Headline: At 12 years old, one preteen and his parents still live with fears of the future (due to premature birth)

**NEED A DIFFERENT SUBHEADER HERE**

My Aunt Carolyn and I have always been close. She chose to call me her “princess” when I was a child, even though I was very far from it. I was a huge tomboy and she was one of the only people who could catch me and brush my hair. So needless to say, I was incredibly excited she became pregnant with her first child in 2003 - I was ready for a baby “prince” or “princess” cousin to call my own.

**Unexpected Arrival**

Carolyn and my Uncle Vince Allred, live in St. Louis, Missouri. In 2003, they were still newlyweds and were excited about their futures: Carolyn was working her dream job as a neonatal nurse, Vince was back in school and they were expecting their first child.

But on September 18, 2003 – at just 25 weeks and 5 days into her pregnancy - things took an unexpected turn. Carolyn went into pre-term labor.

“On the trip, I cried the whole time, screaming ‘My baby's dead. My baby's dead,’” Carolyn says. “It wasn’t until I got there and I heard the heartbeat again that I knew that he was still with us.”

While their son, Jacob Allred, was still alive, there was no stopping it. Jake was born at just 25 weeks and five days at one pound and thirteen ounces. So small that his tiny footprints fit on a standard business card. To this day, my Dad, Carolyn’s second oldest brother, carries “Jake’s Business Card” in his wallet.

**A Rough Start**

Jake was born so unexpectedly that there was no time for Carolyn to recieve pre-labor steroids, which could have reduced Jake’s chances for complications. He spent the next four months in the Neonatal Intensive Care Unit or NICU.

When he was around two weeks old, Jake developed an isolated staph infection, and his condition became critical. Carolyn and Vince were told they should come to the hospital and say goodbye, but, somehow, Jake managed to recover.

Carolyn says that, to this day, she tells Jake the story every year on October 1, the anniversary of his survival.

“Jake laughs, because every October 1, I bawl like a baby when I put him to bed,” Carolyn says. “It’s his favorite story to hear… because he lived and he did good. Did we expect him to do that? No. We didn’t know at the beginning of that day what was going to happen, and we were really okay with him dying.”

During Jake’s four month stint in the NICU, Carolyn and Vince celebrated every week with Jake, since they weren’t sure how long he would be with them. Each week, for his “weekly birthday,” the Allreds would bring him a new Teenie Beanie Baby to put by his incubator. Vince says the uncertainty of Jake’s health during that time was an emotional rollercoaster. But finally there was a turning point.

“I think it was about two and a half months into the NICU stay that [we] thought ‘Man, he's doing alright. He's going to make it’,” he says.

**Growing up with Uncertainty and Hope**

For Carolyn, the first four months were especially terrifying because she had been working in the NICU as a nurse for just over a year. She says she knew just enough to be “lethal to myself.” One thing she was clear on: The chances were great for extremely premature babies, like Jake, to have lifelong health complications that affected their entire lives.

In 2003, the survival rates were just over 50 percent babies born at Jake’s age.

“I remember back then my number one worry wasn’t death; it was having a baby with no quality of life,” Carolyn says. “I was overwhelmed with worry, guilt – every emotion, horrible emotion that was involved with worry that he wasn’t going to have the quality of life that I want my child to have.

She had to keep living with that fear, even after Jake was discharged and they took him home. Carolyn calls the first few years of Jake’s life “one medical extravaganza after another.”

At nine months old, Jake had aspiration pneumonia, where fluids collect in the lungs instead of the esophagus and stomach. At 11 months, Jake was experiencing congestive heart failure from an unclosed blood vessel. During his first year he had multiple ear surgeries, and by two, he had shingles and such severe constipation that he stopped digesting food.

“We didn’t know what the future was going to hold at that point,” Carolyn says.

John Pardalos, a neonatologist in Mid-Missouri says it is very common for parents of premature and extremely premature children to have these fears while they are in the NICU and even beyond it. Pardalos often speaks with parents often about their babies’ potential outcomes and says parents tend to ask “Will my child be able to walk? Will my child be able to care of his or herself? Will they go elementary school? High school? College?”

