

Your Loved One is Having a Baby with Down Syndrome

*Nancy McCrea Iannone, Stephanie Hall Meredith, and Amy Geoffroy
with essays by Beverly Beckham and Herbert D. Hinkle, Esq.*



DownSyndromePregnancy.org

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Audience

This book is meant to be a resource for loved ones of parents preparing for the birth of a baby with Down syndrome.

Acknowledgements

Thank you to all of our loved ones for your help and support through the years. Thank you especially to Dr. Maria Iannone, V.M.D., aunt to Gabriella, who suggested significant changes to the original draft of this booklet. Thank you to reviewers who suggested edits, including Richard Kline, Missy Skavlem, Heather Trammell, and Sarah Hartway, RN, MS.

Thank you once again to Dr. Brian Skotko, M.D., M.P.P. (*BrianSkotko.com*) who provided medical review and suggested edits for this booklet and who works tirelessly for the Down syndrome community.

Thank you to Beverly Beckham and Herbert Hinkle, Esq. for their contributions to this booklet.

Thank you to Justin Meredith of Canister, whose gifted design work on our book and website allows our words to become beautiful. The time and skill you have donated has earned you a place in our hearts.

Thank you to Vincent Iannone and Justin Meredith for their wonderful production work on this relatives booklet.

Thank you to Kelle Hampton (*KelleHampton.com*) for orchestrating our photo contest.

Thank you to the generous contributors of gorgeous photos for use in our products.

Thank you to Mary Dressel and Ana Lorena Beltran for the translation of Resources in Spanish section.

DownSyndromePregnancy.org offers support to new and expectant parents preparing for the birth of their baby. We provide a free downloadable practical guide for expectant moms, *Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome* and new parents, *Welcoming a Newborn with Down Syndrome*. We also host a website with articles about different concerns and ideas for new and expectant parents. See *DownSyndromePregnancy.org* for more information.

WELCOME



Dear Friend, Grandparent, or Relative,

You have just learned that someone you love is expecting a baby with Down syndrome. Your first reaction may be sadness, shock, and worry for your loved one and his or her baby. You may wonder how this news will impact you and the extended family.

Please understand that your emotional reactions are normal. Often people have these initial reactions. Your perceptions will likely change as you learn about Down syndrome and get to know this new person in your life. In this booklet you will learn more about what to expect in the future. We hope you will learn about the growing possibilities and opportunities for children born today. Spend some time now adjusting to this unexpected news, so that when the baby is here, you will be ready to celebrate.

Congratulations to you and your loved one as you begin this journey of awareness, acceptance, and possibility.

Sincerely,

Nancy, Stephanie, and Amy



Katie Ryder with her grandfather, Bob Kewley.

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Rozie Givre with one of her brothers Dowie Givre. myshrub.blogspot.com

WHAT IS DOWN SYNDROME?

People with Down syndrome are each unique individuals. Babies with Down syndrome are babies first—they have the same needs, wants, smiles, and laughs. Children with Down syndrome are children first—they learn to walk, talk, read, ride a bike, and go to school. Adults with Down syndrome are people first—they have a variety of living situations, personal lives, and employment situations, including a growing number leading independent lives, taking college-level courses, and getting married.

All people with Down syndrome have the full range of human emotions and fears—they feel love, rejection, hurt, hope, fear, and happiness, just like the rest of us. As we begin to see people with Down syndrome actively involved in their communities, society's views of Down syndrome are evolving. People born with Down syndrome today have increased educational opportunities, better medical care, more support and information for their families, and more community involvement.

GENETICS

Down syndrome is the most commonly occurring chromosomal condition in babies born today, and about one in every 800 babies are born with Down syndrome.¹

Most individuals with Down syndrome have Trisomy 21, which means that they have three (instead of two) copies of the twenty-first chromosome repeated in every cell in their bodies. This means that while people in the typical population have a total of 46 chromosomes, people with Down syndrome have a total of 47 chromosomes. A small percentage of people with Down syndrome have other variations. One variation is mosaic Down syndrome, where the extra chromosome is in some cells but not all. Another variation is translocation, where there is an extra copy of all or part of chromosome 21, but this extra genetic material becomes attached to another chromosome, still resulting in Down syndrome.

Down syndrome almost always occurs at conception. Nothing the parents did caused their baby to have Down syndrome. It just happens. Down syndrome is generally not an inherited condition, so parents or other relatives have not passed it along. Translocation is a form of Down syndrome occurring in approximately 4% of the Down syndrome population, and some of the people with translocation Down syndrome do have an inherited form. Expectant parents would be specifically told if their baby has translocation Down syndrome, and if so, offered blood tests to see if they are carriers. If a test shows that a parent is a carrier, it is up to that parent to inform his or her family members so that those relatives may seek advice from their own health care providers. For more information regarding the different types of Down syndrome, you may speak with your health care provider, or read a brief description on the *NDSS website*.

PHYSICAL CHARACTERISTICS

Every person with Down syndrome has a unique set of traits and features. A baby with Down syndrome usually resembles family members and is just as adorable as any other baby.

1 de Graaf, G., Buckley, F., Skotko, B.G. (2015). Estimates of the live births, natural losses, and elective terminations with Down syndrome in the United States. *Am J Med Genet Part A*, 167A:756–767.

