Newborn Screening Saves Babies… One Foot at a Time (16:34)

SAVE BABIES

Female Narrator: Before you know it, you will be leaving the hospital with your new baby. Whether it's your first or your fifth, here's some important information we'd like you to take home, along with all of your hopes and dreams for this wonderful new person.

(00:35)

NEWBORN SCREENING SAVES BABIES…ONE FOOT AT A TIME

Female Narrator: Sometime during the first two days of life, your baby will get a simple blood test called the newborn screen or the heel stick.

Female Medical Personnel: So then we just collect this onto the filter paper.

Female Narrator: These few drops of blood contain information that can save babies lives. The samples are sent to a special lab like this one at the Texas Department of State Health Services. They're used to search for dozens of rare conditions which are hidden at birth, but can cause terrible health problems.

Bradley Therrell, Ph.D., Director, National Newborn Screening Resource Center, Texas: What we're doing is taking that blood specimen from the baby, and breaking it down into some of its component parts, and looking for different biochemical markers that might show the presence of one of these conditions before symptoms are present.

Female Narrator: Here's the good news. The work done by Dr. Brad Therrell and his colleagues in public health departments around the country helps locate these hidden conditions before they harm your baby.

Dr. Bradley Therrell: The newborn screening results will tell us what's going on there and they can get the proper treatment, and those babies will lead a normal life. They can have a great life.

Dr. Melissa Wasserstein, Mount Sinai Hospital, New York: Once you see how newborn screening has saved even one child's life, it changes everything.

Female Narrator: Dr. Melissa Wasserstein works at Mount Sinai hospital in New York. She begins treating many of her young patients when they're just a week old, right after newborn screening detects trouble that not even an expert can see.

Dr. Melissa Wasserstein: Most babies who have these diseases are completely normal-looking at birth. They look like every other baby in the nursery, and in fact they act like every other baby in the nursery. So you would have no idea that this child might have one of these rare diseases.

Female Narrator: Four-year-old Kelly has a rare disorder called cobalamin-C deficiency. It prevents her body from using a type of vitamin B-12.

Dr. Melissa Wasserstein: You can have a lot of neurological side effects from this disease. Because we picked her up from newborn screening, and we started her on a special medication, and a special diet, she's done beautifully.

Female Narrator: Ten-month-old Jarius has CPT2 deficiency, which can cause muscle weakness and kidney failure without early detection.

Dr. Melissa Wasserstein questioning parent: And he's doing finger foods now?

Female Parent: Yes.

Dr. Melissa Wasserstein: Great!

Dr. Melissa Wasserstein to parent/camera: Children who have CPT2 deficiency can't use fat properly, and they can't make energy as well as other people can. We do not want him eating a super high-fat diet. So he's going to be on the diet that probably all Americans should be on. With that, he'll grow completely normally. He'll have all the nutrients that he needs to grow, but he won't get sick.

(3:30)

Female Narrator: Macalan has PKU, a potentially devastating disorder, which in its untreated form causes severe mental retardation.

Dr. Melissa Wasserstein: People with PKU can't break down phenylalanine, which is a type of protein. If we start them on this special diet that is low in phenylalanine, we can completely change the outcome.

Female Narrator: Thanks to newborn screening, Macalan can look forward to a full and healthy life. And, if Jeff Bird is any example, the future looks bright. Jeff was diagnosed with PKU shortly after birth, and for 22 years now, he's stuck to a strict low-protein diet that's completely prevented the disorder from affecting him.

Sue Bird, Rochester, New York: If I didn't have a positive on the newborn screening that alerted us to the fact that Jeff has PKU, Jeff actually would be institutionalized retarded. It's so hard for me to even say because I can't imagine Jeff as anything less than what he is. He did the same things that any kid would do – had sleepovers, you know, went to church, went to roller-skating parties. His big sport in high school was lacrosse. He's about ready to graduate from college in a mechanical engineering degree, and he has been having a great life.

(4:49)

WHY DOES NEWBORN SCREENING CONCERN YOU?

Female Narrator: Although the conditions identified by newborn screening are rare, out of more than four million births a year, between 6,000 and 7,000 babies are diagnosed through the program. The fact is they occur in families just like yours.

(5:10)

Laura Larks, Aurora, Colorado: It kind of turned my whole world upside down. There's no family history on my or Dante's side with anything like this at all.

Female Narrator: Laura and Dante Larks had five perfectly healthy children before they were informed that their sixth, Damien, had inherited a disorder called 3MCC. It prevents the body from processing protein correctly.

Laura Larks: My initial approach when they said he tested positive – he has this – was it's just not possible. I have five kids. There's no way my husband and I carry a genetic disorder.

Female Narrator: Although the Larks family never heard of 3MCC before Damien was born, as they would learn, they actually had a 1 in 4 chance of having a child with the disorder with every pregnancy. Here's how it works.

Dr. Melissa Wasserstein: We all have lots of genes in the body, and they come in pairs, kinda just like this. Sometimes people have a pair of genes that might look like this, where one copy isn't working properly. This person has a completely normal copy of that gene. So they're healthy and well, and they have no idea that they're carrying this abnormal copy. In the very rare chance that this person happens to have a child with another person who also has an abnormal copy of that same exact gene, they're at risk to having a baby who inherits both copies of that abnormal gene, and this child might have a genetic disease. They don't have a normal copy of the gene like their parents do.

(6:50)

Female Narrator: There's no way to predict such a rare occurrence, even when parents know a little bit about their genetic background. In 2000, Andrea Williams got a call that her son, Jonathan, had screened positive for sickle cell anemia.

Andrea Williams, Pittsburgh, Pennsylvania: I knew that I had trait, and that I was a carrier, but we had thought for many, many years that my husband wasn't. So we went through life and had three healthy children, and with Jonathan's newborn screen, we were very much caught off guard.

