

# SAVE BABIES THROUGH SCREENING

EDUCATIONAL ACTIVITIES &  
PERSPECTIVES ON INFORMED CONSENT

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Jill Levy-Fisch, Save Babies Through Screening Foundation, presented  
at the  
National Conversation on NBS Research and Informed Consent Meeting



[savebabies.org](http://savebabies.org)



# INTRODUCTION

History

Who We Are

How We Connect & Educate





## Save Babies Through Screening Foundation

is the only national non-profit organization in the US solely dedicated to advocacy for newborn screening. SBTS works to improve the lives of children and their families by working to prevent disabilities and death resulting from disorders detectable by NBS. The Foundation's goal is to see that every child born is screened successfully, effectively and comprehensively.



# GOALS

Increase awareness

Facilitate communication

Educate parents

Support new program

development

Promote prompt clinical

evaluation

Enhance resources



# A BRIEF HISTORY

1998

Founded as Tyler For Life by Dallas and Tera Mize (whose son's NBS sample was delayed and whose results were not available until after he died from galactosemia).

2002

Name change to Save Babies through Screening to reflect mission

2004

SBTS Canada

2004

JLF affiliates with SBTS; personal story

2006

Jill Levy-Fisch becomes president of the organization

2007

NBS Saves Lives Act

2008

SBTS UK

2010

Legacy of Angels Grant



# WHO WE ARE

SBTS is an open organization where all interested parties are encouraged and welcomed to participate.

- Parents helping parents: 3000 members
- Parents advocating with health professionals
- Parents working with and supporting NBS Laboratories and Programs

## Affiliated Organizations

Coalition for Positive Outcomes in Pregnancy

Genetic Alliance

National Birth Defects Prevention Network

National Healthy Mothers Healthy Babies Connection

SIDS Families, Inc.



# WHO WE ARE

## Medical Advisory Panel

**MICHAEL J. BENNETT, Ph.D.,  
FRCPATH, DABCC**

**JEFFREY BOTKIN, M.D., M.P.H.**

**DONALD CHACE, Ph.D., MSFS**

**CAROLE A. FLEVARIS, Ph.D.**

**MICHELE HALL, R.N.**

**W. HARRY HANNON, Ph.D.**

**CHERYL HERMERATH, MBA, DLM  
(ASCP), RM (NCRM)**

**R. RODNEY HOWELL, M.D., FAAP,  
FACMG**

**MICHELE A. LLOYD-PURYEAR, M.D.,  
Ph.D.**

**FREDERICK W. LOREY, Ph.D.**

**PIERO RINALDO, M.D., Ph.D.**

**MICHAEL SKEELS, Ph.D., M.P.H.**

**BRADFORD L. THERRELL, JR., Ph.D.**

**MARI SMITH, RNC, MSN, NE-BC**

**JERRY VOCKLEY, M.D., Ph.D.**

**CATE WALSH-VOCKLEY, M.S., LCGC**

**LYNNE A. WOLFE, M.S., CRNP, BC**



# WHO WE ARE

## Board of Directors

**JILL LEVY-FISCH – President, SCADD family**

**MICKI GARTZKE – Vice President, Krabbe parent**

**ANNE RUGARI – Treasurer, Krabbe parent**

**LAURA LARKS – Secretary, 3MCC parent**

**TARYN PALADIY – Newsletter Editor, LCHADD parent**

**LISA ARCHETTI – Packets for Parents Program, LCHADD parent**

**RUTH CARUTHERS – Heart Defect/Pulse Oximetry Parent**

**KELLY JELLIN – Cblc parent**

**KORISSA OLSON – Galactosemia parent**

**KELLY PETERS – MCADD parent**

**SARAH WILKERSON – MCADD parent**

**TERA AND DALLAS MIZE – Co-Founder, Galactosemia parents**





**HOW WE  
CONNECT &  
EDUCATE**



# WEBSITES

**Save Babies Through Screening Foundation**

FIND OUT YOUR STATE'S SCREENING [DONATE NOW](#)

HOME ABOUT RESOURCES BLOG NEWS EVENTS FAMILY STORIES ADVOCACY SIGN UP CONTACT SEARCH

**FIND OUT YOUR STATE'S SCREENING**

Click on your state. A box will appear with a link to your state's newborn screening website and a link to the list of the disorders screened by your state.

Every newborn born in the United States receives a newborn screening test, how many diseases are screened for is determined by the state a child is born in.

**What is Newborn Screening?**

Learn from families and experts about the importance of comprehensive newborn screening.

[Watch the video >>](#)

**READ ABOUT OUR COMMITMENT TO THE PUBLIC HEALTH VALUE OF BLOOD SPOT RETENTION AND USE**

Number of conditions screened

- 100+
- 40-99
- 29 and under

Source: National Pediatric Screening and Genetic Assessment Center (part of ACGS)

## Savebabies.org

SBTS Foundation Website; our main portal to NBS resources, activities, and educational tools.