There are certain physical traits that are common in the Down syndrome population, but each baby will have a unique collection of these physical traits. Generally, people with Down syndrome are shorter than those in the typical population, and babies may be smaller. They usually have low muscle tone so that babies seem “floppy” or softer. They typically have an upward slant to the eyes, giving the eyes an “almond shape.” Babies with Down syndrome also sometimes have a single, deep crease across the center of each palm. Other possibilities include a slightly different shape to the ears, and extra skin on the back of the neck.

MEDICAL CONDITIONS

Individuals with Down syndrome have an increased chance for certain medical conditions, including heart defects, intestinal issues, thyroid conditions, hearing or vision impairments, and other medical concerns. Most of the conditions can be addressed with good medical care. A baby with Down syndrome often has at least one of these conditions but very rarely all of them. The medical conditions of an individual person with Down syndrome are not necessarily tied to that individual’s abilities. Fortunately, improved access to better medical care has nearly doubled the life expectancy for people with Down syndrome over the past few decades. In fact, the average life expectancy today is about 60 years.²

DEVELOPMENT AND COGNITION

Each person with Down syndrome has individual strengths and weaknesses. Most people with Down syndrome have a mild to moderate intellectual disability. For children with Down syndrome, it usually takes longer to meet the developmental milestones such as crawling, walking, and talking. Each child learns at a different pace, but the vast majority of children with Down syndrome learn all those basic skills—just on a somewhat delayed schedule.

States provide Early Intervention services to young children with Down syndrome. The type and amount of services will vary from state to state and from child to child. Some examples of possible therapies include physical therapy,

2 Glasson, E.J., Sullivan, S.G., Patterson, B.A., Montgomery, P.D., Bittles, A.H. (2002). The changing survival profile of people with Down syndrome: implications for genetic counselling. *Clinical Genetics*, 62:390-393.

occupational therapy, speech therapy, assistive technology, and possibly other services. These services are usually provided at no charge or for a sliding scale fee based on income. In addition, people with Down syndrome have many educational choices ranging from preschool to college, including inclusion with typical peers in a general education classroom. New research into how to teach children with Down syndrome is constantly improving the outcomes for them and giving parents and teachers better techniques for educating their children. Many adults with Down syndrome are now employed, live independently or in support settings, and are active members of their community.

PRENATAL DIAGNOSIS

Expectant parents who have received a confirmed or suspected diagnosis prenatally have usually undergone diagnostic testing such as an amniocentesis or chorionic villus sampling (CVS), or relatively newer non-invasive screening tests (sometimes called NIPT, NIPS, cfDNA, or other brand names). A CVS or amnio is considered diagnostic, and the results are almost always definite. The new screening tests are much more accurate for detecting Down syndrome than traditional screening, but false positives and occasionally false negatives still occur. Sometimes expectant parents who are preparing for the birth of a baby with Down syndrome undergo screening and then confirm the diagnosis for sure with a diagnostic test. Other expectant parents opt to stop with a non-invasive screening because diagnostic tests can pose a very small risk of miscarriage. These are all very personal testing decisions made between the expectant parents and their doctor.

Sometimes we hear and share tales of a friend who was told her baby may have Down syndrome, but it turned out not to be so. These stories happened much more often with traditional screening, but they are less likely now. So if your loved ones tell you “our baby has Down syndrome”—or if they give you this booklet—they have probably had one of these tests and are preparing for the high likelihood that their baby has Down syndrome. Some expectant parents might tell you details about testing if they want you to know, but we recommend that you don’t ask. Moreover, even if they have a small chance that their baby does not have Down syndrome, it can be painful to bring up that topic once they have already adjusted their expectations for the journey of parenting a child with Down syndrome.



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WHAT DOES A DIAGNOSIS OF DOWN SYNDROME MEAN TO OUR FAMILY?

Many families go through a period of shock and readjustment when they first learn that a baby will have Down syndrome. Members of national and local Down syndrome organizations are available to support newly-diagnosed families, share their experiences, and provide information and resources to help families on their own journey. Generally, families move from initial shock and sorrow to a stage of adjustment and acceptance, and finally to joy as they get to know the baby.

If you are worried about the immediate family of this baby, some research may help. Recent research into family life indicates a lower divorce rate among parents of children with Down syndrome³ and a positive impact on siblings⁴, who

3 Urbano, R. & Hodapp R. (2007). Divorce in families of children with Down syndrome: A population-based study. *American Journal on Mental Retardation*, 112:261-274.

4 Skotko, B. & Levine, S. (2006). What the other children are thinking: Brothers and sisters of persons with Down syndrome. *American Journal of Medical Genetics Part C*, 142C:180-186.

are more likely than their peers to embark on careers in social service fields like education, social work, nursing, medicine and research⁵.

Recent research reveals the following responses from those with a family member who has Down syndrome:

- 99% of people with Down syndrome said they were happy with their lives
- 97% of people with Down syndrome liked who they are⁶
- 99% of parents said they love their child with Down syndrome⁷
- 97% of brothers/sisters, ages 9-11, said they love their sibling⁸

See full research results conducted by Dr. Brian Skotko, Sue Levine, and Dr. Rick Goldstein in their article, "Having a Son or Daughter with Down Syndrome: Perspectives from Mothers and Fathers," accessible through Dr. Skotko's website (BrianSkotko.com).

