

An *extraordinary* Life

A Guide for New & Expecting Parents



Down Syndrome Association of Middle Tennessee

somethingextra.org | 1310 Central Court | Hermitage, TN 37076 | 615.454.3129



Congratulations! _____

While the news of your child having Down syndrome may have come unexpectedly, your life will be full of many wonderful surprises and experiences. You may be feeling overwhelmed right now, but you need to know that your feelings are perfectly natural and that you are not alone. We are here to help celebrate with you and support you along the way.

This booklet is intended to help support your family as you begin your journey here in Tennessee. It is filled with local resources and experiences from local families, in addition to other information that we hope you will find helpful.

Congratulations and welcome to our community!

- From all of us at DSAMT





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1 Dear New Parent,

We are your local resource for all Down syndrome questions and are here to celebrate with you and support your family.

If you are like most parents, including myself, learning that your baby has Down syndrome caused an avalanche of emotions, questions and concerns. Everyone's experience receiving the diagnosis is unique, but I can promise you that you are not alone and, most importantly, you have a beautiful new baby who will bring you much joy.

My third child, Ron, has Down syndrome. He enjoys swimming, birthday parties, boy scouts, playing video games, fishing with grandpa and Halloween. He is charming, mischievous determined and affectionate. Every day he teaches me something new, and I am extremely grateful for the gifts that he has brought to our family. You, too, have so much to look forward to!

DSAMT celebrates and supports individuals with Down syndrome and their families. It began with a handful of parents who wanted to make a difference and has grown into an organization that serves families in 40 counties in Middle Tennessee. We provide events for the entire family, support groups for parents, grandparents and siblings, educational opportunities and advocacy.

You may be reluctant to get involved right now, and that's okay. When you're ready or have any questions, we are here for you. We are an active, supportive community and very much look forward to getting to know your family.

In celebration & gratitude,

Alecia Talbott

Alecia Talbott, Executive Director
alecia@somethingextra.org
o. 615-454-3129
c. 615-881-4261



Alecia and her son, Ron





Enjoy your new Baby!

Dear Parents,
I am so happy about your new baby! I am Meghan Maynard and I'm in the 10th grade. I have one older sister and 3 younger brothers and I love to travel on vacation with my family. I am on a swim team, take Dance class, play tennis, and am a Girl Scout and cheerleader at my High School. I love to hang out with my friends and like to sing. I hope to work in a hair salon because I love styling hair and designing clothes. I feel very lucky because my family is supportive and encourages me to try new things. Enjoy your new baby!
Sincerely, Meghan



Meghan Maynard

Age 17

DSAMT Self-Advocate of the Year 2016



Welcome to Holland



by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience understand it, and to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go.

Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."
"Holland?!" you say. "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's

been a change in the flight plan. They've landed in Holland, and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. You must learn a whole new language. You will meet a whole new group of people you would never have met. It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills. Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. For the rest of your life, you will say, "Yes, that's where I was supposed

to go. That's what I had planned." And the pain of that will never, ever, ever, ever go away, because the loss of that dream is a very significant loss. But, if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland.

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Family *Ties*

“ Don't be afraid—most people have a fear of the unknown or a fear of not being able to meet the needs of a child with Down syndrome. If you have love to give and know how to treat children in general, then you're going to do fine. Children with Down syndrome want and need what all other children want—love, a chance, and to be accepted and appreciated for who they are and what they have to give/offer the world.” (Which is really what we all want, isn't it?) - A kindergarten teacher

You may be feeling many different emotions right now. Emotional responses for each parent vary and may include confusion, grief, love, shock, joy, and anxiety. While your feelings may be similar or different, you are not alone. Although initial diagnosis may be an intense time, parents often feel that with information, support, and a realization of their own abilities, a sense of overwhelming joy, love, and acceptance follows.

A survey (Skotko, 2011) of more than 1,900 families with a child with Down syndrome showed:

99%

of parents reported that they love their son or daughter with Down syndrome

95%

of siblings have a good relationship with their brother/sister with Down syndrome

84%

of parents believe these siblings are more sensitive & caring because of their child with Down syndrome





Siblings

Our Sister Kristianna

When I was 8 years old, I found out that my mother was pregnant. I was already used to being a big sister, as I have two younger brothers, but this pregnancy was extra special because I was getting a sister! I had always wanted a sister, and I remember jumping and running around the house the moment I found out my mom was expecting.



