**Headline: Twins Skylee and Cauy were born at the same time, their lives took vastly different turns (?)**

When Shanna Mondy started feeling labor pains at just under 24 weeks into her first pregnancy, she had no idea what to expect.

“We didn’t do any classes,” her husband Rob Mondy recalls. “Because at 24 weeks we didn’t think we needed it at that time.”

The Mondys went to the hospital right away and the doctors were able to prevent the labor for a few days, but the Mondy twins arrived at just 24 weeks and one day. Cauy, a boy, was born at one pound, six ounces and a few minutes later, Skylee, a girl, at one pound, five ounces.

“I just remember freaking out because I didn’t have anything to take them home [in],” Shanna recalled. “And they were like ‘They're not going home anytime soon.’”

At first things looked ok for both infants, even though Cauy was born with severe brain hemorrhages or bleeding in the brain. Then at three weeks, Cauy developed a yeast infection and meningitis. Skylee seemed stable but they weren’t sure Cauy was going to make it.

Shanna and Rob remember those four and a half months in the NICU as a roller coaster of good and bad health events – one step forward and a few steps back. What they didn’t know then was that, for Cauy, the NICU was just the beginning of his journey. The early brain bleeds he had would leave him with lifelong problems.

On the other hand, their daughter Skylee’s first few months were unusually free of major issues, and this would put the children born within an hour of each other on vastly different life trajectories.

Premature birth—especially under 24 weeks—puts children at high risk for many long-term, life-altering complications. But there is great disparity in outcomes for children born prematurely—their long-term health is hard to predict or control in the first few weeks of life. This puts parents and doctors in the difficult position of working to save a life, while knowing that the child they save may face years—or even a whole lifetime of medical, practical and financial difficulties.

**Life back home: Diverging paths**

After about a year, the differences between their children started to become obvious to the Mondys. For the first few years post-NICU, Skylee never needed to go back to the hospital, but Cauy had many health crises. Within just a couple of years he had several shunt revisions, which is an invasive procedure placing a tube in the head to help drain off excess brain fluid, and he struggled with a gastrointestinal condition known as cyclic vomiting syndrome.

And, he wasn’t hitting the developmental milestones his sister was.

“Skylee was rolling, crawling, walking,” Rob recalls. “And [Cauy] was just lying there.”

He couldn’t even sit up, and while his sister started babbling, making eye contact and eventually talking, Cauy didn’t develop as quickly. And the Mondys still didn’t know what was wrong with their son.

The neurologist continued to tell the Mondys that Cauy was just a preemie and that they shouldn’t worry about his lack of development, but the Mondys still felt that something was off.

Finally, when Cauy was two years old, they decided that being a “preemie” wasn’t enough of a diagnosis – they needed answers. So they got a referral to a clinic that specialized in cerebral palsy.

“I remember getting a paper and it had all this information on it, and it says ‘Diagnosis.’ It says ‘Cerebral Palsy’," Shanna recalled.

Despite the severity of the news, the Mondys said it felt “like Christmas” for them. For the first time, they understood what was going on with their child. With the diagnosis in hand, they could start to help him, getting him a wheelchair, appointments for therapies and custom orthotics. And, they were finally able to set realistic goals for Cauy.

“At the time, we wanted him to walk before he could crawl. We wanted him to speak. We wanted him to be able to play,” Rob says.

“Maybe a goal is for him to crawl now instead of walk. Maybe a goal is now to be able to use a button [to communicate] instead of speaking. We weren't living in a fantasy world anymore.”

Survival rates have improved for babies born at 24 weeks or older over the last few decades - at least a 50-50 chance of survival. This is thanks to new technologies and therapies including better ventilators and surfactant therapy, a way of coating the babies’ lung with a substance that makes it easier to breathe.

But as this technology saves more lives, it hasn’t significantly improved the chances for babies born at this age or younger to grow up without serious impairments.

About 45 percent of babies born at 24 weeks will grow up with serious disabilities, according to a 2015 study published in the New England Journal of Medicine. These “severe impairments” could be life in wheelchair from severe cerebral palsy, blindness or severe hearing impairment. And 30 percent will grow up with milder problems, moderate forms of cerebral palsy effecting motor skills, cognitive skills, and other neurological problems like ADHD, autism or learning disabilities.

**Life Moves On**

At seven, five years after his cerebral palsy diagnosis, Cauy is a very happy and social guy who’s always smiling. But he cannot walk, cannot talk and continues to have some health problems like seizures. After his early years of multiple doctors’ visits every month, Shanna says things are starting to level out a bit, and Cauy only sees most of his doctors every six months or a year.

His sister Skylee on the other hand, is a normal, busy seven-year-old girl. She participates in Girl Scouts, takes dance and gymnastics, plays soccer and does CrossFit with her parents. She’s a little small for her age, but shows no other repercussions of her pre-term birth.

The Mondys say that while physically and developmentally being a preemie hasn’t really affected Skylee, her life is different because she and Cauy were born at 24 weeks.

