

Interview of Mother Who Underwent Prenatal Screening

The following is an interview with a mother who underwent prenatal screening. She describes the experiences she had with the medical community and others as a result of that screening. Of note Ds is used as an abbreviation for Down Syndrome, and Dh signifies her husband.

Please tell us about your experience of prenatal testing.

I had pre-natal testing with both my children. I didn't think I would terminate with my first child no matter what. We had a wonderful family Doctor at the time and I did have a triple screen test. It came back with higher odds than what my age should indicate for a child with Ds. My Doc explained the statistics and I told him I didn't think I would terminate even if the child had DS. He told me not to bother with the amnio. But I talked it over with my Dh and we decided to put it in God's hands.

When I told my Doc that he replied that he thought that was a good answer! Fast forward 2 years later and I'm pregnant with my second. Dh was not too happy about having another child as he was pretty exhausted with our 2 yr old and he also had 2 from his first marriage. They were with us 50% of the time and so the 3 kids kept us busy. We had just moved to a new area and I had a new OB. Well this time my triple screen came up 1 in 9 chance for a child with Ds. This time my Dh was not so sure he wanted to deal with a child who may have a disability. He felt that the child would take away from our other children and maybe be a burden on us. He felt if the child was a burden that he didn't even know if he could love him.

The Doctor asked us to come in to his office to discuss. He told me that I should have the amnio to confirm and that many of his patients who have news like this terminate and then have "normal" children later. Dh and I continued our debate with one another and the Doc offered up that he would terminate if it were his decision. I'm getting pretty irritated at this point. I felt he should have been unbiased until we as a couple made our decision. I decided to go along with the amnio but made it clear to my Dh and the Doc that I was still not considering termination.

How would you describe the perspective of the medical personnel who counseled you or spoke to you regarding the screening?

I felt he offered a very personally biased opinion. And he did not seem very knowledgeable. Sure, I was aware of the medical issues, in fact probably more so than the OB was. I felt that if he was going to form an opinion it should have been done after meeting families who live with Ds and a lot of research on the medical issues. Once my amnio came back positive for Ds he told me on the phone right after delivering the news that my baby did indeed have Ds that he could schedule termination as early as the subsequent Monday. I had not indicated that I had changed my mind.

Do you feel that the medical personnel's approach was non-directive? Please describe.

I did not receive much in the way of resources from the geneticist other than a package from the local Down Syndrome Association. I found so much more from researching it myself online. It was such a hard time between my husband and I while we made this decision. I had to make the decision to terminate and deal with the emotional trauma of that or not terminate and possibly lose my marriage. I tried to explain to the Doc that I had already loved this child and I wanted him so badly. Now somehow I was supposed to determine that his life was less meaningful due to him having Ds. I was supposed to end this life because it may be a hardship on me? He seemed to sort of get that and told me that he saw a young man with Ds at his grocery store cleaning and he seemed to be doing pretty well. I'm still not sure why he thought that would make me feel better. He didn't say it like he believed it. I finally decided that while my Dh may not be able to deal with this and it may be the end of my marriage, I could not forgive myself for terminating. My Dh said he understood and he wanted for us to work through this.

When I showed up at my next OB appointment, the Doc seemed surprised to see me and asked in disbelief if I really was going through with the pregnancy. I said yes and he asked "Well how does your husband feel about this?" I replied that he understood my decision and we are dealing with it, but inside my head I thought no way and I coming back here again. I went home and immediately researched midwives and decided to go that route. The lady I found was amazingly supportive and worked to help my hubby as much as she helped me emotionally!

My Dh did struggle with the diagnosis through my whole pregnancy but once our son was born he fell in love with him. I think he thanked me everyday for a year for standing up to everyone and bringing this child into the world. Sure we are sometimes a little melancholy over what Con would have been like if he didn't have Ds but even through all the delays, he's just a person. He's unique, he's funny, he's loving and he's learning. He may not ever achieve what he could have if he didn't have Ds but he has had a profound impact on everyone in our family and it's all been very positive.

Did you have any experiences outside of your prenatal care, say with friends, family or acquaintances that were difficult as a result of prenatal testing? So many people had opinions.

The majority felt we should terminate and the rest just seemed to take pity on us. A handful supported me but I found most of my support from online in the form of online support boards. They were Moms of children with Ds and I don't know how I would have dealt with all of it without them. To this day I they are a wealth of information and support and they have my undying gratitude and friendship! Most of those friends now adore our son and tell us how our journey has made a significant impact on their own views.

What would you like to tell a bunch of doctors, nurses and other health care personnel about prenatal testing?

Do not make it known what your personal feelings are. Find information that you can provide that can help parents make a decision by gathering information. There are support boards and groups for people who terminate due to poor prenatal diagnosis and groups for just about every syndrome imaginable and even several for children that are undiagnosed. Encourage parents to research the diagnosis. Online support boards are great because they can be anonymous and they don't have to worry about being judged. If they feel they are they can always avoid that particular group. But remember that most patients look to medical professionals to aid them in a decision. Remember your opinion can sway a parent's decision. I quite understand why some medical professionals may have a biased view. If they just based it on their interaction with me while dealing with my son's medical issues, I'm sure they would think why put yourself through all that trauma and the child through all that trauma when there's a choice? Because they are not with me and my family 24 /7 so they don't see that the medical issues were just a sliver of what life is like with a child who has a disability. They don't see the joy and the normalcy that takes up the larger part of our lives.

So try and remember that because if you only relay some of what you see from families like mine, you have presented a very slanted view of a life and that view can be responsible for ending a life that actually could have brought mostly happiness to a family. And I can assure you that my other children also bring me mostly happiness but they bring challenges as well. Offer the patient resources that can help them make their decision but try to be unbiased in your opinion because unless you have lived the life as a parent with a disability you really don't have the experience or knowledge to present an adequate picture on life with that child. But whatever the parents choose, supportive and understanding.