**An Uncertain Road: Life After Premature Birth**

**Intro to series:**

A premature birth can cause weeks or even months of uncertainty in the NICU, but for many families, especially those of the smallest preemies, the roller coaster of worry over their child’s health and development continues years after they are discharged from the hospital.

In the last 20 years, science has pushed the frontiers of neonatal care, and doctors are saving premature infants lives at younger ages, some as young as 22 to 25 weeks. These tiniest of infants – micro preemies – are surviving more often than ever, but rarely complication-free. Most will experience lifelong consequences in their health and development.

Experts who work with premature babies every day have to weigh the question: if science can save their lives, shouldn’t it be able to ensure some quality of life? So far the answer is that it cannot. Many children will do well, but most families face years of complicated decisions and expensive interventions.

In "An Uncertain Road: Life After Premature Birth," reporter Rebecca Smith profiles several children, who were born between 21 weeks and 26 weeks of gestation, and their families. Now, as the children grow up, each of them have their own struggles and face uncertain futures.

**Headline: Growing up from 22 Weeks to four years old, facing uncertainty every step of the way**

William Beversdorf gleefully scrambles toward the swings as soon as his father David sets him on the ground. At four years old, William is a little small for his age and is a little unsteady on his feet, but he gets where he wants to go. And once he’s on the swing – his smile lights up his entire face.

Before David begins to push the swing, he leans in close and says “Da-da?” William looks up at his father and in a quiet voice replies “Da-da.” David then leans in again and says “Can you say Mom? Mommy” and in a voice barely above a whisper William replies “Ma-ma.”

Swing time for William is not just simple playtime, but is in fact a way for David to promote language practice for his son; the fun of swinging seems to motivate William to try new words. And he’s picking up new words every week – the most recent: “pretzel.” A full two syllables. This may not seem that astounding for a four-year-old, but when you consider William’s entry into the world, it is pretty remarkable that he is developing at all.

William is David and Shelley Beversdorf’s first child together. The pregnancy went well until Shelley was diagnosed with placenta previa diagnosis, a complication in which the placenta partially or totally covers the opening in the cervix, making an emergency delivery necessary. So instead of the typical 40 weeks of gestation, William came early.

“It just happened immediately. Then we were thrust into this nice little room at the NICU [Neonatal Intensive Care Unit] and there we sat with him full of tubes and wires and everything else,” Shelley recalls.

William was born at just 22 weeks and one day, weighing one pound, three ounces. The youngest premature infant ever known to have survived was born at 21 weeks and 6 days – two days younger than William.

From his first breath, it was uncertain whether or not William would live, and if he did, what kind of life he would have.

In the hospital that day, the doctors were honest. David says they told them that William had less than a five percent chance of survival and if he did make it, “he’d be messed up basically.”

William weighed less than a can of soup. His eyes were still glued shut. His skin was so thin that it was nearly translucent. And when David slid his wedding ring onto William’s arm, it engulfed it.

But the Beversdorfs felt that their son could make it and they told the doctors to do everything possible to save him. Once he was born, a doctor inserted an endotracheal tube down his throat making it possible for him to breathe with severely underdeveloped lungs.

William would spend the next five and half months in the NICU receiving medical assistance for numerous bodily functions. There were several close calls during those months like the time at about two weeks old he needed gastrointestinal surgery and David says it was “very clear he was dying.”

But he made it through. After that, things were going smoothly and the Beversdorfs prepared to bring their baby boy home. But the couple knew this was only the beginning of the battle. For a baby born as small as William every step into childhood, every developmental milestone would be a new challenge and a new source of uncertainty. Would their boy grow like other kids? Would he have health problems? Would he ever be able to walk or talk or go to school?

“We had no idea - we knew there were a lot of possible problems physically - was he going to end up sick? And then end up in the hospital? And then have permanent lung damage? That seemed pretty likely actually,” David said. “We had no idea what would be our issue going forward, but we knew there was still a bit of a minefield.”

**Survival Of The Smallest**

Not every hospital would have encouraged William’s parents to try to save him.

Neonatal care has gotten better and better in the last 25 or so years, regularly saving the lives of more infants born before 28 weeks gestation. But 22 weeks is considered the “limit of viability” for babies; by current standards it is the youngest a baby can be born and have any chance of survival. And there’s lack of consensus among academics and medical professionals about how good those chances of survival are.

“At 22 weeks, they have a less than 10 percent chance of surviving,” says John Pardalos, a neonatologist at University of Missouri Women’s and Children’s Hospital in Mid-Missouri.

George Macones, a high risk obstetrician and the head of the March of Dimes Research Center at Washington University in St. Louis, says he would tell a family in that situation that the chance of survival at 22 weeks would be “zero.”

This disagreement comes because there’s little statistically significant data at this gestational age; babies born at 22 weeks have not been surviving for very long nor in great enough numbers to gather that data.

Even for those that do survive, there’s a high risk of serious, life-altering complications that affect quality of life.

These are what the Beversdorf’s doctor warned them about. Micro preemies or babies born before 26 weeks gestation, have very underdeveloped brains, and the complications of keeping them alive leads to a high risk of bleeding in the brain that can result in cerebral palsy and other developmental disabilities.

