



Debunking the Termination Myth

For years, the myth has been spread that 92% of babies with Down syndrome in the US are aborted; however, recent research shows the termination rate is much lower and dropping.

What is the actual termination rate?

According to a survey of 24 studies across the US that were done between 1995-2011, we know the following:

The weighted average of the surveys from the Natoli study show that the termination rate is actually about 75% among those who get a confirmed diagnosis with an amniocentesis or CVS.** Only about 2% of women in the US get an amnio or CVS, so any termination rate only applies to that group. Termination rates also vary significantly depending on the age of the mother, race/ethnicity, gestational age, and where the mother lives. Evidence shows "termination rates have decreased in recent years, which may reflect progress in medical management for individuals with Down syndrome and advances in educational, social, and financial support for their families."

Where did that termination myth come from?

The 92% termination rate came from an older summary of termination rates that only included US studies from the 1980's and also included international figures where termination rates are higher.

Why is the termination myth harmful for expectant parents?

Quoting the inaccurate 92% termination rate is usually meant to elicit shock and revulsion that so many babies with Down syndrome are aborted. Sadly, many expectant parents say that when they hear that 92% of babies with Down syndrome are terminated, it actually makes them feel alone, as though they would be in a small minority by choosing to continue a pregnancy. Therefore, this myth actually runs the risk of prompting more terminations by making expectant parents feel isolated.

Why is the termination myth harmful for all of us?

This myth also infects our culture leaving many people saying in public forums, "If the vast majority of people terminate a pregnancy when they find out the baby has Down syndrome, then Down syndrome must be really, really bad." This leaves parents of children with Down syndrome feeling like they have to justify their decision to continue a pregnancy when questioned by those around them. Fundamentally, this myth risks creating a culture that is less likely to accept and value children with Down syndrome, and it's based on false information.

What can we do to make sure expectant parents get the support they need?

Down syndrome advocates and organizations can make sure expectant parents get accurate, up-to-date, balanced information and support immediately after receiving a diagnosis. They can distribute the Lettercase "Understanding a Down Syndrome Diagnosis" books that have the credibility of being reviewed by the national medical organizations (lettercase.org); they can link to the National Center for Prenatal and Postnatal Down Syndrome Resources, including Down Syndrome Pregnancy, from their website (downsyndromediagnosis.org); they can provide direct support and baskets to expectant parents; and host support breakfasts quarterly for those who are new to a diagnosis. This insures that expectant parents receive materials immediately from their doctors or online which show the potential of children with Down syndrome, and they feel welcomed into a supportive organization as soon as they are ready.

****Natoli et al. 2012. Prenatal diagnosis of down syndrome: systematic review. Prenatal Diagnosis. 32, 142-153.**

<http://onlinelibrary.wiley.com/doi/10.1002/pd.2910/pdf>

<http://cirge.stanford.edu/Greely%20Nature%202011.pdf>

<http://www.patheos.com/blogs/thinplaces/2012/06/down-syndrome-prenatal-testing-and-abortion-its-complicated/>



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