Grandparents and other extended family members often worry that they won't feel the same instinctive love for the new baby that they have for other family members. They may wonder about the relationship they will have with this child—will it be different? Uncomfortable? These are natural fears for people who have not already experienced a close relationship with someone with Down syndrome. For most grandparents and other relatives, the bond they have with the new baby and the joy they feel watching this child grow is a wonderful, eye-opening experience. And nothing is sweeter than hearing "Grandmom" or "Poppop" for the first time from a grandchild with Down syndrome.

To find out about additional grandparent resources and read perspectives on how grandparents can play an important role in supporting both their children and grandchildren, see the Down Syndrome Pregnancy article: Grandparent Stories.

5 Dykens, E. M. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. *Mental Retardation*, 43:360-364.

6 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Self-perceptions from people with Down syndrome. *American Journal of Medical Genetics, Part A*, 155:2360-2369.

7 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Having a son or daughter with Down syndrome: Perspectives from mothers and fathers. *American Journal of Medical Genetics, Part A*, 155:2335-2347.

8 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Having a brother or sister with Down syndrome: Perspectives from siblings. *American Journal of Medical Genetics, Part A*, 155:2348-2359.



Gabby and her sisters Maria, Sam, and Elena. © Jennifer Tuch Photography

WHAT DOES THE FUTURE HOLD?

There has been and continues to be amazing progress in areas which impact the future of people with Down syndrome. Medical treatments, educational improvements, societal change, and legal advancements have altered the landscape for people with Down syndrome and their families. In addition, ground-breaking research is ongoing into treatments to improve cognition for individuals with Down syndrome. This kind of research was never possible before. Scientists have been able to map the human genome—meaning that they have been able to identify genes found on the chromosomes and investigate causes and treatments of cognitive impairment in people with Down syndrome. Many people believe a treatment to improve cognition will one day be available in your new family member's lifetime.

INFORMATION

Family members and friends are encouraged to look to the following organizations for further information about Down syndrome:

Down Syndrome Pregnancy
DownSyndromePregnancy.org

National Down Syndrome Society (NDSS)

NDSS.org

National Down Syndrome Congress (NDSC)

NDSCcenter.org

International Mosaic Down Syndrome Association (IMDSA)

IMDSA.org

LuMind Foundation

LuMindFoundation.org

Down Syndrome Education Online by DSE International

DSEInternational.org

Your local Down syndrome group:

NDSS.org Find an Affiliate

INSPIRATION

Family members and friends looking for inspiration through beautiful photography and personal stories will find these resources helpful:

Kelle Hampton's photography blog

KelleHampton.com

Conny Wenk's photography blog

KidswithaLittleExtra.blogspot.com

Band of Angels products, including Common Threads, Celebrating Life with Down Syndrome

BandofAngels.com

Gifts 2: How People with Down Syndrome Enrich the World, edited by Kathryn Lynard Soper

WoodbineHouse.com Gifts 2

To read about the everyday lives of families who have a child with Down syndrome, see the ***Down Syndrome Pregnancy article: Slice of Life***.



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FOR RELATIVES WHO SPEAK SPANISH

For our Spanish-speaking expectant parents, and for relatives who speak Spanish, there are a variety of Spanish language materials and resources.

Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome and *Welcoming a Newborn with Down Syndrome: A New Parent's Guide to the First Month*
DownSyndromePregnancy.org

Brighter Tomorrows website in both English and Spanish:
BrighterTomorrows.org

Also, NDSS has information in Spanish:
esp.ndss.org

NDSC has information in Spanish as well:
ndscenter.org Bienvenidos

Additionally, there are many Down syndrome groups in many Spanish-speaking countries. Families may find it useful to take a look at the Gifts website to find websites of groups in their countries of origin (countries listed alphabetically):
GiftsDS.Segullah.org International Links

These websites from Spain are particularly helpful:

SindromeDown.net

Down21.org

Babies with Down Syndrome in Spanish:

WoodbineHouse.com

Find local contacts who speak Spanish:

NDSCcenter.org Spanish groups

A dad blogs in Spanish about bringing up his daughter with Down syndrome:

ElBlogDeanna.es

EN ESPAÑOL

Para nuestros futuros padres que hablan español y para sus parientes, hay una variedad de materiales y recursos en español.

Del diagnóstico al nacimiento: Una guía para las mujeres embarazadas de un bebé con síndrome de Down y *La bienvenida a un bebé con síndrome de Down: Una guía para nuevos padres* en inglés y español:

DownSyndromePregnancy.org

Brighter Tomorrows sitio en Internet en inglés y español:

BrighterTomorrows.org

También, la NDSS (Sociedad Internacional del Síndrome de Down) tiene información en español:

esp.ndss.org

El NDSC (Congreso Nacional del Síndrome Down) también tiene información en español:

ndsccenter.org Bienvenidos

Además, hay muchos grupos acerca de Síndrome de Down en muchos países de habla hispana. Las familias podrían encontrar útil el ver la página de Internet "Gifts" para encontrar páginas de Internet de grupos en sus países de origen (los países están listados alfabéticamente):

GiftsDS.Segullah.org International Links

Unos sitios en Internet de España que son particularmente de ayuda:

SindromeDown.net

Down21.org

Bebes con Síndrome Down en español:

WoodbineHouse.com

Encuentra contactos locales que hablan español:

NDSCcenter.org recursos grupos

Este papá tiene un blog sobre la crianza de su hija de seis años con Síndrome de Down:

EIBlogDeanna.es



Oliver, Megan, and Steve Yen.