We had wanted a little sister for so long, and we didn't care how she came, just as long as she came soon!

When she was born, she spent about six weeks in the NICU (neonatal intensive care unit) before she could come home, and that scared us. I remember visiting her and my mother at the hospital with my dad and my brothers, patiently waiting for her to get to come home.

Once she was finally home, life was so happy. For the first few years of her life, all my brothers and I were concerned with was whether she would be able to laugh! We so desperately wanted to be able to laugh with her and to make her laugh if we could. We would spend hours standing on tiptoe over her crib making silly faces and noises at her. Eventually, she started laughing, and once she did, she didn't stop! Little did we know that the concerns of

our parents and doctors for my sister at that time were much more serious, as they wondered whether she would even be able to walk.

Today, our sister is 11 years old, and is—as our family has been saying she would be her whole life—“walking, talking, and living the independent life!” She loves to sing and dance, watch her favorite TV shows, and hang out with her siblings. She is so loving, so intelligent, and so funny! Her ability to interact with people in such a loving way is miraculous and always so powerful. We feel so blessed to have been given such a precious gift. She is my best friend, my whole heart's joy and, according to her, even my twin! She is our sister Kristianna, and who knows where we would be without her?

Our Brother Jonathan

Jonathan is our little brother. It's fun to watch him dance and play “*Just Dance*” with him. He LOVES dancing, and he loves girls. Girls love him, too. In fact, he is quite the “chick magnet.” We do a lot of things all families do together, like swimming, camping, hiking, festivals and beaches.

Both my younger brother and I were very excited when he was born, and we couldn't wait for him to come home from the hospital. When Jonathan was a baby, my mom asked if I would always love him as much as I did at that very moment. I said, “No. One day he will annoy me as much as William does!” Of course he is going to be annoying – he is my brother, and that is just what brothers do.



Jonathan has taught me patience. Sometimes he might be overstimulated, and sometimes he is challenging, but I have learned that he never means to be. So, even when he is “annoying” we still love him the same. The best thing is that Jonathan will always love us as much or even more no matter what... no matter how annoying we are to him. That is just the way he is.



2 What Do I Do *First*

Enjoy your baby! Get to know your child and treasure these first months with your precious son or daughter. There will be plenty of time to learn about Down syndrome. Celebrate this birth as you would any birth.

Contact the Down Syndrome Association of Middle Tennessee. Through the First Call program, you can be introduced to a parent mentor or family to welcome you into the Down syndrome community. We are here to celebrate with you and support your family with resources, gifts and friendships.

Talk to your doctors to ensure your baby has been scheduled for an echocardiogram and health evaluation at the Down Syndrome Clinic at Monroe Carell Jr. Children's Hospital at Vanderbilt and has been referred to Tennessee Early Intervention System for developmental support.





3 A Baby is a Baby First —

“ What a gift our 15-month old daughter, Sylvia, has been! When she was diagnosed after birth, I was shocked and scared. I knew very little about Down syndrome at the time and assumed the worst. But Sylvia, just by being herself, has shown me that I do not need to be scared. I moved from fear to pure adoration and gratitude. Because she’s brilliant! Sylvia brings her father and me such joy whether she is trying to catch our eye to share a smile, giggling at a ‘peek-a-boo’ game, or babbling and singing to herself while playing with her toys. Sylvia is full of life and brings great meaning to ours. — Christy ”



While your child has an additional chromosome, he or she will be like other babies. Babies with Down syndrome will eat, sleep, cry, smile, giggle, and learn to walk and talk, but they may need extra help in learning to do so. Like any child, your child will either live up or live down to the expectations set for them, so set high expectations for your baby and encourage others to do the same.

Your baby may have some common facial features of Down syndrome such as a smaller nose, upward slant to the eyes, flat facial profile, and small fold on the inner corner of the eyes (Bull, 2011). Your baby will also have characteristics of you and your partner, like similar hair or eye color, skin tone, freckles, dimples, and smile. It is important to remember, Down syndrome is simply a part of your baby, it is not who your baby is.

Other common features your baby may have are low muscle tone and increased flexibility.

Individuals with Down syndrome also have some level of intellectual disability. Though different for each person, intellectual disabilities may result in your child having difficulties learning or requiring more time to learn. Supports and services, such as early intervention, can help with any delays your baby faces.

