Galactosemia, and Sickle Cell Disease (SCD) and Hemoglobinopathies.