HOW CAN I HELP THE EXPECTANT PARENTS?

Many friends and relatives want so much to do and say “the right thing.” They want to help and to comfort, but they are not sure how to move through this new social terrain. The expectant parents may still be adjusting themselves, and they may be more sensitive to certain statements. Many expectant mothers have described themselves as a “raw nerve” in the time between diagnosis and delivery, internally or privately reacting to statements made by others. If you are wondering about something you have already said, please don’t worry too much. Most expectant parents understand some situations are not covered in the usual social training. But we do have some words of advice for you which have been gathered from the experiences of expectant parents.

The most important thing is to tell your loved one that he or she has your full support, that their child will be welcomed and loved, and that you will be there for them. Listen to your loved one. Respect his or her emotional state. This basic game plan will guide you through most of the pregnancy. However, if you wish to learn more, here are a few other tips from expectant parents.

KEEP AN OPEN MIND ABOUT DOWN SYNDROME

It is possible that you may have an impression of Down syndrome that is based on outdated ideas of segregation, institutionalization, and a lack of adequate medical care.

Research. There are some excellent websites listed in this brochure. It is natural to ask the parents questions about Down syndrome, and your willingness to talk will show you care to most parents. However, there is a lot of reliable information (along with some unreliable information) out there on the internet, and it may take expectant parents some time to gather and understand information. It may help if you do your own research so that you can follow along with the discussions. It can also help you deal with your own range of emotions, fears, insecurities about the diagnosis, and feel better about how the baby will fit into your family network.

Track Down Local Resources. If you have friends who have a child with Down syndrome (preferably a young child), provide their contact information to the expectant parents. If you have information about local groups, pass it on. However, recognize that it may take expectant parents some adjustment time before they are ready to make the contact.

Check Your Vocabulary. Expectant parents often can become very sensitive to certain words. Most United States Down syndrome organizations support “people-first language.” We say “***baby with Down syndrome***” not “Down syndrome baby” or “Down’s baby” or “mongoloid.” The word “retarded” (called the “R-word”) in slang can be hurtful, and is being phased out in medical terminology. Speaking in correct terminology shows you understand that this child is a baby first, unique and precious. Also, when some parents hear phrases such as “high functioning” or questions about “how severe” it is, they may be worried that their child will be loved less if he or she does not meet a certain standard.

TRY TO UNDERSTAND THE EMOTIONAL STATE OF EXPECTANT PARENTS

Expectant parents bring their own personalities and life experiences to pregnancy, so there is variation in how they process prenatal diagnosis. Therefore, you should always respect what the parents share about their state of mind or needs, even if it differs from what we share here. However, you can start to support the most common feelings and reactions by doing the following:

Understand and appreciate that expectant moms with a diagnosis will have a range of emotions from joy to despair, sometimes several in a day. Be patient and kind, and offer empathy but not pity. Emotions in pregnancy do evolve as parents progress from anger, denial, shock, depression, then adaptation and excitement. Offer a shoulder to cry on as well as a cheer for good news.

Listen to the expectant parents' information about Down syndrome, appointments with doctors, hopes and fears. Try not to "correct" anything they say or offer up negative information. If your loved one has given you this booklet, know that they plan on welcoming their child with Down syndrome. So, you should avoid bringing up other choices. Expectant parents can be particularly sensitive to this topic, so avoid stories about other people's choices as well.

Follow up. Call or e-mail to ask about the baby, the pregnancy, and the parents' state of mind. Don't let the baby's diagnosis become the elephant in the room. However, be careful not to make the diagnosis the focus of every conversation and be sensitive about the timing of questions. If you ask an expectant mom how she and the baby are doing at a party, she may fall apart or shut down. So, try to gauge her emotions and reactions, and ask when she is in a "safe" place, at home or one-on-one with you in your home or over the phone.

Support, but be careful not to assume. It is wonderful to try to understand what the expectant parents are feeling. However, try to avoid telling them you "know" what they are thinking or feeling. This can sometimes strike the wrong chord with expectant parents.

To read more parent perspectives on the emotions after a diagnosis, see the Down Syndrome Pregnancy article: *Emotional Impact*.

To find out what expectant parents most appreciated from their friends and loved ones, see the Down Syndrome Pregnancy article: *Positive Support*.

AVOID COMMON PITFALLS

As you talk to the expectant parents, hoping to provide comfort and hope, it's good to get some tips on what makes some expectant parents cringe. There are certain phrases that we often say to people going through a tough time. They feel like the right thing to say, and some expectant parents appreciate those sentiments. Other expectant parents have said these phrases have a negative impact, so it's better to avoid saying them. We know they are said out of love

and concern, but expectant parents can hear things we do not intend because of the mix of emotions. So just to be safe, try to avoid the following:

“I’m sorry” or any pity. Parents wind up hearing this dozens of times, and many report that it makes them feel pitied, or that their child is a tragedy. Even if they feel bad, they still don’t want other people feeling pity.

“Special babies are for special parents.” Some parents feel like this is putting them on a pedestal when they are the same people they were before the diagnosis.