Female Narrator: Jonathan was promptly started on a daily dose of antibiotics, which he still takes to help avoid the life-threatening infections that come with the painful blood disorder.

Andrea Williams: If we didn't know that he had sickle cell disease at 10 days old, we wouldn't have known what was happening. He could have gotten sick and, um, he could have gotten an infection and, in four hours, he could have been gone.

Female Narrator: Because newborn screening caught Jonathan's condition so quickly, he got preventive care, and his parents learned what to look out for. When families don't get that kind of help, the results can be heartbreaking.

(7:56)

Anita Bailie, Charlottesville, Virginia: Cassidy was born September 18, 2001. She was beautiful, and she developed normally. At eight months old, she talked. She walked at 12 months. She sat up at six months. And then, she got sick.

Female Narrator: When Cassidy was 17 months old, her parents had to rush her to the ER. That's when they first heard of her rare disorder, glutaric acidemia type 1, or GA1. She should have been on a protein-restricted diet from birth, but they didn't know that. So toxins built up in her body until the flu pushed her over the edge, and her whole system crashed.

Brian Bailie, Charlottesville, Virginia: It changed everything. In a matter of seconds, I saw my daughter walking, talking, to it all goes away.

Female Narrator: Today, Cassie understands what's going on around her, but the permanent brain damage she suffered at 17 months left her unable to walk and talk.

Anita Bailie: If Cassidy had been picked up by newborn screening, she would probably be going to school and walking around, and looking like everyone else. So, her life would be drastically different.

Female Narrator: What happened to Cassidy Bailie could have been prevented, but when she was born in 2001, the test for GA1 had only recently been developed, and many states weren't doing it yet. By the time Cassie's little brother and sister came along, the state of Virginia was routinely screening for the disorder, and they're both okay. But there are still differences in state polices that can leave families vulnerable. Although all of the states require newborn screening by law, some test for 50 disorders – many test for less. Until screening is the same across the nation, it's important that you know and understand which disorders are included in your state's program. You can get that information at Save Babies. The website of the Save Babies Through Screening Foundation offers support and up-to-date news. There, you can learn about the disorders covered by your state's program, and also find out about additional testing that's available to the public at relatively low cost.

Brian Bailie: As a father, I would have loved to had that information and been able to make informed and accurate decisions to help my family. A simple heel prick can change the life of your child.

(10:40)

YOUR BABY'S NEWBORN SCREENING TEST

FEMALE NARRATOR: At UMC Children's Hospital in Nevada, they are trying a new approach to involve parents in the newborn screening process, encouraging moms to breastfeed or hold the baby during the procedure.

Michele Hall, RN, UMC Hospital, Las Vegas, Nevada: Hopefully by doing the heel stick at the bedside while the mom's holding them, they're more aware that, "Hey, a test was done!" Because a lot of them don't even know that the test was done.

Female Narrator: Most likely, your baby is ready to face the world under your watchful eye, but just to be sure, make certain the person doing the test gets the right phone numbers for you and your family doctor. Your baby's health could depend on it. Don't just assume that no news is good news. When you visit the doctor, ask for the results of the newborn screen. They should be in every baby's medical file by the age of two weeks. If you do get a call about your baby's heel stick test, don't panic.

Michelle Hall, RN: People should know that it's not a diagnostic tool. It can't tell you for sure your baby has one of these disorders – that's it's just, you know, raising a flag saying, "Hey, there may be a problem here, that we need to do further testing."

Female Medical Personnel: The minute we get the test results back, I'll give you a call.

Female Narrator: It's only natural to worry while you're waiting for the results of a follow-up, but keep in mind, most parents who come back in for a retest end up reassured that their baby is just fine. If your baby is among the few whose original screening results are confirmed, you might also consider yourself fortunate because this information can save your baby's life.

Dr. Melissa Wasserstein: When they first hear about the diagnosis, it can be absolutely devastating information, but as they see the child growing, no matter what kind of reassurance we offer them,

seeing their child growing and developing speaks far more eloquently than anything we could ever say to them.

Keri Dorazio, Staten Island, New York: It's going to be okay. It's something I'd like everybody to know because you don't think that at the beginning. He's no longer my sick baby. He's just an average child that follows a diet. And I thank God. I thank God for newborn screening.

(13:03)

ONE FOOT AT A TIME

Female Narrator: More than four million babies are born in the U.S. each year. Almost all get the heel stick before they leave the hospital. And now, you know why.

Dr. Bradley Therrell: Newborn screening prevents a terrible amount of suffering. The number of babies that are detected each year in this country is like 6,000 or 7,000.

Sue Bird: Newborn screening is saving lives one foot at a time.

Female Narrator: Newborn screening catches hidden problems that can harm babies one foot at a time.

Sue Bird: You know you can make the best out of this life if you've given the right type of information, and that's what I felt newborn screening did for us.

(13:55)

Female Narrator: Newborn screening helps protect families' futures one foot at a time.

Laura Larks: I absolutely credit newborn screening with saving my son's life. He's happy. He's healthy. And things look good.

Female Narrator: Newborn screening gives kids the best chance to beat disease one foot at a time.

Andrea Williams: If it has a viable treatment, if there's a treatment available, you want to be able to get that treatment. And you want to get it in time. Jonathan has a great outlook. From a little tyke, we've been teaching him that this is something that can be managed.

Female Narrator: Now that you know about newborn screening, help share the facts and spread the word. Newborn screening saves babies.

Jeff) Bird: One foot at a time.

Female Narrator: For more information and support, please know we're here. We're parents like you who want their babies to get the best start in life. Visit Save Babies or call us toll-free.

(ends at 15:00)