

# NEWBORN SCREENING:

*Saving Babies One Foot At A Time*



# Tyler's Tribune

A Quarterly Publication by the Tyler For Life Foundation

## From the President

With the recent terrorist tragedies, all over America this nation hurts. We must ask ourselves what we can do now? I took the time to give blood to help. I sat in awe only wishing I could do more. But, as the initial shock wore off some, I realized that I am alive and I still have responsibilities to help protect the children born with disorders detectable through newborn screening. The terrorism that shook our nation did not stop our children from being born, nor did it stop our children from needlessly dying and suffering from disorders detectable through NBS. Babies are born every day, and it doesn't matter to them what the uncertain state of the nation's affairs may be.

Families go home every night and tuck their seemingly healthy children

into bed, thinking it will never happen to them. New parents hold their new babies in their arms, thinking it can never happen to them. Yet, it is happening. Six children are born everyday undetected with disorders detectable through newborn screening. This number is only for the children that could be detected, but are not - 6 per day. If any other killer crept into our homes, our day cares, our hospitals, and took our children, our society would not stand for it. If any other thing swiped our children's mental or physical abilities away, our society would not stand for it.

I hope on a day like today, when people every where are thinking more about the unthinkable and about all the things we thought never could happen to us, that minds also wander

to what we can do to prevent these tragedies, both in terrorist terms and in our own homes with our own children. Our children are our most precious commodities. As our nation moves towards prevention of more tragedies as those that occurred on September 11, it is my hopes that more people will realize the need for prevention for many other things as well, including newborn screening. I hope that people begin to realize that the unthinkable can happen at anytime. An ounce of prevention is definitely worth a pound of cure.

Children are being born every day with these disorders, so as I pray for peace and love in our world, I pray that children stop dying and suffering needlessly from disorders detectable through NBS. -Tera Mize

## Notes to the Editor

I'd like to commend you for all your hard work and the education you have brought, not only to myself, but also to doctors and to mothers who have found your efforts to be life saving. Without your website, the numerous positive reports on TV, and information in newspapers and magazines about newborn screening, my daughter would be severely retarded and wheelchair bound, if not dead!

For all of her 2 1/2

short little years we have seen numerous doctors, and her tiny little body has undergone numerous painful tests...all to show nothing. Through research on my own from you, I was able to ask the doctors for the test and obtain the kit myself for her testing through our pediatrician. Three months ago it came back positive for biotinidase deficiency. Had she been tested at birth...she would be fine! . . . She is alive... thanks to you and

the rest of the open-minded people who were interested in saving my child's life.

Bottom line ... Save these children's lives and give them as much of a quality life as we can through testing and educating parents and doctors who don't know! This is not something you can wait on. We are losing these children needlessly...they are the ones that count and I would choose my daughter over privacy any day!

-Rhonda, Missouri

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Dallas and Tera Mize

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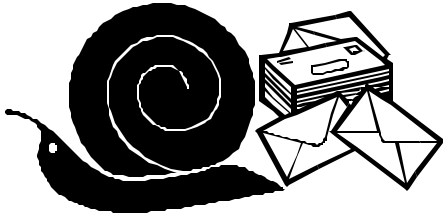
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# Screening Issues Is More Than Expanding Disorders *Part I*



Newborn screening advocacy is not limited to the expansion for which disorders are screened. One specific NBS issue that must be addressed is quicker retrieval time. Losing time in newborn screening can result in losing lives.

When 9-day-old Tyler died unnecessarily in 1998 from undiagnosed galactosemia, his NBS test results arrived a few days after his death - obviously not soon enough. His parents were told that his preventable and unnecessary death was so rare - something that "never happens" and has "never happened before." Yet, Tyler's tragic story did happen again - not once, but twice, to two different American galactosemia affected families in a recent 6-month period. That is twice, of which we are aware. And, in all three of these cases, their disorder was

screened for in the newborn screening test.

Many ask how this could happen. These children were lost because their newborn screening results were delayed in one way or another. Precious time can be wasted in many ways. Numerous collection facilities (hospitals, pediatrician's offices, health departments, etc.) participate in a practice called "batching". "Batching" means they do not send the tests to the laboratory until they accumulate a certain number of tests or they only send them out on a specific day of the week. An example of this is facilities that only send tests when they have at least 10 specimens so they can mail them all at once or if they only mail specimens out on Fridays. This saves cost for postage in the eyes of those partaking in this practice. The practice of batching causes delays in the laboratory receiving the tests, wasting precious time in an affected child's life - time that an affected child may not have.