Visitors from 116 different countries  
8,684 users  
20,658 pageviews

**NewbornHearts.com**

Pulse Oximetry Resources supported by Save Babies Through Screening Foundation

[DONATE NOW](#)

About SBTS FAQs CCHD Resources Which States Screen? Family Stories Contact us

Welcome to Save Babies Through Screening Foundation's pulse oximetry resource website, NewbornHearts.com.

The heart is a very complex organ, so it might not be too surprising to learn that things can go wrong as it is formed in the baby early in pregnancy. In fact, about 1 out of every 100 babies is born with a birth defect of the heart, known as a congenital heart defect or congenital heart disease.

Some of these problems are minor and will repair themselves without help from medical professionals. However, some birth defects of the heart can be very serious, even fatal, and the baby will need immediate medical attention and perhaps even surgery or other procedures to stay alive.

Many of the heart conditions that are part of this group of more severe birth defects of the heart can be detected by newborn screening for critical congenital heart disease (CCHD).

Please take some time to browse our website for important information regarding CCHD pulse oximetry screening for newborns. You will find important news, FAQs and determine if pulse oximetry is required on newborns born in your state.

[Home](#) [About SBTS](#) [FAQs](#) [CCHD Resources](#) [Which States Screen?](#) [Family Stories](#) [Contact Us](#)

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## NewbornHearts.com

A key resource of information and support about pulse oximetry screening for newborn heart defects.



# SOCIAL MEDIA



[Twitter.com/ScreenBabies](https://twitter.com/ScreenBabies)

2, 838 Followers

24,817 impressions

48 new Followers per month average



[Pinterest.com/screenbabies](https://Pinterest.com/screenbabies)

300 Followers

281 Pins

20 Boards



# SOCIAL MEDIA

The Facebook logo, consisting of the word "facebook" in white lowercase letters on a blue rectangular background.

[Facebook.com/NewbornScreeningTest](https://www.facebook.com/NewbornScreeningTest)

3,014 Likes

1st result that comes up when you search Facebook for "Newborn Screening"

110,193 impressions YTD

100 new Likes per month average

[Facebook.com/ScreenBabies](https://www.facebook.com/ScreenBabies)

2,803 Likes



# OUR VIDEOS



# OUR VIDEOS



Utilized in over 136  
countries

over 18,000  
downloads

over 30,000 DVDs  
distributed

AVAILABLE  
LANGUAGES:  
English, Russian,  
Romanian, Traditional  
& Simplified Mandarin,  
Spanish, and Tagalog.

**Newborn Screening Saves Babies...One Foot at a Time**



# OUR VIDEOS



over 1,900  
downloads

over 2,000 DVDs  
distributed

AVAILABLE  
LANGUAGES:  
English and  
Spanish

**Newborn Bloodspots Save Lives...One Spot at a Time**



## OTHER VIDEOS



### Living with PKU

The story of how two moms, with sons born 20 years apart, learned to cope with raising a child born with Phenylketonuria.