The most important thing you can do for your baby is to love him or her as you would any baby.

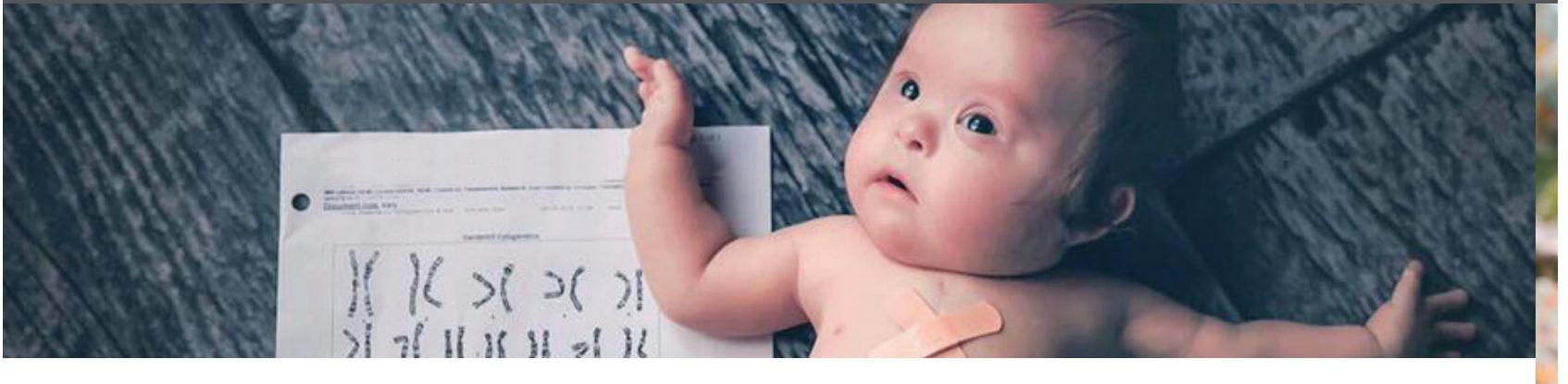


“

Children with Down syndrome are unique individuals that require the same amount of love and care as any child does.

”

— **Angela Maxwell-Hom, MD**
Assistant Professor of
Development of Pediatrics
Monroe Carrell Jr. Children’s
Hospital at Vanderbilt



A Healthy Beginning

To ensure your baby has a healthy start to life, talk with your medical provider about potential medical concerns. Your provider is aware of any medical problems that may arise and will help guide you in addressing them. While some health issues may be readily noted, **regular check-ups** should occur with your doctor to monitor your baby's health.

When looking for a **pediatrician**, find one who works for you and your baby; you are the expert on your family. Call and schedule a consult with a pediatrician to meet him or her and assess his or her knowledge of Down syndrome; don't be afraid to ask questions! Ensure your pediatrician is familiar with the American Academy of Pediatrics Health Supervision for Children with Down Syndrome and the Developmental Milestones chart. Your pediatrician can become a valuable partner in your child's journey and may help advocate for needed services and supports.

Although babies with Down syndrome are more likely to develop certain medical conditions, advances in medical treatment are able to correct most of the health issues. Some health issues may include heart defects, respiratory issues, and gastrointestinal problems (Bull, 2011).

Heart defects, which occur in about 50 percent of individuals with Down syndrome, may require surgery,

while others resolve on their own. All babies with Down syndrome receive an echocardiogram, which allows doctors to view pictures of their heart. This painless, quick ultrasound will provide information about your baby's heart health.

Due to **low muscle tone**, babies with Down syndrome often experience respiratory problems such as reflux, bronchitis or pneumonia. Gastrointestinal issues can result from a malformation in a baby's digestive tract. While successfully treated, it is important to look for any signs of vomiting, swollen abdomen, lack of stool, or poor feeding.

The sooner medical concerns are identified, the easier treatment becomes and the faster you and your baby can be happy. These health issues may develop later, while **some children do not develop them at all**. Each child is different. It is important to discuss your child's health with your doctor and identify any potential medical conditions early. While you are encouraged to learn about Down syndrome at your own pace, it is important to discuss your child's health with your doctor and identify any potential medical conditions early. Please take advantage of **DSAMT's First Call Program** to be connected to the most up-to-date, accurate information and resources when you have questions.