Precious time is also lost due to delays in the regular mail system. Use

of the regular mail provides no real tracking of specimens and lost tests can sometimes go unannounced. Tests lost in the regular mail system may never be found. Regular mail is the culprit of why many tests have slow arrival to the laboratory. Some tests have been reported to take weeks to arrive. Tests sent through the regular mail are also exposed longer to heat and humidity, which affects the tests' reliability and accuracy. The majority of states currently use the regular mail in their newborn screening programs. Hospitals in some states voluntarily use courier services instead to help facilitate the arrival of their tests at the laboratory.

Every second counts in the life of an affected child. It is imperative that newborns are screened comprehensively for inherited disorders without delay and that the tests arrive at the laboratory as soon as possible. Even a minor delay can cost a child his or her life. Every newborn screening test must be treated as if a child's life is depending on it - as this is exactly what the case may be.

## SIDS Cases Explained through Metabolic Autopsy

A recent report in Clinical Chemistry (July 2001) stated that the metabolic autopsy could now provide answers to some sudden infant death syndrome (SIDS) cases.

Researchers report the ability to identify the cause of death in previously unexplained SIDS cases through the use of a newborn screening method, tandem mass spectrometry (MS/MS).

More than 7,000 filter paper blood specimens were collected from medical examiners in the US and Canada for this study. The results showed that 66 specimens suggested that the infants had detectable metabolic

disorders. The majority of the infants had MCAD, but infants with VLCAD, GA-I, GA-II, CPT-II, LCHAD, and IVA were also found.

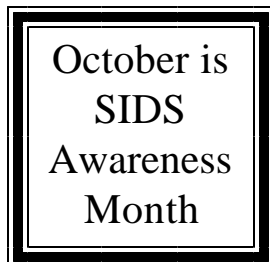
This report sparked yet another outcry from affected families as they feel this report provides yet more data that children are not being screened properly at birth. Families are concerned that not only does failure to properly diagnose such

metabolic disorders lead to these children's early deaths, but a diagnosis of SIDS does not alert the family to the possibility of having more children with the same disorder (and what measures they can take to save these

children's lives) or to the possibility of existing siblings also being at risk for having the disease.

The report concluded that postmortem metabolic screening can explain numerous infant deaths and can provide estimates of the number of infant deaths that can be attributed to metabolic disorders. The full article is available online at <http://www.clinchem.org/cgi/content/abstract/47/7/1166>.

October is SIDS Awareness month. There are approximately 3,000 SIDS cases every year in the United States. Studies have suggested that approximately 5% of all SIDS cases are actually cases of undiagnosed metabolic disorders detectable through newborn screening.



# Missouri Passes Legislation to Add More Disorders

The state of Missouri recently passed legislation to mandate the addition of numerous disorders in its newborn screening panel. Testing for Congenital Adrenal Hyperplasia (CAH), Cystic Fibrosis (CF), Biotinidase Deficiency, and disorders detectable through tandem mass spectrometry (MS/MS) are included in this expansion.

The bill was signed into law by the Missouri Governor on June 13, 2001. The Missouri Department of Health is required to expand the newborn

screening requirements by January 1, 2002.

Much of the consumer support for this expansion was led by John and Carol Hall. Mr. and Mrs. Hall are Missouri residents who lost their 2-year-old daughter, Sarah Ann, to undiagnosed MCAD in 2000.

MCAD is currently screened for in 9 states: Iowa, Maine, Massachusetts, Minnesota, North Carolina, Ohio, South Carolina, South Dakota, and Wisconsin. Several other states are scheduled to

start screening for MCAD in the near future.

The other disorders being added to the Missouri newborn screening panel are also screened for in several other states. Biotinidase deficiency is screened for in 23 other states, CAH in 25, and CF in 6. Screening for the full spectrum of disorders detectable through MS/MS is currently occurring in approximately 4 states and is planned in numerous others.

## Public Service Announcements



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 folic acid before conception. PSA's have helped educate

millions of people and have helped change attitudes and behaviors about many important issues. These useful tools can also be a great avenue for mass education about newborn screening.

The Tyler For Life Foundation is working to produce newborn screening PSA's for several different media outlets, including television, radio, print, outdoor (buses, subways, billboards), and the internet.

