

## **Please Be Balanced: A Parent's Ask of Healthcare Professionals**

*Karen Todd*

Since the birth of our daughter, a beautiful 19-month-old girl with Down syndrome, I've paid a lot more attention to the world around me and specifically to the subtle and not so subtle messages conveyed by healthcare professionals both in person and in print. And I've found myself increasingly upset with what I'm hearing and experiencing.

In October, 2003, a study published in the *New England Journal of Medicine*, received a lot of publicity. This study suggested that a blood test combined with measurements of the neck-fold of a fetus by means of ultrasound during the first trimester of pregnancy would allow detection of babies with Down syndrome (trisomy 21) and another chromosomal disorder called trisomy 18 (Wapner et al., 2003). One article in a magazine in a clinic waiting room explained how this approach now allowed the detection of Down syndrome at a very early stage of pregnancy (Warwick, 2003). To me, the title and tone of the article was encouraging and almost celebratory in the manner in which it talked about the benefits of such testing. Prenatal blood screening has reduced the birth incidence of Down syndrome in many places by about 50%. When blood screening reveals an elevated chance of having a child with Down syndrome, women proceed with further testing like amniocentesis or chorionic villus sampling. This means that many women and their partners choose to end their pregnancies when testing results reveal their unborn child has Down's. By failing to be explicit, people who do not understand that Down syndrome is a chromosomal abnormality, can be left with the impression that if detected before birth, the condition can be "fixed". In this article, along with others I have read, there has been no exploration of what comes after learning the results of testing, especially when it reveals a problem. No information has been provided on what support families receive in making the difficult decision of whether to continue or end the pregnancy.

I strongly believe that people need to use the information from prenatal testing to make the decisions that are right for them and their families even if that means ending a pregnancy. While many families make the painful decision to do just that, let's remember there are plenty of others that decide to have their children.

For us, knowing our child would have Down syndrome, gave us the opportunity to prepare ourselves before her arrival. We grieved the loss of the child we thought we were going to have, told our family, friends and colleagues, and did as much research as we could. It would have been so difficult to do this after her birth when my hormones were out of whack; I was exhausted, and had a baby to nurse. When Meghan arrived we were in a position to simply welcome her to our family and celebrate her birth.

I felt supported by the Genetics Department at North York General which gave me a wonderful booklet entitled "Precious Lives, Painful Choices," that provided an objective look at the options for ending our pregnancy (Ilse, 1993). They followed up with me knowing we had a limited amount of time in which to make a decision to terminate our pregnancy. I clearly felt an unspoken bias that seemed scientifically based – if it's broken and can't be fixed, why not discard it and try again.

One of the things that contributed to this feeling was that there was no package of information ready for me on Down syndrome so that my decision-making could be supported immediately by knowledge of the disability. However, when I asked for it, some information on the Internet was quickly printed for me. Remember, at this point, in the pregnancy, families have a week or two in which to decide whether or not to end the pregnancy. We spend most of that time grieving. By the time you feel up to doing research, there isn't a lot of time left to gather information. *UPS and DOWNS, An Information Package for New Parents From Parents of Children with Down Syndrome*, is readily available from the Canadian Down Syndrome Society (<http://www.cdss.ca/>). The package consists of a booklet of messages from other parents, facts about Down syndrome, a newsletter, Resource Catalogue, and list of helpful websites.

Balance came from the perspective of Dr. Roland Beaulieu, our pediatric cardiologist who has worked with lots of families of kids with Down syndrome. Just under 50% of children with Down syndrome are born with some type of heart defect, many of which are correctable with surgery (American Academy of Pediatrics, 2001). A fetal echo is an ultra sound that focusses on the fetus' heart. The pediatric cardiologist is able to detect whether the heart is developing normally. Fetal echoes are often offered to women who have learned their unborn baby has Down syndrome in order to provide as much information as possible about other related conditions.

Dr. Beaulieu came in from his vacation on a Friday afternoon to perform the fetal echo knowing we had a short window of time in which to make the decision to continue or end our pregnancy. Dr. B. spent time talking about his experiences and his beliefs that much was possible with the right kind of early intervention programs and integration into the community. He told us our baby's heart looked healthy and, in the elevator leaving his office, we made the decision to continue our pregnancy – a decision we haven't regretted for even a moment!

I was deeply offended when the hospital wouldn't let Meghan and I leave until the Social Worker had seen us. It was January 2nd, the day after New Year's Day, and at the tail end of the holiday season; we waited and waited until she arrived. The Public Health Nurse who visited me at home a few weeks later pushed and pushed trying to get me to accept services and support our family didn't need. Both the Social Worker at the hospital and the Public Health Nurse, wanted us to talk about our feelings. The Public Health Nurse was trying to provide information about hearing tests and support groups. While their intentions were good, I kept repeating that since I'd known for months that Meghan would have Down's, I'd already done my research, arranged support from Surrey Place and had come to terms with things. We had chosen to bring this child into our family knowing she had Down's. The assumption from the medical community was that we needed help dealing with this tragic thing that had happened to us. I insisted we were fine – our situation far from tragic. I remember wondering and worrying about whether my insistence that everything was fine was being received as classic denial.

My ask of healthcare professionals is to be truly balanced in your work with clients. Be aware of your personal biases and beliefs and keep them check. Be armed with all the information your clients need to make the decisions that are right for them and their families. Don't assume your clients are devastated. Recognize those who are and provide them with appropriate support. Recognize those who see the glass half full and are ready for the incredible opportunity for personal learning and growth inherent in raising a child with Down's and deal with us differently.

### References

- American Academy of Pediatrics. Committee on Genetics. (2001). *Health supervision for children with Down syndrome*. *Pediatrics*, 107(2), 442-449. Canadian Down Syndrome Society. Retrieved October 1, 2005, from <http://www.cdss.ca/>.
- Ilse, S. (1993). *Precious lives, painful choices: A prenatal decision-making guide*. Maple Plain, MN: Wintergreen Press.
- Wapner, R., Thom, E., Simpson, J. L., Pergament, E., Silver, R., Filkins, K., Platt, L., Mahoney, M., Johnson, A., Hogge, W. A., Wilson, R. D., Mohide, P., Hershey, D., Krantz, D., Zachary, J., Snijders, R., Greene N, Sabbagha R, MacGregor S, Hill L, Gagnon A, Hallahan T, Jackson, L. (2003). First trimester maternal serum biochemistry and fetal nuchal translucency screening (BUN) Study Group. First-trimester screening for trisomies 21 and 18. *New England Journal of Medicine*, 349(15),1405-1413.
- Warwick, L. (2003). Women benefit from early detection of birth defects. *Bulletin of the Centre of Excellence for Early Childhood Development*, 3(2), 4. Retrieved October 3, 2005, from <http://www.excellence-earlychildhood.ca/documents/Page4Vol3No2Sept04ANG.pdf>

### Correspondence

Karen Todd  
188 Darlingside Drive  
Scarborough, ON  
M1E 3P7

[karen@karentodd.com](mailto:karen@karentodd.com)