“She lives it. She knows it. She knows there are certain things we can’t do because we’re saving for another piece of equipment [for Cauy],” Rob says.

Rob and Shanna say both their children are a joy. But they admit that Cauy’s needs can be a financial struggle for the family.

There are a lot of expenses when you’re raising a disabled child, things like pricey medications—Cauy takes one that costs $12,000 a month—formula for sustenance and specialized equipment like a wheelchair accessible van that cost $20,000. Rob gets frustrated at these costs, which seem unnecessarily high, especially because insurance doesn’t cover everything.

"There is no reason for a stroller to cost $10,000,” Rob says. “It’s not fair, and then people don’t see that sometimes that is money that we have to take out of our pocket. They see the equipment that we have and they just assume that everything is paid for.”

He adds that insurance covers part of the costs, and there are a few agencies that help with the bigger and more expensive items they need for Cauy. But even with insurance, meeting the necessary deductibles can be difficult for the family. Rob says they often meet their deductible within the first month and a half of the year, but “if we don't have that extra amount of money just laying around it can be difficult to meet.”

According to the Centers for Disease Control and Prevention, the average lifetime cost to care for a person diagnosed with cerebral palsy is nearly $1 million.

**Looking Toward the Future**

For Shanna, it’s the very long-term implication of Cauy’s premature birth that worry her the most.

She knows when they get ready to retire, they can’t dream of traveling the world, leaving their son behind. And who is going to take care of Cauy once they can’t? “We have to think about what’s going to happen when we die, and it’s just a lot of hard decisions,” she says.

Shanna has come to accept her son’s condition though it is still hard.

“If you say ‘What do you think he's going to be like in 15 years?’ This is what I see,” she says gesturing toward Cauy. “I can't imagine him talking. I can't imagine him walking. I cannot - in my head - imagine him saying words. I couldn't even imagine what it would sound like. I probably would cry, I think I'm going to cry now just thinking about it.”

But Shanna says they are used to the way things are, and they plan to carry on how they have for the past seven-plus years – balancing Skylee’s busy social calendar, Cauy’s needs and fun family activities like CrossFit.

Like any family, they have their milestones. Skylee recently got a favorite birthday present: a diary with a lock, And Cauy is getting a new wheelchair that lets him maneuver himself up and down the hallways – giving him a taste of independence.

Both Shanna and Rob say they wouldn’t change a thing, but they do sometimes wonder how their lives would be different if the twins had been born full-term and perfectly healthy.

“I figure [in the future] he'll just be bigger, taller, but I feel like we’ll still be doing the same thing.” Shanna says. “I feel like we're at a point where we're good, you know, like we're not having emergencies. And, you know, we're good. This is life.”

**Medical Progress**

As new technologies have helped raise the survival rates of babies born extremely prematurely, it hasn’t significantly improved the chances for babies to grow up without serious impairments.

These outcomes have led some neonatologists and other medical professionals to question the definition of survival for these micro preemies born long before their due dates. And to question if intensive medical intervention is always the best choice given the burden of suffering, continued medical needs, disability care and expenses to their families and society.

One study published by the American Academy of Pediatrics in 2006 calls the use of neonatal intensive care on infants born before 27 weeks gestation the “fundamental controversy in neonatology.”

“As more of these babies are surviving now, we are creating a generation of babies that will need more help in elementary school and in high school because of the learning issues that they might have or the physical disabilities they might need to overcome when they get older,” says John Pardalos, a neonatologist at University of Missouri Women’s and Children’s Hospital in Mid-Missouri.

Pardalos says that in most cases, the choice to save a preemie’s life is the parents’ decision, with information provided by their doctors. But Pardalos says, it’s terribly hard to predict outcomes or advise parents because no two infants have the same trajectory.

“Yes, I think we are creating more disabled kids, but I think we also have a lot of kids that are completely normal even though they started little, and are full, participating humans in our society 20, 30, 40 years down the road,” says Pardalos. “So it's hard for me to say ‘You're going to be great and you’re not.’ We just have to take the chances and treat everyone like they will be able to survive and do well on their own in the future.”

So while more babies are being born with long term complications of some sorts, what motivates some doctors in the field is the thought that medical progress is still happening.

George Macones a high-risk obstetrician and the head researcher for the March of Dimes Research Center at Washington University in St. Louis says that neonatal care is following the normal progression of medical research: medicine focuses on saving patients first, bettering outcomes second.

“Everything is in steps,” Macones says. “First is survival and then we try to work on survival without any complications. [It’s] the same as cancer - the first thing you want to do is get people to survive, the second thing you want to do is make sure they're not sick for the rest of their life from their radiation treatment that they got. I think the same is true for prematurity.”

But he says the stakes for premature infants may be even higher than for some other conditions.

“If you are 65 and you have cancer and you have 15 years left to live that is a lot different than the complications you see in a baby that's born that's going to have a 75-year lifespan - that's going to have a whole lifetime of disability and problems,” Macones says. “So I think the stakes are higher for us, which is why you know we are all working so hard to make some progress.”