“They are all so loving.” (or similar statements) Some parents may perceive that this takes their child’s individuality away.

“Down syndrome is no big deal.” Although some parents may appreciate this statement, many others will feel that their concerns and fears are being dismissed. (But definitely keep that optimism and cheer—after this adjustment time you may all be making this statement some day!)

Cards that resemble sympathy cards. Parents appreciate so much your love, reassurance and support, but certain “we’re thinking about you” cards feel like a sympathy card, and emotionally sensitive expectant parents may be upset. A handwritten or typed note during the pregnancy and a “Congratulations” card after the baby is born will be much more appreciated. We have a sample note at the end of this section that an expectant mom may appreciate receiving from a friend. It may give you some ideas about what to write in your own letter.

To read more parent perspectives on the comments to avoid, see the Down Syndrome Pregnancy article: *Dealing with Comments*.

DO SOMETHING NICE

Tell the expectant parents you are available to help, both now and in the future. This shows the parents that you care about them and about their baby.

Babysitting. Before the baby is born, you can offer to babysit for other children during mom’s medical appointments. After the baby is born, parents may need help as they juggle a possible NICU stay, medical appointments, or surgery.

Errands. Both before and after birth, providing meals or transportation for other children’s events may also be helpful. After the baby is born, parents may appreciate meals, gift cards, or a gift certificate for a house cleaning service. There

are also great websites to coordinate meals and errands at LotsaHelpingHands.com and SignUpGenius.com.

Small gifts. Buying a book or a video about Down syndrome is both useful and thoughtful. *Woodbine House* is an excellent source for these items.

Baby shower. Many parents report welcoming a baby shower, although it might be good to check with the expectant parents first instead of going ahead with plans for a surprise shower. Many expectant moms are fighting a range of emotions through the remainder of their pregnancy, and some don't deal well with surprises, however well-intentioned. Others do not want to miss out on the typical surprise baby shower. Think about what you know about the expectant mom's personality, and try to gauge her emotional state.

For specific baby items, toys, and resources recommended for the baby with Down syndrome, read the Down Syndrome Pregnancy article, *What will baby need? (It's a Baby Shower!)*.

Siblings. With the expectant parents coping with emotions, appointments, and possible issues after the baby's birth, siblings may be picking up on some stress. Giving the other children some extra attention and gifts may help. To read more sibling perspectives, see the Down Syndrome Pregnancy article: *Sibling Perspectives on Down Syndrome*.

Celebrate. After the baby is born, tell the parents how adorable he or she is. Offer your congratulations, and comment on the resemblance to other family members, and ask to hold the baby. Be understanding if there are restrictions to prevent germ exposure.

Participate or donate. If your loved one wishes to attend a Down syndrome event, such as a Buddy Walk, volunteer to participate, donate, or spread the word. Donations to organizations like those listed in the Information section of this booklet, or a local organization can also show you care and you are committed to welcoming this child.

DO NOT FORGET ABOUT YOURSELF

We know that you too may be coping with your own emotional adjustments. You may feel the need to cry on someone's shoulder, or share your fears. You may be experiencing grief, despair, hopelessness, and worry for your family. We suggest that you do not share these concerns with the expectant couple, who may not be able to handle it yet. However, you too may need some kind of sup-

port as well. It may be a good idea to talk with other extended family members, or other friends in your circle. The local Down syndrome group may have a grandparents' group, or suggest specific members with whom you can talk. If the relationship to the expectant couple is very close, and the emotions very intense, some type of therapy may be a good idea as well.

For other tips, visit these links:

Stone Soup "What to say"

KatrinaStonoff.wordpress.com

Simply Modern Mom: "Simply Said . . . Stephanie about Down Syndrome"

SimplyModernMom.com



Marie Meredith Mattinson with her nephew, Andy. © Justin Meredith

SAMPLE LETTER OF SUPPORT

Written to a friend who is expecting a baby with Down syndrome

Dear Friend,

I know you are probably facing one of the most emotional times in your life and I just want to let you know that I'm here for you in whatever capacity you need. If you call me crying, I promise I will listen without ever making conclusions about how you are "handling things." If you want to tell me about any doctor's visits, I will listen. If you want me to go with you, I'm there. If you call me excited about the pregnancy and the baby, I will share in your joy.

I've read the words of parents who have had a prenatal diagnosis. I have learned that pregnancy post-diagnosis is a really emotional, very isolating time. Many moms say they were overwhelmed, scared, and felt like they were on an emotional roller coaster. But they say the good news is that life with their children with Down syndrome is a very far cry from that scary time.

I have learned about several resources that exist just for you. The first is a pregnancy book for moms with a prenatal diagnosis, and it is a free download at DownSyndromePregnancy.org. There are also articles on the site with stories from other parents of children with Down syndrome about different pregnancy topics.

Other books include *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives* at **Woodbine House** and *Unexpected* by Jennifer Jacob, which both include many prenatal diagnosis stories from others who have travelled a similar path.

Internet support groups are also available for moms in pregnancy post-diagnosis. In those groups you can talk with other moms who are pregnant or have recently had their babies, including **Baby Center's Down Syndrome Pregnancy Discussion Board** and Down Syndrome Diagnosis Network (dsdiagnosisnetwork.org).

