

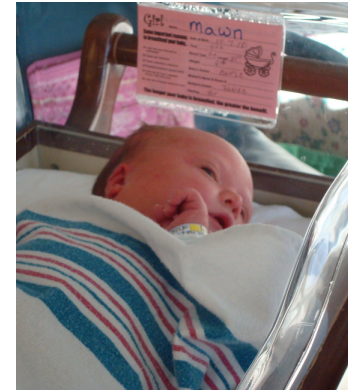
## A Reflection for Respect Life Sunday

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Last October, a few days after Respect Life Sunday, my wife and I finally had our first child, a daughter. After many years of trying, with miscarriages, false positives and tests galore, little Teresa certainly is extra special for the two of us and to our family and friends. Actually she came with something extra herself, an extra chromosome. The result is a condition called trisomy 21 otherwise known as “Down Syndrome”.

The Center for Disease Control estimates that each year about 6,000 babies in the United States are born with Down syndrome. It is one of the most common genetic birth defects with about 1 out of every 691 babies born in our country each year being born with it. This extra chromosome changes the body’s and brain’s normal development and causes mental and physical problems for the baby.



Every baby born with Down syndrome is different. In addition to the physical signs, some might have major birth defects or other medical problems. They may also have delayed language development and difficulties with physical coordination. There are over fifty clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. Despite these symptoms and issues, many people with Down syndrome live happy, productive lives well into adulthood. As a matter of fact, the *American Journal of Medical Genetics* just reported on a study by the Children’s Hospital Boston which found that the Down syndrome experience looks far different – and far happier – than the one most of us are used to picturing.



Although some blood tests during the relatively early stages of the pregnancy had triggered an alarm that our baby may have Down syndrome, as the due date approached these concerns were downplayed. When she was born, however, the Ob-Gyn told us moments after delivery that it appeared as if the concerns had been realized given her low muscle tone. Yet it still took a couple of weeks before the diagnosis was confirmed via an analysis of her chromosomes. If our heads weren’t already spinning with our being first time parents, our life got even more topsy-turvy as we were introduced to the world of Early Childhood

Intervention and the challenge of caring for a baby with a little “extra”.

Early childhood intervention is a support system for children with developmental disabilities or delays and their families that is mandated by the Federal Government. Its purpose is to ensure that families who have children ages birth to three, with diagnosed disabilities, developmental delays or substantial risk of significant delays receive resources and supports that help them in maximizing their child’s development. Thus, before she reached three months of age, Teresa was already having physical and speech therapy sessions to help promote her growth and development. In the months since she has seen more than her share of medical specialists. But should this have been cause enough to have snuffed the life out of her before she was even born? Wouldn’t it have been easier on all of us if we had simply terminated the pregnancy? Sadly each year thousands of women do just that when it is discovered that their unborn child has Down syndrome.

If current health policies and trends continue, Denmark could be a country without a single citizen with Down syndrome in the not too distant future. Since 2004, the Danish government has offered all pregnant women free prenatal screenings to determine if the fetus has Down syndrome. In 2004, when the free and widespread screenings were introduced, 61 babies with Down syndrome were born in Denmark. The following year, the number was reduced by more than half. In each successive year, the number continued to drop by an average



annual rate of around 13%. The reason for the steady decline is that most of the fetuses that test positive for the defect are aborted. If the current trend continues, it is predicted that the last Down syndrome baby in Denmark could be born in 2030. And this is not only true about Denmark. Recently there have been reports that a new blood test to determine Down syndrome early in pregnancy is expected to be available within months here in the United States.

As we lived through the first trimester I was quite surprised how doctor after doctor was concerned about the timing of blood work and ultrasounds so that if we chose to end the pregnancy we could still do so; of course there were a handful of states with slightly later deadlines if necessary. In our brave new world of genetic testing and managed health care it may eventually become “unacceptable” for parents to continue a pregnancy knowing that their baby has Down syndrome. Recent US studies have indicated that when it is diagnosed prenatally, 84-91% of those babies will be killed by abortion. This trend is not isolated to the United States; in England, a 2004 study showed that 94% of babies who were diagnosed prenatally with Down syndrome were subsequently aborted.



