

I Think We're Done Here

By: Jenna Gensic

Other critical babies in the unit had their victory days; now it was Mikan's turn. Prior to his birth, we'd never thought extubation day, the day the hard plastic breathing tube was finally removed from our son's throat, would be the most anticipated event of Mikan's life. But now, as we stood by Mikan's crib, we cherished the "e" word as a covenant to eliminate the ventilator from the bedside, to move into the "non-critical" room, and to discuss discharge dates in the weeks ahead.

"That nasty tube down your throat is uncomfortable, right?" My husband prompted him. "Let's breathe like a big boy and we'll be out of here soon."

I stared at the white tape above and below Mikan's mouth that helped secure the breathing tube. We didn't even know what our son's face looked like.

A respiratory therapist and nurse arrived, setting up new equipment: a CPAP machine, one step down in respiratory support for Mikan.

"It's Mikan's big day!" The therapist smiled as she connected sterile tubing to a humidifier and a canula with nasal prongs the size of ear plugs. I imagined the tubing plugging his nostrils and wondered if Mikan's face would maintain a pig shape after the mask was no longer needed. The therapist and nurse pried the tape off Mikan's lips, careful to hold the breathing tube in place. I could almost glimpse his mouth around their hands. The neonatologist arrived.

"Are we ready?" The doctor's glance darted around the room, then fell on Mikan. He tucked one hand underneath an arm and rubbed his chin with the other. My husband and I backed a few steps away from the bedside. The respiratory therapist hovered over Mikan's face with the new mask, holding his breathing tube until she was given the order from the doctor. He nodded.

She deftly removed the tube and shoved the large canula into Mikan's nostrils, forcing pressurized air into his upper airway. Mikan used every bit of strength to fight the hands in his face. Without the ventilator tube restricting airflow past his vocal chords, we heard his gurgled cry for the first time. I watched him struggle and prayed he would calm down and breathe normally.

The computer monitor by his bed began to beep. The bright green numbers revealing his oxygen saturation and heart rate were dropping.

"Turn his oxygen up," the doctor ordered the nurse.

"He's at 80%."

"Give him 100."

The nurse cranked the oxygen to its maximum output. The monitor beeped, his green numbers flashed, and Mikan continued to squirm, shaking his head in a fury to avoid the monstrous prongs. Other nurses glanced worriedly at Mikan, perhaps hoping for a miracle. But his saturations wouldn't rise to a healthy level. Then his heart rate dipped into the 60s for several seconds. Everyone's eyes darted between Mikan and the monitor. The doctor massaged his chin with unconscious aggression.

"I think we're done here."

His words slapped me. They meant our day of hope and celebration was one of disappointment, worry, and frustration. It was a reminder that our son wasn't following the typical premature baby's healing path. Most devastating was that it left us with no end in sight. No forward progress. No sense of when our son might sleep at home. He had months to go.

"You should leave. You don't want to see this," his doctor said. We had hundreds of questions for him, but they had to wait until Mikan's breathing tube was reinserted, and he was stable.

The therapist tossed his CPAP canula and tubing into the trash nearby.

We began a phone chain to out-of-town parents, relaying the disappointing news. I was annoyed by the trite promises of future progress in phone call after phone call. My brain stopped decoding when a relative began with, "It'll get better," "He'll be home before you know it," or "This will all be a blur soon." Our situation was dismal then, and no one seemed willing to accept it. No one wanted to talk about what we were currently enduring; they wanted to focus on the elusive future normalcy.

It wasn't until I spoke to my Dad, who talked to me in terms of the present, that I revisited my pessimism. He said, "In God's eyes, Mikan is perfect just the way he is."

It was true. So why couldn't I see my son as perfect too? Why was my happiness dependent upon a timetable I had no control of, established on naïve comparisons? My Dad's words allowed me to see my son as the beautiful, determined miracle he was— tubes and all, and not the one he would become. I treasured those additional days and nights in the NICU when I embraced Mikan's condition, knowing I was doing everything I could as his mother.

Mikan's final extubation day wasn't as anticipated as the first.

Several weeks later, I chose to observe Mikan's rounds, one of two brief periods each week where his nurse, and every doctor, therapist, social worker, and March of Dimes liaison in the NICU met to discuss Mikan's condition and agreed on a progress plan. His doctor calmly began the meeting with news that battered my emotional reserves.

"Mikan hasn't made any progress. He needs a trach." He outlined the reasons leading up to his decision while I focused on the black dots in the countertop before me.

A hole cut into my baby's neck. Another tube. Another learning curve.

When we had been periodically briefed on Mikan's roller-coaster respiratory condition over the previous three months, a trach was always mentioned as a "worst-case scenario." But with my Dad's gentle reminder, I prayed for strength

When Mikan arrived back from his tracheostomy, eyes glossy and distant from the anesthesia, tubing and gauze wound tightly around his neck, my husband and I stared down at him from each side of his crib. Neither of us spoke.

I'd thought I had seen it all— tubes down his throat and nose, IVs from his hands, feet, and head, bandages from surgeries all over his body, and plastic cords attached to his chest and back. But his neck was always naked. He no longer had a neck that we could see. His dazed stare seemed a result of the new tubing and gauze strangling him like a python. Mikan's detached expression said that he'd had enough.

But we could see that detached expression.

His cheeks were ruddy, most likely from the tape that was finally removed from them and not the natural newborn glow, but it didn't matter; they were plump and soft. And he had an upper lip. When I saw it purse for the first time, I knew he would look like his father.