And since babies born premature can have vastly different outcomes – he can never give a definite “yes.”

**Looking Forward to the Future**

After those first few years, the medical issues became less serious, but they never stopped. Ear and eye surgeries continued, he had to go to therapies for behavior and development, and Jake got braces at a young age to fix the shape of his pallet. He was diagnosed with autism. There was some hearing loss, and he had abundant sensory issues. For years, he only ate and drank while in the bath, and exclusively had Diet Coke.

“[You] have to modify the world to fit their son or daughter,” Carolyn says. “Like with Jacob, he would not - at 18 months - drink anything at all. My Mom actually gave him Diet Coke one day, and he guzzled it, and we were so excited. He drank Diet Coke from 18 months to three years because that's the only liquid that he would drink.”

But now, 12 years later, even with some health and developmental issues, Jake is a pretty healthy and happy guy. He’s quick to laugh, and his laugh is both infectious and booming. He loves music and God and his family. Jake and I are pretty close, and in celebration of his 12th birthday I registered us to do his first 5k – a nighttime color run.

Jake knows he was born extremely prematurely. He has discussed it with his parents and listened to their yearly retelling of his survival. He knows he’s different.

“My brain will never be like anybody else’s. Like a normal human being’s would be,” Jake says, “I face social issues. If I don't understand something and I really want to know, but I still don't understand it, I kind of get a little anxious.”

Carolyn says he’s right – at 12, his big issues are social – knowing he’s different and wanting to fit in, but not knowing how.

A study published the Journal of Pediatric Nursing in 2009 examined kids who were 12 - Jake’s current age. Researchers followed up with babies born prematurely at that age, and the study found that being a preemie still affects a child’s health as they reach adolescence at 12.

When compared to infants born prematurely, babies born full-term were 90 percent less likely to have “abnormal health” at 12 years-old.

“To this day, there are repercussions of the things that have happened to him because of being born early,” Vince says.

It’s hard for Vince and Carolyn to watch Jake struggle, especially with social issues, which could affect his chances of being successful as an adult.

While he is at grade level for nearly everything academic at school, he is just now making his first real friend. He struggles to fit in, even at family functions. Instead of being engaged with others the whole time, he needs to sit by himself and listen to music so he doesn’t become overwhelmed.

Jake is also still dealing with absence seizures, where he stares off into space, unaware of what is going on around him and unable to hear or react to people when they call him, which can make school challenging.

Carolyn and Vince say it’s nearly impossible for them to know which health issue is causing him not to acknowledge them.

“We still can’t tell you if he's seizing. We've never seen one [a seizure] to say that’s 100 percent a seizure,” Carolyn says. “Is it the hearing deficit? Is it the autism? Or is he having a seizure? … Is he just being a 12 year old that is being a snot or does he really just not hear us?”

But Carolyn says, it’s okay. They have learned to adjust to the complications that she believes are a consequence of Jake’s premature birth. She says that, in her opinion, if Jake hadn’t been born extremely premature he would have “a heck of a lot less issues today.”

Jake understands what his premature birth means for him now, but his visions of the future don’t seem to extend must past the near future.

His wish on his 12th birthday was for everyone to have an “awesome time” at his birthday party, which was going to include apple picking, pig races and a haunted hayride. But when we spoke about the next year of his life, Jake’s wish was a little more serious. It was about his seizure condition.

“I think that it’s uncontrollable,” Jake says. “I just hope for it to reduce a little bit. Just that I don’t seize as much.”

Carolyn says that the Allred family is “totally dedicated” to Jake being included in everything, and they all support him and are prepared for the road ahead and the challenges that may arise.

Will Jake’s seizures reduce? Will Jake be able to get a driver’s license? Will Jake go to college?

It doesn’t matter, Carolyn adds, because no matter what the future holds and no matter what obstacles Jake will face, the Allreds are ready for whatever may be thrown their way.

“He has a future,” Carolyn says. “Who knows what that's going to be, but, you know, I think he’s going to be a productive citizen in society.”