Understanding — Down Syndrome —

Down syndrome, the most commonly occurring chromosomal condition, occurs when a person is born with three copies of chromosome 21 rather than two. Three types of Down syndrome exist: nondisjunction, translocation, or mosaicism. Your doctor or genetic counselor can give you information about what type of Down syndrome your child has.

Approximately 1 in every 700 babies is born with Down syndrome. There are approximately 8,000 individuals with Down syndrome living in Tennessee. Although the chance of having a child with Down syndrome increases as women age, most babies with Down syndrome are born to women younger than 35. The cause of the extra chromosome is unknown. No scientific research indicates that Down syndrome is caused by environmental factors or the parents' activities before or during pregnancy.

Most importantly, each child with Down syndrome is his or her own, unique, beautiful self.





Early — Intervention —

The most rapid and significant developmental changes happen during the first few years of life for all children. This is when they learn those basic physical, cognitive, language, social and self-help skills that are needed for future progress. Children with Down syndrome typically experience delays in these areas, so early intervention is strongly recommended. It can begin any time after birth, but the sooner it starts, the better. Early intervention is a free service that works with children 0-3 years old and provides a systematic program of therapy and activities to address developmental delays experienced by those with Down syndrome. These services are mandated by a federal law called the Individuals with Disabilities Education Act (IDEA), with the goal of enhancing the development of infants and toddlers and helping families understand and meet the needs of their children.

In Tennessee, this system is called the **Tennessee Early Intervention System or TEIS.**

<https://www.tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis.html>

You may make a referral to TEIS by calling **1-800-852-7157**. If you have questions, just call DSAMT for help.





Little Steps to a Big Future

When a baby is born with Down syndrome, other people – including very well-meaning family members, friends and even some “professionals” or “experts” may tell you what your child will or will not accomplish in his or her life. You will read about typical milestones for children with Down syndrome and general guidelines. **However, no one can predict what your child will or will not be able to do from birth.** Every child with Down syndrome is a unique child, and just as it is impossible to know what a typically developing child will or will not accomplish, it is impossible to predict the future of your baby. What is most important is that you give your child opportunities to succeed. DSAMT holds regular workshops where we ask presenters for their best advice and resources for new parents.

“Parents and caregivers play an important role in their young child’s communication development. Modeling speech and gestures during play is an easy way to facilitate language growth.” Denise Bryant, MA, CCC-SLP, ATP

➡➡➡ Early Communication Skills for Children with Down Syndrome: A Guide for Parents and Professionals, Third Edition; By: Libby Kumin, Ph.D., CCC-SLP

“Remember, every child develops at his or her own pace. Early Intervention, with the help of family, is a key resource for assisting children in meeting gross motor milestones in a manner that is specific to the child’s learning.” Ashley Allen, PT, DP

➡➡➡ Gross Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals, Second Edition; By: Patricia C. Winders, P.T.

“Each child develops his or her fine motor skills differently, with unique interests and motivations. As a new parent, you will begin to see your child’s personality develop and learn what motivates him or her best.” Sarah Wilson, MS, OTR/L

➡➡➡ Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals, Third Edition; By: Maryanne Bruni, BScOT

“Follow your child’s cues and let his/her development guide diet advancement. You don’t have to rush to meet ‘standards,’ but know when to seek help if you get stuck or progress is not being made. Remember to have fun with food and relax at mealtimes to promote a positive environment.” Melissa Duke MS, RD, LDN

➡➡➡ Fearless Feeding: How to Raise Healthy Eaters from High Chair to High School, By: Castle, Jill, Jacobsen, Maryann (2013); <http://fearlessfeeding.com/>





Connecting with — Other Families —

Why Connect to DSAMT and Your Local Down Syndrome Community?

Some parents are reluctant to reach out and connect to local groups for a variety of reasons. Others are hungry for information and support and reach out quickly. Either way, connecting to other families with similar experiences can have a very positive effect on your family. Consider these benefits of connecting:

- You can benefit from DSAMT's First Call Program, which provides information, resources and cool gifts!
- You can be connected to a parent mentor, who can help you 1:1 and connect you to other parents, resources and county groups. This can mean a discussion with other local parents to talk about delivery experiences, school, community, medical issues, support, employment, family, tips on what works best, or anything!
- You can receive free books or other research based information about Down syndrome.
- You can attend DSAMT's educational workshops & webinars.
- You can find out about opportunities to involve family and friends in local events, such as the Buddy Walk®, Family Picnics, Grandparents Group, Siblings Group, D.A.D.S, Moms Night Out, etc.
- You will benefit from DSAMT's advocacy efforts – local, state and national.
- You will receive tips from parents who can share what worked best and why.
- You will learn about other community programs and services.
- You will receive e-newsletters that highlight activities, news, important information and celebrate achievements of those with something extra!
- DSAMT can make referrals for you to TEIS or the Vanderbilt Down Syndrome Clinic.
- Enjoy yourself! DSAMT has many fun family events throughout the year, like our Spring Picnic at the Nashville Zoo, trips to Nashville Shores, Sounds Games, Baby Showers to meet other children with Down syndrome and their families, and more.
- You can, and most likely will, make friends that will last a lifetime and whose children will become friends with your children and who will be there for you.
- A Sunshine Program to give a little joy and light back to those with Down syndrome of any age who are either in the hospital or going through a tough time by way of meals, Sunshine Bags or other needed items.

“ Connecting with DSAMT and other families helped me not be scared anymore and not feel alone. It gave me hope and excitement about our new journey. It made a very scared mom in premature labor and a baby in distress feel like I had a lifeline that somehow helped me realize that everything will be okay. – Leigh ”



4

A Life

Full of Possibilities

Tremendous strides have occurred within the last 30 years for individuals with Down syndrome regarding education, inclusion, social acceptance, healthcare, employment, and housing.

Many people with Down syndrome hold jobs, live away from their parents, pay taxes, get married, and become active members of their communities. While no one knows what the future holds, **there is no better time for your baby.** The staff and families of DSAMT are here to help your baby reach his/her potential throughout his/her life.

KAREN GAFFNEY



Advocate, swimmer, public speaker, started her own nonprofit: karengaffneyfoundation.com

ELI REIMER



First person with Down syndrome to climb Mount Everest

LAUREN POTTER



Accomplished actress who appeared on the hit TV show "Glee"

ZACK GOTTSAGEN



Star of the movie, "The Peanut Butter Falcon"

JAMIE BREWER



Became the first woman with Down syndrome to walk the red carpet at New York Fashion Week

FIONA HAWKS



Drives her own car and works in the accounting department at a local utility company

DAVID DESANCTIS



Lead actor in feature film "Where Hope Grows" (2014)

MATT MOORE



2013 graduate of Vanderbilt University's post-secondary program, Next Steps. Employed at Best Buy

CAILYN WHEATON



Entrepreneur of Little Big Dog Treats in Lebanon, TN

SUJEET DESAI



Accomplished musician who graduated from the Berkshire Hills Music Academy in 2003



Education

Even though your little one is years away from his or her academic career, many expecting and new parents ask, "Will my child go to school?". Or, "Where will my child go to school?" **Your child will go to school.** All children, regardless of ability, receive a free and appropriate education (FAPE) because of the Individuals with Disabilities Education Act (IDEA).

Not only will he or she go to school, but depending on your child's individual needs, he or she will be educated in the general education classroom (with access to special education services) alongside his or her typically-developing peers.

At age 3, children with Down syndrome leave TEIS and enter the public school system for preschool and special education services. There are also several private blended preschools (meaning they include both students with and without disabilities) in Tennessee.

The majority of students with Down syndrome graduate high school. A growing number of students move on to one of over 290 post-secondary college programs (www.thinkcollege.net). DSAMT assists teachers in their efforts to meaningfully include students with Down Syndrome and help them reach their potential.



Carrie DePauw, Will McMillan and Matt Moore at Next Steps at Vanderbilt graduation ceremony, April 24, 2013. Photo credit: Joe Howell, Vanderbilt University.



5 Advocacy and Awareness

DSAMT promotes awareness, acceptance and inclusion of those with Down syndrome by supporting local, state and national legislation that benefits our families. We assist families with individual advocacy needs in schools and in their communities, and there are lots of ways you can get involved. When you're ready, contact our executive director, Alecia Talbott, at alecia@somethingextra.org. Current DSAMT advocacy information can be found at <https://www.somethingextra.org/programs/advocacy>.

Each year, DSAMT is one of more than 200 organizations that hosts an annual National Down Syndrome Society Buddy Walk®. The Nashville Buddy Walk® has become a whole community event for Nashville - bringing together more than 5,000 people from Middle Tennessee and beyond to celebrate and support those with something extra. It is also DSAMT's primary source of funding for all its programs. More information can be found at www.nashvillebuddywalk.org.