Several PSA's for use on radio

have already been developed and new PSA's are released at regular intervals. Many volunteers have helped to get the current PSA's aired throughout the country. Help will be continually needed in developing and broadcasting the PSA's. Anyone interested in helping in this aspect, please contact Wendy Nawn at [wendy@tylerforlife.com](mailto:wendy@tylerforlife.com) or (610) 251-9876. Visit our online listing of currently available PSA's on the TFL website at [www.tylerforlife.org](http://www.tylerforlife.org).

## Featured Disorders This Month

The featured story for October, 2001, is Ella Heberer, who has Tyrosinemia Type I. Ella was not screened at birth for Tyrosinemia and went into liver failure when she was 3 months old. Customarily liver transplantation was the only treatment for Tyrosinemia Type I. However Ella was started on a low protein diet and a new medication called NTBC. Ella is now almost 3-years-old and seems to still be responding very well to diet and drug therapy.

Brett Revenski was the third child born to his family and was declared healthy by his pediatricians.



Brett (pictured above) was fortunate to survive his first crisis as many children do not.

Only three months later, Brett lay in the NICU and it was unclear whether or not he would survive.

Brett's family searched the internet and located a support group for fatty-acid oxidation disorders and received a packet of information from the group. In desperation, Brett's family started calling FOD families and found a family who lost their child to undiagnosed VLCAD. The family referred the Revinski's to a doctor who could help them. Brett was finally diagnosed with VLCAD, a disorder that could have been detected at birth through

comprehensive newborn screening. VLCAD and Brett's story are the featured disorder for November 2001.

The featured disorder of the month for December, 2001, is Short-Chain Acyl-CoA Dehydrogenase Deficiency (SCAD). Kyle Miller was born a seemingly healthy infant, but his health slowly deteriorated. Kyle suffered many unexplained seizures, mental and physical delays, constant fatigue and stomach problems. Kyle suffered for many years before he was finally diagnosed with SCAD at the age of 5. Since diagnosis and initiation of treatment, Kyle has had increased energy, and he is better able to fight infection.

*Many thanks to the families that have shared their stories for this segment.*

# State Screening Table

Although every state in the US has a newborn screening program, the disorders screened in each state's tests vary from state to state. The state in which your child is born will determine for what disorders he/she will be screened. Find out from this table the disorders screened for in each state.

	Total #	Amino Acid Disorders						Organic Acid Disorders												
		Disorders	HOMO	HYPER	MSUD	NKH	PKU	TYRO	2MCD	HMG	3KETO	3MCC	3MCH	5OXO	GA-I	ICD	IVA	MMA	MACT	M
Alabama	5					1														
Alaska	6			1		1														
Arizona	7	1		1		1														
Arkansas	4			C		1								C		C	C			
California	4					1														
Colorado	7					1														
Connecticut	8	1		1		1														
Delaware	4					1														
DC	7	1		1		1														
Florida	5					1														
Georgia	8	1		1		1	1													
Hawaii	7			1		1														
Idaho	5			1		1														
	Disorders	HOMO	HYPER	MSUD	NKH	PKU	TYRO	2MCD	HMG	3KETO	3MCC	3MCH	5OXO	GA-I	ICD	IVA	MMA	MACT	M	
Illinois	6					1														
Indiana	8	1		1		1														
Iowa *****	36	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Kansas	4					1														
Kentucky	4					1														
Louisiana	4					1														
Maine	26	1		1		1	1	1	1	1	1			1		1	1			
Maryland	8	1		1		1	1													
Massachusetts	28	1		1		1	1	1	1	1	1			1		1	1			
Michigan	7			1		1														
Minnesota	23					1	1	1	1	1	1			1		1	1			
Mississippi	5					1														
Missouri	4			B		1								B		B	B			
Montana	5					1														
Nebraska	5					1														
Nevada	6			1		1														
New Hampshire	5	1		1		1														
New Jersey	4	B		B		1	B													
	Disorders	HOMO	HYPER	MSUD	NKH	PKU	TYRO	2MCD	HMG	3KETO	3MCC	3MCH	5OXO	GA-I	ICD	IVA	MMA	MACT	M	
New Mexico	6					1														
New York	9	1		1		1														
North Carolina	35	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
North Dakota	4					1														
Ohio	7	1		1		1														
Oklahoma	4					1														
Oregon	6			1		1														
Pennsylvania	6			1		1														
Rhode Island	8	1		1		1														
South Carolina	6					1														
South Dakota	4					1														
Tennessee	5					1														
Texas	5	C		C		1														
Utah	3					1														
Vermont	7	1		1		1														
Virginia	7	1		1		1														
Washington	4					1														
West Virginia	3					1														
Wisconsin	24	1		1		1	1		1	1	1			1		1	1			
Wyoming	8			C		1														
TOTAL SCREENING FOR		17	2	24	2	51	8	5	6	6	6	2	2	6	2	6	6	2		
	Disorders	HOMO	HYPER	MSUD	NKH	PKU	TYRO	2MCD	HMG	3KETO	3MCC	3MCH	5OXO	GA-I	ICD	IVA	MMA	MACT	M	