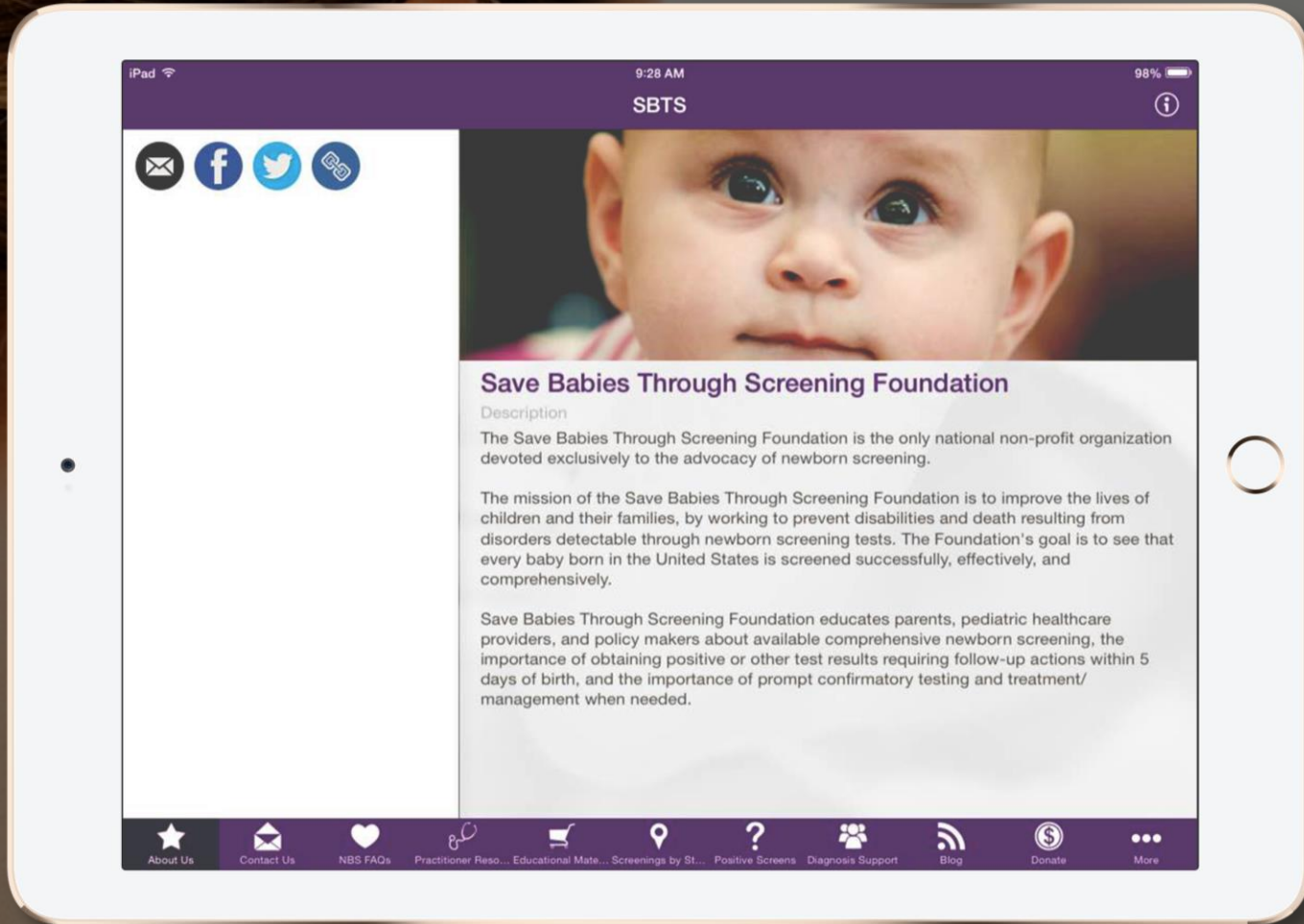
### Growing up with Galactosemia

One family's unexpected journey.





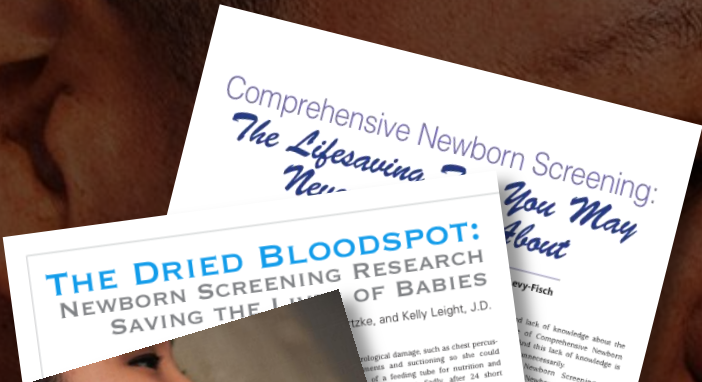
# MOBILE APPS



Soon to be available on both iOS and Android



# PRESS & PR



Magazines



TV Appearances



Radio Appearances



# OTHER EDUCATION & OUTREACH EFFORTS

## WEEKLY EMAIL NEWSLETTER

*featuring current information on NBS (articles, CDC activities, state activities)*

## CONFERENCES

*Speaking at conferences for educational purposes (NSGC, AWHONN, APHL)*

## MEETINGS & EXHIBITIONS

*Exhibition hall educational displays – targeting key partner-professional organizations*

## NBS AWARENESS MONTH (SEPTEMBER)

*for local awareness and advocacy activities; toolkit recognized by Library of Medicine*

## TOLL-FREE NUMBER

*maintained by board member 24 hours a day, seven days a week*

## BROCHURES

*“This Test Could Save Your Baby’s Life” available in English and Spanish*





**PERSPECTIVES ON  
SECTION 12 OF NBSSLA**

# PERSPECTIVES ON SECTION 12 OF NBSSLA

Residual dried blood spots are a valuable resource for the infant, the family, the newborn screening program, and others seeking to improve the newborn screening system.

Dried blood spots should be used for research that benefits infants and children.

Use of unidentified residual dried blood spots for program operation purposes by the newborn screening program or other investigators working with the newborn screening program should not require informed consent.

We advocate for the development of interpretive information that will preserve Newborn Screening Program operations and will carefully exempt such operations from the definition of 'research' under this Section.

A statement should be included in the Common Rule that defines the term 'research' in a way that does not impair newborn screening program operations.



**CONCLUSION**





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**[savebabies.org](http://savebabies.org)**