How DSAMT Can Help

D SAMT is a community of parents, grandparents, siblings, physicians, educators, professionals, friends and self-advocates from 40 counties in Middle Tennessee who celebrate and support individuals with Down syndrome and their families. There is no fee to join, and we strive to offer our programs and activities at no or low cost to our families. We never want financial obligations to prevent you from participating.

Our mission is to ensure individuals with Down syndrome are valued for their extraordinary gifts and contributions, empowering them to pursue meaningful, included lives by providing education, advocacy, support and community for people with Down syndrome and their families, and serving as a resource for educators, healthcare professionals, employers and the entire Middle Tennessee community. DSAMT strives to be recognized by people with Down syndrome and their families, educators, healthcare professionals, employers and the community at large as the leading resource in Middle Tennessee for education, advocacy, support and community for and about Down syndrome. We envision a world in which individuals with Down syndrome are accepted, included and valued for the extraordinary gifts they bring to our lives. Let DSAMT be your first call, email or message regarding Down syndrome to receive the most up-to-date, accurate information available.

Our First Call program connects new parents of children with Down syndrome to trained, experienced parent mentors. These “veteran” parents are available to meet, answer questions, listen and provide support. If you are interested, Contact our program director, Tanya Chavez, at c. 615-294-8736 or email tanya@somethingextra.org or executive director, Alecia Talbott, at c. 615-881-4261.

DOWNLOAD THE DSAMT APP!



Social Media: DSAMT has a variety of social media pages and several active Facebook groups, including different groups for grandparents, specific Tennessee counties, parents, siblings, self-advocates & DADS. Friend Alecia Talbott or any other current member of those groups to join.



/dsamt



@DownSyndromeTN



@dsamt



@dsamt



/DSAMT MiddleTN



The First Call parent support through DSAMT not only connected our family with services and education regarding Down syndrome, but it also connected us to an ever-growing family of friends, support, encouragement and empowerment. – Chris





Local

Organizations

Down Syndrome Association of Middle Tennessee: An organization that has facts about Down syndrome, resources for new parents, and information for news and events about the Down syndrome community in the Nashville area. somethingextra.org | facebook.com/dsamt | 615-454-3129

Down Syndrome Clinic at Children’s Hospital at Vanderbilt: A clinic that serves all health needs of individuals with Down syndrome beginning at birth.
childrenshospital.vanderbilt.org/downsyndrome | 615-343-3696

Gigi’s Playhouse: A center that provides free programs that are educational and therapeutic in nature to individuals with Down syndrome from birth through adulthood, their families and the community.
gigisplayhouse.org/nashville | 615-370-1500

Tennessee Disability Coalition: An alliance of organizations and individuals joined to promote the full and equal participation of people with disabilities in all aspects of life.
tndisability.org | 615-383-9442

Tennessee Disability Pathfinder: A statewide information and referral service for people with disabilities and their family members, with a searchable database of programs/services by county. This website can also be used to find interpreter services for non-English speaking families.
kc.vanderbilt.edu/pathfinder | 1-800-640-4636

The Vanderbilt Kennedy University Center: The Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities (UCEDD) provides a variety of services, training and research-based programs for people with disabilities and their families. vkc.mc.vanderbilt.edu



National & Regional Organizations

Dads Appreciating Down Syndrome (D.A.D.S.): An organization of fathers of children with Down syndrome across the United States. dadsnational.org

National Down Syndrome Congress (NDSC): A not-for-profit organization that provides information, advocacy, and awareness for individuals with Down syndrome and their families. ndscenter.org/resources/new-and-expectant-parents

National Down Syndrome Society (NDSS): An organization that advocates for the value, acceptance and inclusion of people with Down syndrome. ndss.org

National Institutes of Health - DS-Connect®: An online resource where people with Down syndrome and their families can connect with researchers and healthcare providers, express interest in participating in certain clinical studies on Down syndrome, and take confidential health-related surveys aimed at better understanding the health of people with Down syndrome across their lifespans. dsconnect.nih.gov

The Arc US: The largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. Tennessee has a state chapter, and several of our communities have local chapters, as well. thearc.org