REFERENCES: 1 = Screening currently performed; A = screening currently performed on selected population only; B = screening mandated, but not being performed; C = pl

\*\*\*\*\*The state of Iowa has not specifically outlined the names of the disorders they are screening for through MS/MS but are reporting all abnormal results (for all disorders).

Fatty-Acid Oxidation Disorders (FOD)									Other Disorders							Urea Cycle Disorders						
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	
										1			1	1		1						AL
									1	1			1	1		A						AK
					D				1	C	D		1	1		1						AZ
					C								1	1		1						AR
													1	1		1						CA
									1	1	1		1	1		1						CO
				C					1	1	A		1	1		1						CT
										B			1	1		1						DE
												1	1	1		1						DC
										1			1	1		1						FL
									C	1			1	1		1						GA
									1	1			1	1		1						HI
									1				1	1								ID
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	
									1	1			1	1		1						IL
									1	1			1	1		1						IN
1	1	1	1	1	1	1	1	1		1			1	1		1		1	1	1	1	IA
													1	1		1						KS
											C		1	1		1						KY
									1				C	1		1						LA
	1			1	1	1	1	1	1	1			1	1		1			1	1	1	ME
									1	D			1	1		1						MD
	1			1	1	1	1	1	1	1	1		1	1		1	1		1	1	1	MA
									1	1			1	1		1						MI
	1			1	1	1	1	1		1			1	1		1			1	1	1	MN
										1			1	1		1						MS
					B				B	B	B	B	1	1		1						MO
											1		1	1		1						MT
					C				1				1	1		1						NE
									1				1	1		1						NV
													1	1		A						NH
				B	B	B		B	B	B	B		1	1		1		B	B	B		NJ
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	
									1	1			1	1		1						NM
					C				1	1	C		1	1	1	1						NY
1	1	1	1	1	1	1	1	1		1			1	1		1		1	1	1	1	NC
										1			1	1								ND
					1								1	1		1						OH
					C					C	C		1	1		1						OK
									1	C	C		1	1		1						OR
										1			1	1		1						PA
					D				1	1	D		1	1		1						RI
					1					1			1	1		1						SC
					1								1	1								SD
										1			1	1		1						TN
									C	1			1	1		1						TX
										D			1	1		D						UT
									1				1	1		1						VT
					D				1	D			1	1		1						VA
										1			D	1		1						WA
										D			1	1		A						WV
1	1			1	1	1	1	1	1	1	1		1	1		1						WI
									1	D	1		1	1		1			1	1		WY
3	6	2	6	6	9	6	1	6	23	26	5	1	49	51	1	44	1	2	6	6	5	
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	

way (recommendation from NBSAC and/or drafted or introduced legislation already); D = considering/formally discussing

## Hold A Fundraiser

The need for continued awareness of newborn screening has created another important need - funding. Tyler for Life Foundation (TFL) has grown substantially in the past two years in terms of media attention, professional attention, awareness programs and volunteers. We have accomplished much, yet we have so much more to accomplish. We have many ideas and not enough resources to implement ideas. Too many ideas and not enough funding is a good



problem to have, as it shows we are growing. Nevertheless, it is a problem with which we need your help.

We are asking advocates to hold fundraisers to benefit Tyler for Life Foundation's ongoing mission to improve the lives of babies through prevention of mental retardation and death caused by disorders detectable through newborn screening. Fundraisers can be holding an event such as a walk-a-thon, car wash, benefit singing, community yard sale, fun day, raffle, softball/golf tournament, donut sales, auctions, dances, car shows or simply passing out our general purpose fundraising flyers.

To participate, please contact Marcia Dunahoo at 1-888-454-3383, email [marcia@tylerforlife.com](mailto:marcia@tylerforlife.com). All types of fundraising are welcome.

