



ds medpress

A NEWSLETTER FOR HEALTHCARE PROVIDERS

THERE'S NO SUCH THING AS A PERFECT CHILD

Sue Robins, The Globe and Mail, 2/16/2010 (condensed)

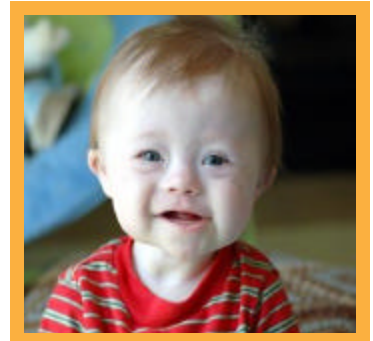
A word to the wise to those of you dying to ask a parent of a child with Down syndrome if they had prenatal testing: Don't do it. Bite your tongue. Shut up. Swallow it. Believe me, justifying the very existence of our beloved children hurts. One day a mom stopped me in the playground on my way to my car. She chit-chatted a bit. Then she got to her point. She really wanted to know why I didn't get prenatal testing.

It seemed like a funny question to ask, and staggeringly inappropriate to boot, but I had been asked it before. I thought, rationally, "Here's your chance to educate – I am an ambassador against ignorance." I answered her cheerily, "Well, testing wouldn't have changed my pregnancy outcome, so I turned the testing down."

I said my (pleasant) goodbyes and motored to my vehicle as fast as I could in the winter snow. I slid into the driver's seat and burst into tears. I'm not much of a crier. But it was as if I had been slapped. I continued crying all morning. *Why do I have to justify my son's very existence? Why isn't it okay that he's alive? What are you afraid of?*

For those of us who have children whose extra chromosomes could have been detected prenatally, it is a long and lonely road. We get asked these questions. The whole genetic testing thing is fraught for parents who have kids with disabilities.

One day it won't just be "us." With the clever mapping of genes, there may be tests for all the lovely imperfections of life that make us human. **All in the quest for the blue-ribbon baby.** What I should have asked the mom in the playground was, "What if your daughter was in a car accident tomorrow and had a brain injury? Would you love her any less?" When you can answer those questions, I will answer your questions.



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**VISIT OUR
WEBSITE**

www.dsagc.com has many resources for medical professionals under our Program/healthcare tab. You will find helpful resources, handouts and links to websites for prenatally and postnatally diagnosed families. Contact Sally@dsagc.com for more information.

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Early Feeding Issues for Babies with DS

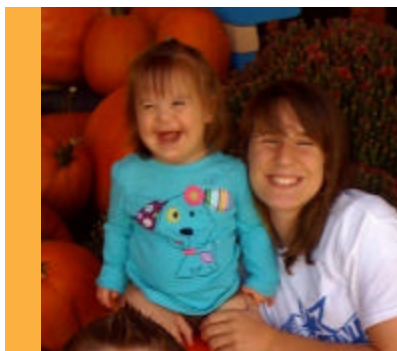
Oral anomalies associated with DS include reduction in the length of the palate, tendency to protrude tongue and mouth breathe. Hypotonia, poor coordination of suck/swallow/breathe sequence and poor lip seal also contribute to possible feeding difficulties.

However, just as with typical babies, breastfeeding is recommended for all the same reasons. Some babies with DS breastfeed with no difficulty. However, some babies struggle with latching on, sucking and fatigue. A lactation consultant can be very helpful for babies with DS.



FAMILY COMFORTED BY REASSURANCE OF OB/GYN

“The experience of the birth of our daughter at Good Samaritan



Hospital was amazing. We were shocked to learn that Ellie may have Down syndrome, but our wonderful obstetrician, Dr. Sandy Gardner delivered the news with nothing but compassion and support. Our nurse Michelle was also very supportive. There was never a

sense of sadness, only understanding and support. Down syndrome is not something to be sad about; it is only a difference, just like we are all different in many ways.” Lisa Hammonds.

Ellie is shown here with her big sister.

PARENTS SENSITIVE TO EARLY REMARKS

In 2008, the DSAGC surveyed families who had given birth to a baby with Down syndrome within the last 5 years. 63 families completed the survey.

When asked to share their emotions upon learning of the diagnosis, both groups (prenatal and postnatal diagnosis) described their reactions using similar terms: fear, terrified,

devastated, sadness, shock, hopeless, depressed, etc. Some reported that the doctors made them feel as if it were somehow their own fault for not having prenatal testing performed during their pregnancy. Some felt as if they were being scolded for attempting to conceive later in life. One mother was asked if she had taken drugs or smoked during her pregnancy. Four families reported that the doctors whispered, poked, prodded their baby, avoided eye contact and would not directly address them.

These anecdotal reports highlight the importance of refraining from offering an opinion or attitude which reflects judgment. Nothing can be accomplished by causing the parents to feel guilt or somehow responsible for their baby's extra chromosome.