I know things are tough right now in more ways than one. But I'm here for you, and please call me if you need to talk about anything. This baby is going to be an amazing part of your life, and I already know what a great mom you are, so this baby will be so lucky to have you!



Ellie swinging at the park with Grandma Sally. mystubbornmiss.com

GIVING MONETARY GIFTS FOR A BABY WITH DOWN SYNDROME

by Herbert D. Hinkle, Esq. and S. Paul Prior, Esq.

Many family members plan on giving monetary gifts for a new baby, and wonder if a diagnosis of Down syndrome changes things. Because there may be issues with financial planning, it is essential that you take certain precautions with monetary gifts:

- For small monetary gifts, checks or savings bonds should be in the name of a parent rather than the child.
- For substantial monetary gifts, family members should consult with an attorney experienced in estate planning and special needs.

Why these precautions? A child with Down syndrome born today may someday need to access certain government funded programs and benefits. However, many programs and benefits use financial means tests to determine eligibility, so an agency will look at the assets owned by an individual with Down syndrome. As a result, a well-intended gift can cause serious problems.

To illustrate: Once such a child turns 18, the resources of parents are no longer counted to determine eligibility for programs like Supplemental Security

Income (“SSI”) and Medicaid. A child who otherwise meets certain disability requirements will be declared ineligible if his or her resources total \$2000 or more. Thus a child who has several savings bonds worth a total of \$1500, a \$500 certificate of deposit and \$300 in a checking account will be ineligible for SSI and Medicaid. Worse yet, parents who are unaware of the savings bonds (because the donor wants to someday surprise them) when they make the application for SSI might be required to pay back thousands of dollars if the Social Security Administration later discovers the bonds.

What should be done? The easiest thing is to make gifts to the parents directly, leaving the child’s name off the check or bond. Avoid accounts such as “in trust for” and Uniform Transfer or Gifts to Minors Accounts (UTMA or UGMA). Do not rely upon the advice of bank employees.

As an alternative, families can establish an “ABLE” account for the benefit of a child with Down syndrome. The Achieving a Better Life Experience Act (“ABLE Act”) permits families to save up to \$14,000 per year in an ABLE account. Under the Act, the amount is to be adjusted periodically for inflation. It is important to note, the \$14,000 limit is from all donors combined. Under the ABLE Act, a person with Down syndrome can have up to \$100,000 in an ABLE account before losing SSI. If the amount exceeds this number, the individual still keeps their Medicaid benefits. The interest that grows in an ABLE account can be used tax-free so long as the funds are used to pay for “qualified disability related expenses.” Because the ABLE Act is still relatively new, many regulations have not yet been finalized. At the time of the drafting of this article, ABLE Accounts are not yet commercially available, however it is anticipated they will become available sometime in late 2016. It is likely these type of accounts will be a good way for families to hold a collection of smaller gifts for the benefit of a child with disabilities.

A word of caution about ABLE accounts: there will be a cap on the amount of money which can be saved in an ABLE account – likely around \$300,000. While this is a significant sum, it is not enough to meet all of the lifetime needs of a person with Down syndrome. In addition, families should be aware any funds remaining in an ABLE account when the person with a disability passes away will be returned to the government to satisfy any governmental liens based on the value of services provided. Therefore, it is not a good idea to overfund an ABLE account.

While an ABLE account will likely be a very useful tool to parents and families, it will not take the place of a special needs trust.

Parents should create a special needs trust for the child. However, such trusts are best suited to receive large bequests, not modest gifts made throughout childhood. When a trust is created by a parent, when drafted properly, these trusts usually do not require a governmental payback. This allows families to also provide for other family members or charitable interests when the individual with Down syndrome passes away.

It is important to recognize these precautions in no way preset the future of a child with Down syndrome. However, practical planning can afford the greatest flexibility to families and can make the difference between receiving vital benefits and being declared ineligible.

For more articles on related topics see the website of Hinkle, Fingles & Prior, PC (hinkle1.com).

Mr. Hinkle has represented people with disabilities since 1974. He is the founding partner of Hinkle, Fingles & Prior, PC with offices in New Jersey and Pennsylvania. Mr. Hinkle has served on the boards of a variety of non-profit organizations in the disability field. He is an adjunct professor of law at the Rutgers School of Law – Camden, teaching trusts, estates and taxation.

Mr. Prior is a partner at Hinkle, Fingles & Prior and has spent his entire legal career representing people with disabilities. As the younger brother of a man with autism, he has a life-long commitment to disability law. His legal work focuses on special education, guardianship, financial entitlements, and access to appropriate services. A substantial part of his practice is devoted to assisting families in estate and trust matters. He has successfully argued leading cases before the New Jersey Supreme Court, Third Circuit Court of Appeals, as well as other state and federal courts. He serves on the board of directors of The Arc of New Jersey and Autism New Jersey. Previously, he served on the Board of Special Olympics New Jersey and the Eden Foundation.



Brookann Bolton with her brother Braydon.

A GRANDPARENT'S STORY

by Beverly Beckham

A CHRONOLOGY OF EMOTIONS

I will have to apologize to her someday. I will have to tell my grandchild that I cried the day she was born.

