

## ***YOU MEAN THERE IS NO GUARANTEE?***

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October, 2004

This newsletter enters your mailbox during the time of the year collectively referred to as Down Syndrome Awareness Month, a specific time of the year when the positive messages surround the capabilities and strengths of people with Down syndrome are highlighted to encourage equal participation in the daily social fabric of our lives. For those who have a loved one with Down syndrome, this is preaching to the choir. For those who do not, we struggle to raise awareness that this condition is not a life sentence of insurmountable struggle and grief.

Speaking only as a parent of a son with Down syndrome, I can honestly say parenting a child with Down syndrome is not an easy task. But then again, neither is parenting my other child, a son on the verge of puberty. You may be asking yourself how that could be. How could a child with a visual handicap not be more difficult? As I have only been Alec's mom for ten years, I can only say that it is different. Parenting in Holland is not the same as parenting in Italy. Every child, no matter who it is, comes with his or her own challenges and rewards.

The reason for this preamble is to bring to the forefront of discussion the current news of medical testing for fetal abnormalities in the first few weeks of pregnancy in an effort to give prospective parents the information they need to make the choice as to whether or not to continue the pregnancy. From a personal standpoint, I do not feel this is a question of abortion rights as much as common sense.

Fetal genetic tests are now used routinely to diagnose diseases as well known as cystic fibrosis and as obscure as Fragile X. High resolution sonograms can detect life threatening defects like brain cysts as well as treatable conditions like a small hole in the heart or cleft palate sooner and more reliably than previous generations of technology. The risk of Down syndrome, one of the most common birth defects, can be assessed in the first trimester rather than waiting for a second trimester blood test or amniocentesis.

Some couples say they are both profoundly grateful and hugely burdened by the new information and the choices it forces them to make. What defect, if any, is reason enough to end a pregnancy that was very much wanted?

Perhaps I missed picking up the brochure in my gynecologist's office that indicated that there was a guarantee that my offspring would be perfect in every way. What is wrong with us as a society that sees something out of the norm as a reason to stamp it out? As a child grows, their value as a person will be assessed not only by parents, but also by those outside the home. And that's where we, as advocates for those with Down syndrome, step in.

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It wasn't that long ago that people with Down syndrome were pigeonholed into a lifetime of loneliness. We are so lucky to be living today with education opportunities, workplace and living opportunities that just did not exist previously.

Just because a child is born with a birth defect doesn't mean that the child will not contribute to society. This is not to say that I have always been an advocate for those with Down syndrome. Quite the contrary. I attended both elementary and high school without ever seeing a student in my school with Down syndrome. I did not know anyone with Down syndrome prior to giving birth to my son nor did I seek out the opportunity to do so. When confronted with his diagnosis I, too, felt that sense of loss for the perfect child I would never have. But life has a way of changing things. Where there once was grief there now is hope. I have learned, through time, that the wishes I have for my "normal" son are the same that I have for my son with Down syndrome. Live, love, learn and laugh.

We at DSAW, through the newsletter, have tried to share with you stories of others that do provide hope and laughter. No one has a crystal ball. No one can tell you what your future will unfold for you, good or bad. That's the point of living; you get the good with the bad. Just because you get the good news that your fetus is "normal" is no guarantee that your life will be. Life happens. There are no guarantees. Our job as caregivers of those with Down syndrome is the same as those without. Help our loved one rise to their potential. No more, no less. In October, perhaps that is what we should focus on.