Prematurity can also lead to vision impairment or blindness, and is tied to higher rates of developmental delays or impaired cognitive skills, hearing impairments, problems with teeth, behavioral disorders like ADHD or anxiety, developmental disorders like autism and other chronic health issues.

Research has shown the earlier an infant is born, the higher risk there is for these problems. Because of this, not all hospitals will try everything possible to save a baby’s life, when it is delivered at 22 weeks or under. This is a process known as active intervention. In fact, just one in five of the hospitals in the study actively intervened at this gestational age, according to research published in the New England Journal of Medicine.

Both the American Academy of Pediatrics and the American Congress of Obstetricians and Gynecologists recommend that doctors and parents make decisions on a case-by-case basis when babies are born this early. And according to same study, active intervention is generally not recommended for babies born before 22 weeks.

When doctors do intervene, using state-of-the-art treatments like surfactant therapy to help the lungs function, ventilator support, and a number of other interventions, survival rates are as high as 23 percent according the same study. Other studies show a lower rate of survival, down to 7 percent.

Over the last 20 years, survival rates have improved for preemies of all ages. But even though more babies are surviving, the rates of severe complications are still high. For the smallest of preemies, those born at 22 to 24 weeks, rates of survival without severe health and developmental disabilities *have not improved*, according to a 2015 article in JAMA.

Of 334 infants studied in the article, zero left the NICU without severe complications.

**No Stone Unturned**

William was relatively lucky. In the early weeks in the NICU, he only dealt with a few serious complications. At two weeks old be had a low-grade brain bleed and the abdominal issues that turned him grey and required gastrointestinal surgery.

“At the time you don’t know why his belly’s swelling up and he's turning grey,” David says.

It could have been much worse. Other than those few nail-biting events, William didn’t experience some of the extremely damaging events, such as severe infections, sepsis, severe hemorrhages, lung problems and retinopathy of prematurity that can affect a baby’s life later down the road.

When they brought him home from the NICU, William was physically healthy, exceptionally so for a micro preemie. As a toddler, other than a few colds, he didn’t show any long-term physical complications of the NICU except for missing the finger tips on his left hand – though it doesn’t seem to affect his dexterity.

But they learned—as many parents of micro-preemies do—that William’s chance of success developmentally is no more certain now that he’s home from the hospital than his chance of survival was in the NICU. How well he will develop, whether he will ever speak, read, or go to school depends partially on the interventions and therapies the Beversdorfs take him to and partially on William’s response to these treatments.

Not long after he got out of the hospital they took him to a development clinic that specializes in children born premature. It was at that clinic that William was diagnosed with autism. They prepared themselves for the fact that various milestones might be slow in coming, or never come.

“When he first started walking, we were thrilled. It was late. Not monstrously late,” says David. “[Then] we started speaking a little bit and we were really excited, and then that was kind of much slower.”

William’s language skills are delayed, but at three he started using what David calls “meaningful consonants” and within the last few months he has added a few words to his vocabulary. Socially, he doesn’t spontaneously interact with other kids at preschool.

Shelley Beversdorf jokes that caring for William has become a “full time job,” as she and David try to do everything they can to help William catch up developmentally.

They take him from different therapies to doctors’ visits to horseback riding to gymnastics to language school to a church daycare, all while raising William’s little sister as well.

“I don’t know what to expect there. Nobody knows what to expect,” David said. “We're just going to keep giving him everything to try and maximize his chances.”

Tracy Stroud, a developmental behavioral pediatrician at the Thompson Center for Autism, oversees the development clinic William goes to for regular therapy. The clinic includes a speech pathologist, an occupational therapist, a physical therapist, a nutritionist, and a nurse practitioner.

Stroud sees many children who were born prematurely – a group she calls “at risk” for developmental disabilities.

She says the clinic looks at head growth, head shape, MRI readings, and tries to identify subtle signs of developmental abnormalities early on so they can change the course of a developmental delay or diagnose a serious condition before it gets worse. She adds that no two preemies have the same trajectory, therapies can play an important role in later life success.

There are clearly babies that have lifelong struggles from being born premature,” Stroud says. “[But] for many of the babies, they do really really well.”

**Onward into the Unknown**

The costs of all these classes and therapies add up – even with good insurance coverage – and even for David, a well-paid neurologist and Shelley.

“We could rent a small apartment for the amount that we're having to go out of pocket on the copays,” David said. “It’s a real problem and if it’s a problem for me with our resources, think about what kind of a problem it would be for others.”

While the Beversdorfs are trying to give William as many tools as possible to succeed, David said they don’t set goals for him.

“[He’s] going to do what he’s going to do, and that’s a really healthier attitude for any child,” David said. “To just help them do what it is they want to do as much as possible.”

Now four years old, William is continuing to make gains. He is still on the autism spectrum, and doesn’t spontaneous interact with others the way many other children his age do.

But the Beversdorfs have begun to look at starting school prep for kindergarten, something they didn’t dare dream of in those early months in the NICU.

“At the beginning, you went from ‘Hey, he’s gonna be such a smart kid’ to ‘I hope he survives somehow,’” David said. “So now you're back to saying, ‘Maybe we can maximize some cool stuff and maybe we'll have to struggle with something.’ Maybe he’s not going to be a skilled athlete, but really good at something else.”