Not immediately. Not when I first held her and she looked into my eyes and I looked into hers. There's a picture of this. Lucy, just minutes old, almost saying hello. I never shed a tear in the first 12 hours of her life when I thought she was USDA-approved-top-of-the-line perfect Grade A baby girl. Then I was all smiles. I called my friends and said the baby has come. Lucy is here. Lucy is perfect - round cheeks, red lips, downy skin, blond hair, blue eyes.

We joked with her father. We all hugged one another. We were so lucky. We got our miracle, we exclaimed. And there was no doubt that we had.

And then a doctor walked over to the bed where Lucy lay and he unwrapped her and inspected her. And he said the word test. And then he said Down syndrome.

We cried then. All of us. Instantly. Because what had been perfection just seconds before, what had been all joy and gladness and light, became, with two little words, imperfection and fear.

Stupid, stupid us.

How will I tell Lucy that we wept while holding her? How will I explain that in those first few hours we looked at the gift God created just for us and wanted Him to make it a better gift? To fix it. To make our little Lucy just like everyone else. There's been some mistake, God. This isn't what we prayed for.

But isn't it?

Give us a baby to love, we begged, and we have her and what sweeter, better, bonnier baby could there be?

People told us that it's only natural to grieve the loss of a dream. And that's what I like to think we did. We dreamed one Lucy, the perfect little girl - like Margaret walking with her mother, like Shiloh on the stage in her toe shoes.

In those first few hours it was this dream that tormented us. And it blinded us, too, because all we could see was what Lucy wouldn't be. Here she was, infinity in our arms, fresh from heaven, in such a hurry to get to us that she arrived two weeks early. And we were judging her.

She left the angels to come here. She gave up Paradise for us. And we cried.

Funny thing is she hardly cried. She opened her eyes and took us in, one at a time, and amazingly she didn't seem disappointed at all.

One in 800 babies is born with Down syndrome. The rarer the jewel, the more value it has. That's the way it works with things - with pearls and Lottery tickets and horses and art.

But in our world and in our culture, we like our people to be all the same.

How will I tell her that I wanted her to be just like everyone else? That I was afraid of different when it's what's different that stands out? Are the black sand beaches in Hawaii sad because they're not soft and white? Do four-leaf clovers ache to be three? Does the life that grows above the tundra wish it were rooted in a valley instead?

The red rocks of Utah. Icebergs. The Lone Cypress. The Grand Canyon. And Lucy Rose.

We expected our life with Lucy to be lived on paved highways with well-marked signs, the rest stops never far from one another.

Lucy is taking us down a different road, a blue highway, instead. It's scary not knowing what's ahead. But no one, even on the wide smooth roads, knows the future.

We yearn for paradise. Lucy just came from there. She is heaven in our arms. We didn't see this with tears in our eyes. But we see it now.

FROM LUCY, A FULFILLING YEAR

It's one year later. One year after the ground caved in and the world blew apart and the center failed to hold. One year after we were told, "I'm sorry" so many times that we were sorry, too.

Three hundred and sixty-five days, some of them terrible. The day my granddaughter Lucy Rose was diagnosed with Down syndrome. The cold, rainy day she came home. The day the doctor said she needed heart surgery. The day of the surgery when the operation didn't go as planned. The days after, at the hospital, when we felt helpless at her side.

So many days at home, holding Lucy, begging, "Hang on, little girl. Don't leave us." Winter closing in, doors closing everywhere.

More surgery. More problems. Hope frayed.

Fifty days? 100?

We clung to each other - mother, father, grandmother, grandfather, aunt and uncle. It'll be OK, we said over and over.

And when we didn't believe this anymore, friends came and took our hands and kept us from drowning in sorrow and fear.

We worried Lucy would die. We worried she would live and not know us, live and not respond, live and not see, not hear.

We worried about everything.

We still worry. But not the way we used to. We're standing on solid ground, for now anyway - and now is all any of us has. Lucy is healthy and happy and is turning a year old Sunday. And we know, because of this year, just how lucky we are.

We ask ourselves, why did they shake their heads when she was born? Why did they say "We're sorry" and not congratulations? Why even now do doctors say, "We have tests. This won't happen again," as if Lucy shouldn't have happened. As if they would erase her if they could.

Erase the heart problems. Erase the need for surgery. But don't erase Lucy.

Lucy is like a crayon Crayola has yet to invent. So many colors - burnt sienna, maize, mulberry, raw umber, razzle dazzle rose.

But no Lucy Rose. Because she is the color of wind. The color of moonbeams. The color of stars that are too far away to see.

She is rare and she is different and she is beautiful and bright and we have been blessed because she is ours.

Before she was born, I talked this prayer to her. "Throughout life you will be both a student and a teacher, for you have much to learn and perhaps even more to teach."

I imagined teaching her "Pat-a-cake" and "This Little Piggy" and the names of things. And I have done all this.

What I never imagined is what she would teach us.

The children will lead you. And she has.

Lucy has led us through the toughest of times. The ground caved in, the world blew apart and the center failed to hold.

But Lucy endured. And grew stronger. And thrives.

And because of family and friends, so do we.

We held her so much. Maybe that's why some of her rubbed off, some of her joy, her good nature, her smile, her pluck.

When I was in second grade, Rosemary, the most popular girl in class, picked me to be her best friend. We walked arm in arm. We sang. She invited me to her house. We had fun all the time.

That's how it is being with Lucy.