An estimated 70% of all pregnant women in our country will choose to have prenatal screening tests. And when a woman finds out that her unborn baby has Down syndrome, what is she facing? In a 2004 Harvard Medical School study it was reported that women in this situation felt anxious and scared when learning about the diagnosis, and about half felt rushed or pressured into making a decision about continuing the pregnancy. It seems that many health care professionals assume that if a woman consents to prenatal screening or diagnosis, she is



willing to discuss abortion as an option. And many doctors in these cases may see advantages in ending the pregnancy as soon as possible to avoid the medical risk to the woman. Combine this predisposition with the perceived “burden” of raising a child with Down syndrome, and many women could convince themselves that abortion is their most prudent “choice”.

Well, my wife and I chose life. To us it was a no brainer. Granted she has had to see a plethora of specialists in addition to the two therapists in her short life and this has meant all sorts of schedule juggling between my wife and me, but as Teresa approaches her first birthday this October we can celebrate her life. So she may be, developmentally, a bit slower than her peers, but so what – she is our

little baby, our pride and joy. She can bring a smile to our faces and can brighten up the room as she rolls across the floor or plays with her toys. Our family and friends rejoice in her young life and those that work with her in therapy and daycare exult in her achievements. They realize that given her low muscle tone it is more difficult for her to do some things, but that she is progressing. Always moving forward, even if that means simply rolling across the floor to get to a favorite toy or snuggle up next to mommy or daddy.

It says a lot about a society when a group of obstetricians and geneticists needs to be told by an 11-year-old girl that her life is worth living. According to a May 2007 article in *The New York Times*, this is just what happened. “Sarah” told a roomful of medical specialists that she “likes to read. ... Math used to be hard, but it is getting easier. She plays clarinet in her school band. She is a junior girl scout and an aunt, and she likes to organize, so her room is very clean. Last year she won three medals in the Special Olympics. I am so lucky I get to do so many things,” she concluded. “I just want you to know, even though I have Down syndrome, it is O.K.” Why would such a gathering be necessary? Because many of these specialists—like so many others in our society – have begun to think of babies as material goods, as products adults create to enhance their lives. And if the “product” is flawed and beyond the power of medicine to correct, we simply send it back.



Down syndrome is almost universally seen as something to be avoided. No wonder the number of children born with this condition is steadily decreasing as prenatal screenings become more commonplace and mothers-to-be opt to have an abortion to avoid the complications and challenges that may lie ahead of their unborn baby. That is truly a shame when we consider the recently reported results of a national survey that showed that most parents who answered the survey (79% of 2,044 parents or guardians) said they were proud of their child with Down syndrome, felt that their own outlook to life was more positive because of their experience, and how they have no regrets about having their child. A similar study which evaluated how adults with Down syndrome feel about themselves reported that 99% responded that they were happy with their lives, 97% liked who they are, and 96% liked how they looked.

As we get the hang of Early Intervention and get over the dumbfounded shock of hearing that our child has an incurable condition, we realize that the outlook for individuals with Down syndrome is brighter than it once was and that most of its associated health conditions can be treated, greatly increasing her life expectancy. And while the myriad of therapy sessions can get a bit confusing and can interfere with our work and social lives, when you get down to it, who cares? When something is important you make the time for it.

At one year of age, Teresa is too little to read or handle math problems like the *Times*' 11 year old Sarah, but she clearly enjoys my reading some of her board books to her each night before bed and is fascinated by her mom's iPod, cell phone and other electronic gizmos. Of course, we also trust in our Amazing God who watches over all his children and who blessed us with this little girl who defied the odds. As the pregnancy progressed last year we were told there was a one in 1,400 chance of her having Down syndrome. Well you know what? She beat the odds. She's our one!



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