## Those Who Are Not Forgotten

**Nora Hannele Waananen**  
LCHAD  
Chico, California  
Mar 29 - Aug 9, 2001

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

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



## Calendar of Events

October 1-30

### **NBS Unity Quilt Viewing**

Tyler For Life Foundation  
More Info: 1-888-454-3383  
Web: [www.tylerforlife.org](http://www.tylerforlife.org)  
Virtua Memorial Hospital  
Burlington County  
Mt Holly, New Jersey

October 14-17

### **Connections 2001 - Biennial Partnership Conference**

National Healthy Mothers  
Healthy Babies Coalition  
*Offering NBS session*  
More Info: (813)974-6682  
Web: [www.hmhb.org](http://www.hmhb.org)  
Clearwater Beach, Florida

November 3 & 4

### **2nd International Professional Conference and Maternity & Baby Fair**

Childbirth And Postpartum  
Professional Association  
(CAPP)  
Phone: 1-888-548-3672  
University of Alabama  
Birmingham, AL

November 4-7

### **20th Annual Education Conference**

National Society of Genetic  
Counselors  
*Offering NBS session & course  
on Counseling & Management of  
Metabolic Disorders*  
Web: [www.nsgc.org](http://www.nsgc.org)  
Washington, D.C.

## AAP Publishes Article on Diagnosing VLCAD through NBS

The American Academy of Pediatrics published an article in the July 2001 issue of Pediatrics entitled 'Diagnosis of Very Long Chain Acyl-Dehydrogenase Deficiency From an Infant's Newborn Screening Card'. The article evaluated a patient who was belatedly diagnosed with VLCAD. The child's diagnosis came only after a crisis had occurred. The child went into a crisis at the age of 3 months, suffering a heart attack.

The child was born in a state

that did not screen for VLCAD through its newborn screening panel. The child's original newborn screening card was obtained from the state and analyzed for VLCAD. Although the card was more than 2 years old at the time it was analyzed, it still showed that the child had VLCAD.

The report concludes that more than \$400,000 in medical bills probably could have been avoided had the child been presymptomatically diagnosed with VLCAD (through

newborn screening).

VLCAD was first discovered in 1992. Much progress has been made in treatment and early detection of the disorder. VLCAD is one of the numerous disorders that are detectable through the tandem mass spectrometry (MS/MS) method of newborn screening.

The full AAP article is available online at [www.aap.org](http://www.aap.org). For more information about VLCAD, visit the FOD (Fatty-acid Oxidation Disorder) Family Support Group at [www.fodsupport.org](http://www.fodsupport.org).

# School Project Raises Awareness

Fourteen-year-old Megan Evers of Great Valley Middle School in Malvern, Pennsylvania, does not know anyone who has suffered symptoms of a metabolic disorder. Megan devotes her time to the things in life that are important right now: friends, family, school, sports, and baby-sitting.

Toddlers are one of Megan's favorite age groups to baby-sit. Megan is well aware that one particular toddler she baby-sits might likely have died suddenly at age two if not for the \$25, preventive, general-population newborn screen that detected a silent time bomb waiting to go off years later. Megan cannot even tell you how she might feel if the little boy who plays outside, under her care had died unnecessarily from lack of a \$25 test. Megan knows that because of early detection, the little boy's parents were able to become educated and to take steps to preserve his life.

Megan thought of newborn

screening when every student in her 300-plus-member 8<sup>th</sup> grade class was assigned a 20<sup>th</sup> Century research project. Under the 20<sup>th</sup> Century project, students were required to compile information throughout the school year on an issue that began in the 20<sup>th</sup> century: a historic event, famous person, scientific finding, etc.

Then, she had to present her findings on May 31 in a format open to the public. Alongside hundreds of middle school classmates, Megan set up a table within a mile-long trail throughout the middle school in a fashion not unlike that of a trade show. Megan's table included a brightly colored poster, "Newborn Screening: It Saves Lives,". She displayed pictures of children, living and deceased, who are or were affected by the presence or absence of newborn screening. There were several binders of information, fact sheets, handouts, and even baby dolls. The 20<sup>th</sup> Century project was an



opportunity for students to become knowledgeable and to speak confidently with members of the public, who were asking all kinds of questions.

It required a lot of work all yearlong, from 8<sup>th</sup> graders. Megan spoke well, answering questions with confidence, grace and knowledge. Clearly, she had done lots of homework. Despite her teacher's initial hesitation (Many people today are still unfamiliar with information relating to newborn screening), Megan was able to gather all sorts of information thanks to several sources, including people from health departments across the country.

