

Newborn Screening Saves Lives (10:34)

MICHIGAN

Lisa Halushka: This is Michael. He's 18 months old. He's our youngest. And my name is Lisa Halushka. There's something that you can do that's so simple, and so easy, and could make sure that your baby is okay for life, and that's prenatal care and the newborn screening.

(0:53)

NEWBORN SCREENING

Dr. Derek Bair, Director of Neonatology, Oakwood Hospital & Medical Center: Newborn screening has been present in the state of Michigan for some time. However, we have developed many new techniques for advancing screening that weren't possible, say, 15 to 20 years ago.

(1:08)

WHAT TO EXPECT

Dr. Derek Bair: The procedure itself is extremely simple; very little discomfort for the part of the baby, and the rewards for it tremendously outweigh any risk.

Lisa Halushka: It is extremely routine, and very little discomfort to him.

Dr. Derek Bair: It's a simple test requiring just a simple blood spot that we can obtain a tremendous amount of information by doing this simple test that may prevent long-term problems for the baby that can involve mental impairments, or possibly even death. At 24 to 36 hours of age, the baby's heel will be prepped with alcohol, wiped clean; a simple lancet will make a small poke in the baby's heel. A few drops of blood will be obtained. We basically fill these small circles on the state newborn screen. The card is allowed to dry for a minimum of three hours, and then it's forwarded on to the state lab in Lansing for processing.

Larry Halushka: This is Drew. He's a bit of a miracle child in a lot of ways. There were some challenges and some real concerns when he came out. I was scared during part of it, and I didn't want to show Lisa that I was scared. But in the end, everything worked out okay, and the doctors said all the tests seemed fine. So, newborn screening to me was just one more check that we had to make. I was familiar with that they were going to poke him and take some blood. We had other kids, so we'd seen lots of that done.

Lisa Halushka: Never expected that there was going to be anything out of the ordinary.

(2:45)

WHY IS IT IMPORTANT

NEWBORN SCREENING SAVES BABIES

Jena Wilson, Clinical Manager, Neonatal Intensive Care Unit: Newborn screening is important because we're able to detect early-on medical conditions that otherwise would not have been detected by having this test done. All of our babies here are tested. A lot of times they don't find anything.

Female Narrator: Each year in Michigan, about 225 babies are diagnosed as a result of newborn screening.

Jena Wilson: I actually had a daughter that was identified through the newborn screening 21 years ago, and she has a sickle cell trait. And, had I not had that test done, I would have never known there was a problem.

Larry Halushka: Got the call four days after he was born. And I picked up the phone, and they said, "This is the Michigan state lab." And the preliminary tests for Drew were positive.

Jena Wilson: It is always better to know, and to be prepared, than to find out something later on that could have been detected at birth.

Dr. Derek Bair: The likelihood of any child developing or having a condition that we screen for on the state newborn screening process in the state of Michigan is exceptionally low. We know after years of experience that if a disorder is found early that can be treated, and treatment is started early, the outcome is much better.

(4:00)

Female Narrator: About 1 in every 100 babies has a newborn screen that needs further follow-up. This does not always mean the baby has one of the medical conditions. A second screening test may be needed.

Lisa Halushka: I remember reading briefly about it in the hospital when you get all the forms and information from newborn screening. The only thing I remembered was that PKU was first on the list.

(4:30)

Female Narrator: Phenylketonuria/PKU is an inherited disorder in which the baby is unable to use a certain part of protein found in food and milk.

Dr. Derek Bair: For children like Michael, the identification of a disorder such as phenylketonuria, or what's affectionately called PKU, would not have been probably possible without newborn screening. The problem with many of these disorders that we screen for is that these children look perfectly fine initially, and it might be days, weeks, or months before problems are identified. So the importance of the newborn screen, in a sense, speaks for itself. Find the problem early, identify it, and treat it. Any parent that has a question regarding the testing can always contact the state, or discuss it with their pediatrician who should have basic information on newborn screening.

Female Narrator: For a complete list of medical conditions detected by Newborn Screening, visit michigan.gov/newbornscreening. These conditions may affect: Blood Cells, Brain Development, Hearing, How the body breaks down nutrients from food, Lungs and breathing, and Hormones. The cost of newborn screening is part of the hospital delivery charge. If you cannot afford to have your baby screened, or plan to have a home birth, please call 1.866.673.9939 to obtain a newborn screening card.

Lisa Halushka: I can't state it more bluntly, but to say that newborn screening saved my boys. Without newborn screening, I would have lost the essence of my children, who they are. And this relatively simple, routine, relatively pain-free heel poke that's done in the hospital was everything.

(6:33)

MICHIGAN BIOTRUST FOR HEALTH

Dr. Nigel Paneth, University Distinguished Professor, Michigan State University: There's now an added benefit to the newborn screening program, and it's a program called the Michigan Biotrust for Health. And that program stores leftover, unused blood spots from newborn screening.

Dr. Frances Downes, State Laboratory Director: It's very important. It enables us to improve the newborn screening program; enables us to assist in important public health research.

Dr. Nigel Paneth: Well, what the blood spot is, is a snapshot of some of the processes that are going on at birth, and perhaps even during pregnancy. And that information could be vital to the prevention of disorders like asthma, juvenile diabetes perhaps, the neurodevelopmental disorders like cerebral palsy and autism. And therefore, that information could be extraordinarily helpful to reduce the burden of disease in children.

(7:33)

HOW MICHIGAN BIOTRUST WORKS

Female Narrator: One full bloodspot is stored forever, specifically for future use by you and your baby, in case it is ever needed. The other remaining bloodspots have all directly identifiable information removed, and are properly stored for potential use in future health research.

Dr. Frances Downes: Generally, before you leave the hospital, you'll be approached to sign a consent form that will enable us to put your specimen into the research studies. The Michigan Department for Community Health is responsible for the Biotrust. So, any researcher who wants access to the dried blood spots must make an application, and provide a description of what they plan to do with the dried blood spots. The research applications are reviewed by a scientific advisory board who identify the merit of the research that's proposed.

Female Narrator: The Community Values Advisory Board provides guidance on Biotrust policies, and is made up of residents that represent the people of Michigan.

(8:50)

BENEFITS OF RESEARCH

Dr. Nigel Paneth: The kind of health research we're thinking about might be able to prevent major diseases of childhood or even of adulthood.

Dr. Frances Downes: We will ask you to give us permission and use those specimens for research. But again, they won't be identified to you as an individual, or your baby.

Dr. Nigel Paneth: This leftover blood spot could be the thing we need to really begin a program of preventing some of the real problems that children have that we don't yet understand. So, permission to study these blood spots in this way is vital to the future of child health.

(9:30)

NEWBORN SCREENING SAVES BABIES

Consenting to the Michigan Biotrust for Health is Your Choice. For more information, call: 1 (866) 673-9939.

Female Narrator: Let's be clear. Allowing your baby's blood spots to be used for possible research is voluntary, and may help other people someday. But newborn screening is important for your baby's own health now. That's why it's required by state law. Remember, newborn screening saves babies.

Larry Halushka: I would say the difference between the testing and not testing, as a father, is the difference between being able to provide for your family and keep them safe. And, as a father, your first duty is protecting your children. This should be the first decision you make as a father is to get your kid newborn screened.

(Credits roll at 10:12)