

Rising to the Occasion: Reflections on Choosing Naia

by Tierney and Greg Fairchild

For Greg and me, prenatal testing was not something we talked a great deal about at the onset of our pregnancy. We expected that our OB-Gyn would guide us on what the “right” tests for us would be, given our individual circumstances. We did not expect to have an amniocentesis, given that I was only 31 at the time. We did do a blood test – the triple screen – that came back negative for Down syndrome and negative for spinal bifida.

It wasn't until a routine ultrasound, when Naia's heart defect was detected, that our thoughts and approach to prenatal testing became real and not theoretical. We were offered and accepted the option of an amniocentesis at the diagnosis of the heart defect – which we could have declined. We felt that it was important to know sure whether our child had Down syndrome, which was highly correlated with the heart defect they detected. We also agreed to do a FISH test, because it could provide results quicker than an amniocentesis. The FISH test, which can provide results in three rather than 10 days, is less accurate than amniocentesis.

So what happened to that triple screen result? Turns out it was a false negative. The test was only 60% accurate. For my next two pregnancies, I would decline the triple screen. As my OB once said during my second pregnancy – “You only need tests that are 100% accurate.” For us, that meant relying on ultrasounds, and considering an amniocentesis only if there was a reason to do it. Some have asked why we wouldn't readily do amnios since we did one with Naia. We've felt that we know what raising a child with special needs is like, and it that it isn't traumatic or significantly life changing. Given the amniocentesis risk of miscarriage, one in 300, we couldn't consider putting an otherwise healthy baby at risk. The risk of miscarriage in our estimation is greater than the psychological comfort we might have in knowing with certainty that our child would be without a defect. We feel differently about conditions like Naia's heart defect. In those instances, we feel that having the knowledge would prepare us and our medical providers for procedures like open-heart surgery. We've felt that the preparation for medical procedures differs from the psychological and social preparation for a child with special developmental needs.

At a recent visit, we were introduced to a new test that wasn't available with my first two children. It's the nuchal translucency test, and it is the combination of an ultrasound and a blood test done around the 13th week. With 90% accuracy and no risk to the child, it looks at fluid behind the neck and combined with other measurements and given the mother's age and other factors gives a probability that the child will have a chromosomal defect (Down syndrome, Trisomy 13 or Trisomy 18).

The main questions we ask ourselves when faced with prenatal testing now are: First, how accurate is the test? Second, is the test intrusive and potentially dangerous to the fetus? Third, what is the nature of our need for the information – that is, how would the information change what we would do in the future?

For some, a decision of termination never comes into play and therefore they often feel that an amniocentesis or any other testing is not worth considering. Others feel that the uncertainty surrounding a potential unexpected outcome calls for an answer -- they must know. One thing Greg and I remember from that first pregnancy was how little time we spent up front discussing what we would do if any test came back with news we didn't want to hear. How would we decide? Who would we tell? What information might we seek? What would we do once we had the information?

Our rules of thumb now are that we won't do anything intrusive or risky to the child's health unless that risk is offset by a greater medical risk. We feel that our faith will guide us as we face challenges that might be developmental, and we are blessed with the child in hand.

We labor to make decisions collaboratively, and we allow each of us to ask exhaustive questions until there are no more questions to ask. When we found out about Naia's diagnosis, there was one question I kept asking over and over with each doctor we'd see. It involved whether there would be any interactive complications due to her heart defect and her Down syndrome. Again and again, I was told that the two conditions did not bear on each other. Even though I continued to receive the same answer, I continued to worry and asked the question of a number of medical professionals.

Throughout, Greg was patient allowing me to repeat this question – until he finally had to ask, what was I waiting to hear that I didn't hear? I had to reflect on this and realize that my fears were preventing me from accepting the answers given. What was most important was that we allowed each other to have these thoughts, and our relationship was based on an openness that allowed us to challenge each other. This set of exchanges also led us to realize that we would only have a decision if both of us could entirely agree -- there can't be second thoughts later.

When receiving the unexpected news that the child you're carrying has a defect, it's important to allow ourselves the chance to grieve for the loss of the child we originally expected to have. On the way back from receiving the ultrasound results and taking the amniocentesis that changed our lives in a matter of an hour, Greg said to me "Tierney, God never promised you a perfect baby." His words rang true. I just had spent so little time considering that God would hand me anything but a typically healthy child that this was devastating.

After we gave ourselves the chance to grieve for this loss, then we turned our energy toward finding out enough the information we needed to make an informed, and not a rash, decision. We didn't focus much on the Down syndrome until that was confirmed. Rather, we learned about heart defects, our child's prognosis and the success rates of the prescribed open-heart surgery. Then, once we learned we'd also be dealing with Down syndrome, we read books and relied on our genetic counselor to help us find information, including talking with other families, to give us multiple perspectives about the disability.

The information search was not always direct. The answers to some questions led us to more and more questions. We made many visits to doctor's offices, read many books and articles, and confided with close family and friends. In the end, we had to rely on each other and all the information we had assembled to determine the best course for us. Even with all the information, we eventually realized that no test or person could tell us how "severe" her Down syndrome would be. We prayed a lot together and in the end, we took a leap of faith to say we would continue the pregnancy.

One key and difficult challenge along the way was to sift through the reactions of family and friends and even some of the medical professionals to be sure we weren't hearing their own biases. We realized early on in the process that while we had a hard time being objective, so did our family and friends – and we tended to be getting more recent information that they were. What happens to people when they hear of something like this is that they think if they've known anyone with the disability – or anyone who dealt with the same problem. While that can be helpful, many times, it's a past experience and advances in early intervention and medical technology were not in play. Also, what people tend to recall about the person with a disability was how tough things were, not any of the positives or wonders of the situation. Imagine preparing to learn to drive and all anyone ever talked with you about was tragic accidents they

had seen. Not many would want to get behind the wheel. The bottom line is that you can let fear drive you during a crisis and you will tend to seize on all the negatives – or you can let the desire to make a well-rounded decision drive you and you can consider all points of view, knowing in the end that your decision is yours and all those you consulted won't agree with you. It's often amazing that when faced with this situation, very few people ever speak with someone that has a child with the same disability. They tend to rely only on the perspectives of medical personnel, who generally deal with the disabled when they are having problems. When things are going well for the person with a disability, they have limited interaction with a doctor.

It's important to note that in making a decision to continue a high risk pregnancy, your fears don't go away, at least until the baby is born and you realize many of them are unfounded. I remember a specific conversation we had about how our decision to have Naia might mean that friends wouldn't be comfortable coming over to dinner at our house – or having us over to theirs. We thought they would be so uncomfortable. Yet, what we have found is that people take their cues from you. Since we have never felt or acted like Naia is a big trauma, a burden, an embarrassment or anything but a typical child with some extra challenges, when others see her, they see her beaming smile, outgoing personality and her contagious energy. Having Naia hasn't produced the significant changes we feared. In fact, it has us – and those around us – rising to the occasion and learning how much people who are different from us can teach us.

Tierney and Greg Fairchild are the parents of Naia (4 1/2) and Cole (2 1/2) and are expecting their third child in September of this year. Greg and Tierney hold high expectations for all their children, including Naia who has Down syndrome. Naia is fully included in her preschool, and Greg and Tierney are committed to ensuring Naia has every opportunity to continue in an inclusive environment and to reach her potential. While they cannot predict Naia's future, they hope her accomplishments might include those achievements that more and more people with Down syndrome are reaching – driving, college, living on her own, getting married.

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