



If you or someone in your life receives a poor prenatal diagnosis, please use or share these resources:

Be Not Afraid is an online outreach to parents who have received a poor or difficult prenatal diagnosis. The family stories, articles, and links within this site are presented as a resource for those who may have been asked to choose between terminating a pregnancy or continuing on despite the diagnosis. www.benotafraid.net

Chesapeake Down Syndrome Parent Support Group serves families of and persons with Down syndrome by providing information and support. cdspg.info/cdspg/

National Catholic Bioethics Center is a team of widely respected theologians, ethicists, clergy, and medical professionals faithful to the magisterium and religious directives of the Catholic Church. NCBC consults can help families come to morally good decisions about an unborn baby or medically fragile child. www.ncbcenter.org

Pope Paul VI Institute/Center for NaPro Ethics will provide assistance with ethical consults, high-risk obstetrics care (for those in proximity), referrals to a network of medical professionals who will help you carry your baby to term, or as long as is possible. www.popepaulvi.com

Being With is a charitable organization that trains healthcare professionals and volunteers “how to look for, and see, the intrinsic dignity, unique mystery, and inherent “lovableness” in every person, no matter how severe the suffering.” www.healingtheculture.com

Children too are a gift
from the LORD.

Psalm 127:3

You formed my inmost being; you knit me
in my mother's womb. I praise you, so
wonderfully you made me. Psalm 139: 13-14.



Special Blessings, Special Vocabulary

by Kimberlee Kadar-Kallen. Available online at www.benotafraid.net.

Kimberlee Kadar-Kallen is mother to Eliza, born with Down syndrome and AVSD. Eliza spent her first months in heart failure until her heart repair. But now at almost four years of age, she is thriving as a homeschooled child alongside her six siblings. Kimberlee blogs at Pondered in My Heart.

When a family first receives the news that they may have a child with Down syndrome, they are likely to encounter some new vocabulary not previously part of their everyday lexicon. Over time these new, unfamiliar words lose their cumbersome feel and become a comfortable part of everyday life, much like an unyielding new pair of shoes softens and grows familiar. I thought I would explain some of these terms and what they have come to mean for our family.

Nuchal fold - This is the delicious area of skin at the back of the neck that is extra thick and soft and smooshy in children with Down syndrome and therefore the perfect place to snuggle, nuzzle, bury-your-nose-in and cuddle your sweet baby. Michael says it's his favorite spot to kiss Eliza.

Trisomy 21 - Trisomy means there are three copies of each chromosome instead of two, and it has been discovered that cuteness is located on the 21 st chromosome. Be prepared for unprecedented levels of cuteness, even if you have many other children who you think are cute.

Hypotonia - Sometimes referred to as poor muscle tone, what this really means is that all of Baby is super soft and cuddly. Synonyms for this condition are smoosh-ball, teddy-bear, snuggle-puss, honey-love, and so forth. Squeezing and hugging Baby is a frequent and irresistible temptation.

Short stature - Children with Down syndrome are typically short in stature due in part to short limbs. This just means parents and other loved ones will have abundant opportunity for exercise in the form of deep knee bends.

Speech therapists- This is another word for siblings. These are the children who will spend countless hours teaching your child with Down syndrome to talk and speak clearly. They will mimic sounds, invent oral exercises, play word games, demonstrate proper mouth movements, repeat key phrases, practice letters and numbers and loads more ad infinitum. Some therapists have unique methods such as requiring the client to say, 'Guard, release the faun!' in order to have the car seat unbuckled, or repeating unusual words like 'gastrovascular', but you have to just put up with their quirks.

Developmental delays - What this really means is that for once you don't have to say, 'Oh, they grow up so fast!' The delight of babyhood and toddlerhood is prolonged and there are ever so many more moments of it to savor. Baby will grow and learn in a slow and gentle manner and there will be plenty of opportunities to practice cheerleading along the way. You will also marvel and appreciate each little milestone that you may have taken for granted in all of your other children.

Congenital heart defect - This is really one of several code phrases for an intensive training course in learning the true meaning of **Jesus, I trust in you**. This training involves great spiritual growth and opportunity for deepening and greatly magnifying one's prayer life. There may even be a special retreat involved where one can really progress in prayer. The special code term 'open-heart surgery' is often used for this unique retreat that takes place in a hospital.

Special needs child - All children are special and all children have needs. Both of these facts can sometimes be taken for granted, but that is less likely with special needs parenting. This child will force you to see things more closely to the way God sees things, which is very, very contrary to the way the world sees things. The 'special needs child' instantly and unequivocally obliterates the blather of the world's view of life. Each and every life is a precious gift from His hand, of equal value in His sight, and the special child makes that especially clear, every moment of every day.