All children bring joy. Lucy brings something more. Maybe that's because we came so close to losing her. "Eat, baby." "Look at us." "Say Dada." "Go to Mama."

And she did.

And she does.

And life is good.

Beverly Beckham is a columnist for the Boston Globe and Grandparents.com, the author of "A Gift of Time" and "Back Then," a frequent contributor to the Chicken Soup for the Soul series and the proud grandmother of Luke, Megan, Charlotte, Adam and Lucy Rose.



Emerson (18 months) with big sister Adysen. © Corie Green Photography

CONCLUSION

You are embarking on a new and exciting part of your life involving your soon to be born loved one with Down syndrome. We know it seems a bit scary now, but soon you will have an adorable child to help guide you through this new terrain. Also, thank you for your commitment to love and support these expectant parents. An educated and sincere support network is often key to the emotional health of expectant parents. By reading this booklet, educating yourself, and making a plan for effective support, you show this family that you have their best interests in mind. We hope this will benefit both them and you in the coming months.

To access the hyperlinks in this booklet, go to the DownSyndromePregnancy.org and download the online version.

ABOUT THE AUTHORS

Ann Marie “Nancy” McCrea Iannone, J.D. was an original founder of Down Syndrome Pregnancy. She is also an adjunct teacher at Rutgers University School of Law in Camden, New Jersey. Nancy is a contributing author in *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives*, and co-author of the book *Diagnosis to Delivery: A Pregnant Mother’s Guide to Down Syndrome* and *Welcoming a Newborn with Down Syndrome*. She has also provided active internet support to expectant parents for many years.

Nancy received a prenatal diagnosis of Down syndrome and AVSD for her daughter Gabriella in 2004. The support received from friends and family was invaluable. Nancy lives in New Jersey with her husband Vincent and their four daughters Samantha, Maria, Elena, and Gabriella.

Stephanie Meredith, M.A. is the author of *Understanding a Down Syndrome Diagnosis*, a prenatal diagnosis booklet created with input from the national medical and Down syndrome organizations (www.lettercase.org). She is also the co-author of *Diagnosis to Delivery: A Pregnant Mother’s Guide to Down Syndrome*, *Welcoming a Newborn with Down Syndrome*, and a contributing author in *Gifts 2: How People with Down Syndrome Enrich the World*. Stephanie also facilitated the translation of *Babies with Down Syndrome* into Russian and continues to provide support in Russia as an international advocate.

Stephanie was twenty-three years old when she learned about her son’s diagnosis after his birth and relied on a close network of friends and family for strength during that time. Stephanie currently lives in Georgia with her husband Justin and children Andy, Kate, and Lily Jane.

Amy Geoffroy is a former president of Network21: Supporting Families with Down Syndrome. Amy received a prenatal diagnosis of Down syndrome and partial AV canal with her younger daughter Abigail in 2003. She was fortunate to be connected quickly to the Down Syndrome Clinic at Children’s Hospital in Boston at the time of her diagnosis and to receive support from the new parent lead. The family moved to New Jersey soon after the diagnosis and struggled to find resources and a support network, prompting Amy to become involved with Network21.

During her tenure at that organization, Amy led efforts in new parent and medical provider outreach as well as inclusive education advocacy. Amy served on the program board for New Jersey Coalition for Inclusive Education for two years before moving with her family to Portland, Oregon. Her daughter Abigail is currently thriving in a general education classroom with additional specialized support and instruction.

“This booklet takes the punch out of Down syndrome for family members and replaces it with information, acceptance, and, yes, celebration.”

– *Dr. Brian Skotko, Co-Director, Down Syndrome Program,
Massachusetts General Hospital*

“This booklet provides factual information about Down syndrome in the context of real people with Down syndrome and their families. It should offer hope and information to any friend or family member preparing to welcome a child with Down syndrome. I could not recommend this booklet more highly.”

– *Amy Julia Becker, author of “A Good and Perfect Gift: Faith,
Expectations, and a Little Girl Named Penny”*

“When a loved one is expecting a child with Down syndrome, this booklet offers accurate information, practical advice, and a realistic yet positive view of the future. An excellent resource.”

– *George Estreich, author of “The Shape of the Eye”*

“I am very glad “Your Loved One is Having a Baby with Down Syndrome” is available as a resource today. Not too long from now you will be celebrating milestones and accomplishments in this child’s life that will put Down syndrome in perspective. Congratulations for taking the first step in creating a more welcoming world for all our children.”

– *Pamela Wilson, Children with Special Needs Editor, BellaOnLine*

“Three years ago my sister told us her amnio was positive for Down syndrome. We did not know what to say or do. We feared the challenges she and the baby would face. The more we learned, the less we feared. I wish this booklet was available when my sister was pregnant.”

– *Victoria Stebbins, aunt of Brady Zook*

“After learning that our soon to be granddaughter has Down syndrome, we have gradually moved from disbelief to acceptance and joy, awaiting eagerly to meet this welcomed addition to our family. This booklet moved me to tears as I allowed my heart to feel and understand about this precious gift that is about to enter our lives. As a NICU Neonatal Nurse Practitioner who has cared for many babies born with Down syndrome, I look forward to sharing this booklet of hope and invaluable resources with other family members of patients.”

– *Colleen Young, grandma to baby girl Peters*

