

Please Help

Save Babies Through Screening Foundation was founded by the parents of Tyler Wayne Mize.



Tyler Wayne Mize
May 1, 1998 – May 10, 1998

Tyler Wayne Mize was born May 1, 1998. Tyler appeared to be perfectly healthy, and was discharged from the hospital. Tyler had galactosemia, a serious inability to process milk. Tyler had the routine newborn screening test for galactosemia; however, it was 15 days before his newborn screening test results became known. Unfortunately, *God gave him only 9 days to live untreated.* Simply giving Tyler a special formula, and possibly an antibiotic for a short time, would have saved his life.

This foundation is dedicated to the memory of all the children who have lost their lives or suffered irreversible damage needlessly to disorders detectable through newborn screening.
You will live in our hearts forever.

Save Babies Through Screening Foundation, Inc.



Raising the Awareness of Newborn Screening and Related Disorders

www.savebabies.org

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Save Babies Through Screening Foundation
www.savebabies.org
Toll Free: (888) 454-3383 | Fax: (610) 993-0545
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What Is Save Babies Through Screening Foundation?

Founded in 1998, Save Babies Through Screening Foundation is a national, nonprofit organization whose mission is to prevent mental retardation, physical disabilities and early death in babies, resulting from disorders detectable through the newborn screening test. Because newborn screening recommendations are not up to date, Save Babies Through Screening Foundation educates parents and pediatric healthcare providers to give newborns comprehensive newborn screening for all disorders detectable through newborn screening programs, and to ensure that positive test results are reported in 5 days or less after birth.

The routine newborn screening (PKU) test may not be enough, and positive newborn screening test results may not be reported fast enough. Over two thousand babies each year in the US die, suffer brain damage, or experience complications due to newborn screening tests that are lacking or reported late. **These consequences are preventable** in most cases.

MISSION:

The mission of Save Babies Through Screening Foundation is to improve the lives of babies by preventing mental retardation and death resulting from disorders detectable through newborn screening.

OBJECTIVES:

The organization promotes its mission through the following objectives:

- Improve awareness of disorders detectable through newborn screening
- Improve awareness of the newborn screening test
- Facilitate communication between screening programs, support groups, and consumers (parents)
- Improve newborn screening guidelines and regulations
- Enhance resources for screening and follow-up programs
- Improve clinical identification of affected infants
- Promote national consistency among programs

What Is Newborn Screening?

Every baby born in the United States and most developed countries gets a newborn screening test. **However, many newborns receive less than the full screening we recommend, or receive positive test results late.** As a consequence, babies suffer brain damage or early death. Save Babies Through Screening Foundation recommends screening newborns for over 50 disorders (all testing can be done with the same blood sample) and that positive test results be reported within 5 days after birth. The list continues to grow as technology evolves.

Screening programs can prevent mental retardation, physical impairments and death, and were initially implemented in most states in the 1960's, to screen infants for Phenylketonuria (PKU). Thus, many people refer to the test as the "PKU test."

All states in the US have passed laws requiring that every baby born be tested for disorders through newborn screening. However, each state screens for different disorders. Babies with one disorder will **die** in one state, and babies with that same disorder will **live** in another state. This variation from state to state leads to confusion for parents and healthcare professionals. Save Babies Through Screening Foundation promotes nationwide consistency of the screening programs, for all infants and all disorders detectable through existing routine newborn screening programs, and raises the awareness of how important these programs are to the health of our babies. Every baby born deserves the right to live a normal productive life and newborn screening makes this possible for thousands of babies born every year.

To find out what your state screens for, and other information, contact

Save Babies Through Screening Foundation
(888) 454-3383
www.savebabies.org

