

Dreams of a Perfect Child



by Rick Bowers

Perhaps every prospective mother's dream - at one time or another - is that her baby will be perfect; that it will be healthy, intelligent, and beautiful; that it will one day be a baseball player, a movie star, or president.

But sometimes, dreams don't come true.

Steffini Vandever knew that something was terribly wrong shortly after the premature birth of her baby. "The room went deadly quiet," she recalls, "as a trembling nurse brought my son for me to see. A whole realm of feelings swept over me. I had lost a child 11 years before, and the thought of losing another wrenched my heart. I asked the nurse if he had legs since all I could see was feet up by his face. She said, 'Yes, but they're not normal.'"

Over the next six weeks, Steffini, now 34, was on an emotional roller coaster as the reality of what those words meant began to sink in. Tears became her constant companion.

Her baby weighed just 4 pounds, 1 ounce. He had backward knees and clubbed feet, with a missing baby toe on each foot; his hands were malformed; and he had no forehead.

"I was very shocked," Steffini says. "I was told he would be a very small - but perfectly formed - baby, and what I got wasn't."

In fact, Steffini had begun feeling that something was wrong months before the birth of her son. "I often questioned the doctors and had over 13 ultrasounds done only to be told I was hyper," she recalls.

Steffini was frightened because she had so little information about her son's problems, and questions bombarded her mind. "Can I, a single parent, handle such a difficult task? Why me? What did I do wrong? What will people think? Will he die?" But no one was able to give her a satisfactory answer.

On the verge of giving up, Steffini went to visit her son, Jonah, in the intensive care unit. "I told the nurse I didn't think I was going to be able to bond with my son," she recalls. It was the nurse's reply that opened Steffini's eyes. "I think you already have bonded with him," the nurse said. "You have not stopped touching him since you have been here."



The nurse was right. "After I got through all of my losses - the loss of a perfect pregnancy, the loss of a perfect delivery, and, the most painful loss, the loss of a perfectly formed baby - I decided it was time to fight for my son's rights," Steffini says. "I said that if my son was only going to live the six months predicted by the doctors, then it would be the best six months any kid would ever have. But if he was going to live a lifetime, then the choices I make today would need to benefit him tomorrow."

That's when Steffini became an advocate for her child and dedicated herself to giving him the best life she could provide.

At five months, doctors constructed a forehead for the child. They had regularly been putting his legs in casts since he was a week old to try to straighten them; however, there was little improvement, and it looked as if Jonah would never walk.

Then, the young mother decided to stop passively accepting other people's opinions, including the doctors', and began to educate herself. After consulting 43 doctors from around the country, Steffini made perhaps the most difficult decision of her life - the decision to ask the doctors to amputate her son's legs. "The amputations were requested by me," she says, "and this was hard for Shriners Hospital because no parent had ever requested it in over 40 years."

At 18 months and at Steffini's request, doctors amputated both of the child's legs through the knees. When the doctors operated, Steffini explains, "they found that Jonah's knees were actually elbow joints, not knees. That's why they bent in the wrong direction."

Less than a week after the amputations, Jonah started to bear weight on the ends of his residual limbs, and Steffini was overjoyed. "I knew then that I had done more than most parents would have and that my decision was the best one," she recalls.

"Get educated on what your child has," she encourages parents of children with disabilities. "The more you know, the better you will be equipped to make

the right decisions. The doctors won't like it, but who cares? It's your child, not theirs."

Soon after his legs were amputated, Jonah was fitted with prostheses and quickly began to walk independently. "When you have a child with limb deficiencies and/or amputations and they crawl, stand, and walk, that is the best day anyone could ever bless you with," Steffini explains. "These often-taken-for-granted moments are major triumphs for our kids. When Jonah first walked without assistance, just seeing me smile was the greatest present I could give my son. He was so proud of himself, and he knew I was too."

So far, Jonah's life has been very different from what Steffini feared. "He is such an inspiration to so many people and loved by our community in so many ways," Steffini says. "I never thought my son would be as accepted as he is."

A single mother, Steffini also has two daughters (Amber, 12, and Maddi, 8) and runs a home-based day-care business, which she has owned for 15 years. "Owning my own business has made it easier for me to take care of my son and be home for my daughters as well," she says. "Plus, having the kids around has helped Jonah. Seeing them do things encourages him to try, too."

Before Jonah was born, Steffini was pursuing a law degree in criminal justice and was about to go into the police academy. "But when my son was born with his defects," she says, "I knew the best job to have was to stay at home and be his mommy."

She dedicated herself completely to that job, and Jonah has flourished as a result. "Jonah is doing great," she says proudly. "He is smart beyond his years and has the best personality - very outgoing, fun, silly, and downright playful." Jonah is also learning French, his fourth language. He already speaks English and Spanish and understands Philippino.

Steffini, who lives in Reno, Nevada, has tried to expose her children to "the many wonderful things this world has," she says. The family travels, goes hiking in the Sierra Nevada Mountains, fishes, and lives a pretty normal life.

Since Jonah was 2, he has attended Children City, an all-inclusive day-care center because Steffini wanted to give him a break from her home day-care business and the opportunity to meet other kids. "Children City has been a wonderful place for him, and never once has my son been excluded or rejected by any teacher or student. I don't feel my son has ever been discriminated against, but I have encountered an uneasiness among a few people, which I diffuse by introducing them to Jonah. This usually catches them off guard long enough for them to see him as a wonderful person with many great talents. That's not to say that my son will never be discriminated against, but I hope to instill in Jonah the ability to use his personality to overcome the public's ignorance."

Steffini has been amazed at Jonah's abilities. "Everything my son does I never thought he would do, but I never gave up hope," she says proudly. "The doctors gave such a grim report regarding what my son couldn't or wouldn't do that I never expected much. So when he sat up for the first time, I cried. When he crawled with his legs backwards, I cried. And after he was fitted with his first pair of prostheses and stood upright for the first time, I cried. Although these were tears of joy, they signified things I never thought Jonah would do. I was ready to accept Jonah anyway he came, and I got far more than I ever expected."

Three-year-old Jonah is now a sparkling child with a lot to look forward to. Although Steffini has had to take him to many doctors and prosthetists over the years, he is able to walk independently on prostheses, he is intelligent, he has a great personality, and - most of all - he has a loving and devoted mom.

Steffini has learned a lot from the experience, she says. "I have learned about unconditional love and not to take things for granted, and I have learned how truly wonderful our children are no matter how they come into this world."

Sometimes, maybe dreams do come true - even when it looks as if they haven't. ■