Says Megan, "Everybody, whether they are a parent or not, should know about the effects that can happen if these babies are not tested."

# NBS Unity Quilt Showing



The Newborn Screening Unity Quilt was unveiled Tuesday, September 4, 2001, at Virtua West Hospital, Voorhees, New Jersey. Many thanks to all the people at Barry D. Brown Education Center for their hard work in displaying these panels. It is truly a breath-taking experience to see our children represented in this way.

Participants in the event were introduced by Richard P. Miller, President and Chief Executive Officer of Virtua Health. Dr. John M Tedeschi, Chairman of Pediatrics at Virtua West Jersey Hospital, spoke about Virtua Health's comprehensive screening

efforts. Diane DiFrancesco, wife of New Jersey's Acting Governor, Donald DiFrancesco, presented the Governor's Proclamation. Tera Mize, President of Tyler for Life Foundation presented Dr. Adrienne Kirby, Vice President for Programs of Excellence, Virtua Health and Governor DiFrancesco with plaques recognizing their successful efforts in newborn screening at Virtua and in New Jersey. Mindy Rosen, past President of National Urea Cycle Disorder Foundation, presented crystal desk clocks to both Dr. Kirby and Governor DiFrancesco on behalf of NUCDF.

Also in attendance at this event were some very special people who are directly affected by these disorders. Brett Rosen (Arginase Deficiency), Ashley Cajuste (MCAD) and Charlene Maloney (Glutaric Acidemia Type I) were all in attendance at the

unveiling. Thank you to them for being there, and an extra thank you goes to the families of these beautiful children.

For those of you who were not able to attend the unveiling ceremony, the quilt will be on display through September 30 at Barry D. Brown Education Center, Main Lobby, 106 Carnie Boulevard, Voorhees, New Jersey. The quilt will also be displayed October 1-31 at Virtua Memorial Hospital, Mt. Holly, New Jersey.

Tyler for Life Foundation will be accepting panels for display throughout the year. If you were not able to participate, please do not think you have missed this opportunity to share and celebrate your child's life with us. For information about creating a panel, please contact [unityquilt@tylerforlife.com](mailto:unityquilt@tylerforlife.com) or call TFL at 1-888-4LI FE83. Thank you to all who made this event a success.

# Tyler For Life Foundation

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

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**Saving Babies One Foot At A Time®**

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Editor Email: [editor@tylerforlife.com](mailto:editor@tylerforlife.com)

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## Donate To TFL Through the United Way

You can help Tyler for Life Foundation by donating through the United Way through the United Way. The United Way begins its annual fundraising drive in the Fall of each year. The United Way provides a way for many charities to obtain funds by individuals contributing a small portion of their paycheck through payroll deduction. Each United Way chapter lists a variety of local organizations that may be chosen for payroll deductions, and since the Tyler For Life Foundation is a national organization, our name is not usually provided on this list of charities. However, the majority of United Way chapters also allow individuals to **write in the charity of their choice**. This is sometimes referred to as a "Donors Choice" program. Our 501(c)(3) nonprofit status qualifies us for this write-in option and provides us with much-needed funds for our advocacy, education and research projects.

You can initiate a write-in (Donors Choice) campaign in your workplace by contacting your company's United Way chairperson to ask whether the write-in option is offered and, if so, how the rest of the employees might be informed about the Tyler for Life Foundation.

Most coworkers are eager to donate to a cause that is personally tied to a colleague. You may want to reach out to other employees to let them know of the United Way write-in campaign and about the Tyler For Life Foundation. You may want to post a letter or flyer on the office bulletin board or place a poster in the lunch area to encourage your fellow employees to join you in the write-in campaign to benefit the Tyler For Life Foundation. You may also want to circulate the information directly through the inter-office mail system or through email. A flyer for this purpose is available from our website at [www.tylerforlife.org](http://www.tylerforlife.org).

If your company United Way chairperson has any questions, please ask him/her to call us at 1-888-454-3353. The United Way campaigns have been a successful source of revenue for many other organizations, and with your help we hope it will be just as successful for TFL. Please reach out to your friends, relatives, coworkers and neighbors about this "Donors Choice" write-in campaign for Tyler for Life Foundation as you can help make the difference in what can be accomplished in the months to come for newborn screening. Even if only one life is spared....your help is what makes it possible.