The Global Down Syndrome Foundation: An organization that provides awareness, education, and advocacy for individuals with Down syndrome and their families. globaldownsyndrome.org

Sibling Support Project: The Sibling Support Project is an organization that seeks to increase peer support and information opportunities for siblings of people with special needs and to increase parents' understanding of sibling issues. siblingssupport.org

REGIONAL DOWN SYNDROME ASSOCIATIONS: If you don't live in middle Tennessee, you can connect with other Down syndrome associations and awareness groups that provide support, information and resources, and advocacy for individuals with Down syndrome and their families:

Building Up Down Syndrome (BUDS): Alabama - www.budsonline.org

Chattanooga Down Syndrome Society: www.chattanoogadownsyndrome.org

Clarksville Association for Down Syndrome: cadstn.org

Down Syndrome Awareness Group of East Tennessee: dsagtn.org

Down Syndrome Association of Memphis and the Mid-South: dsamemphis.org

Down Syndrome Association of West TN: www.dsawt.com

Down Syndrome of South Central Kentucky: www.dssky.org

Friends Tri-Cities: www.dsfriends.net

B.U.D.S Being United & Developing Support: www.facebook.com/groups/263764497605735



6 Resources

+ MEDICAL INFORMATION

Health Care Guidelines for Parents of Children with Down Syndrome

Family friendly information about development from birth through adulthood that includes information about potential health concerns for which individuals with Down syndrome are at risk.

A Promising Future Together

A Guide for new and expecting parents published by the National Down Syndrome Society.

➔➔➔ <http://www.ndss.org/wp-content/uploads/2017/11/NDSS-NPP-English.pdf>

Brighter Tomorrows

Information for families and physicians; includes videos, printable resources, screening, diagnostic tests and evidence-based practices when delivering a diagnosis of Down syndrome.

➔➔➔ <http://www.brightertomorrows.org/>

Diagnosis to Delivery

Program administered by the National Center for Prenatal and Postnatal Resources at the University of Kentucky's Human Development Institute providing honest, compassionate, medically-reviewed, and informative support for those preparing for the birth of a baby with Down syndrome.

➔➔➔ <http://downsyndromepregnancy.org/>

📝 EARLY INTERVENTION/EDUCATION

Tennessee Early Intervention System (TEIS): This page includes information for parents, facts about eligibility, costs, and regional contacts.

➔➔➔ <https://www.tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis.html>

Think College: A website dedicated to information about college options for individuals with intellectual disabilities.

➔➔➔ thinkcollege.net





BOOKLETS

The following booklets provide information and resources for new and expectant parents of babies with Down syndrome:

➤➔ **A Grandparent's Guide**

<https://www.dsacc.org/support/grandparents/>

➤➔ **A Promising Future Together: A Guide for New and Expectant Parents (NDSS)**

https://www.ndss.org/wp-content/uploads/2020/06/NEPG_v14.pdf

➤➔ **Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome**

downsyndromepregnancy.org

➤➔ **Understanding a Down Syndrome Diagnosis**

<https://understandingdownsyndrome.org/>

ONLINE COMMUNITY/ PARENT BLOGS

Down Syndrome Diagnosis Network: An online community and website for parents of children diagnosed with Down syndrome that provides supports regarding diagnosis and services.

➤➔ <https://www.dsdiagnosisnetwork.org/>

Parent Blogs: The following is a list of parents who blog about raising a child with Down syndrome:

➤➔ bakerisourdreamcometrue.blogspot.com

barryandashley.wordpress.com

dashoftheunexpected.com

deartessa.com

felixsmum.blogspot.com.au

kellehampton.com

nickspecialneeds.wordpress.com

noahsdad.com

sippinglemonade.com

thesassysouthernGal.com





VIDEOS/DVDS

"Congratulations Project"

➡ <https://www.congratulationsproject.org/>

"Dear Future Mom"

➡ <https://www.youtube.com/watch?v=Ju-q4OnBtNU>

"Just Like You"

➡ justlikeyou-downsyndrome.org



BOOKS

➡ Books for Parents

A Good and Perfect Gift by Amy Julia Becker, 2011

A Parent's Guide to Down Syndrome: Toward a Brighter Future by Siegfried Pueschel, 2002

An Uncomplicated Life: A Father's Memoir of His Exceptional Daughter by Paul Daugherty, 2015

Babies with Down Syndrome: A New Parents' Guide, Third Edition by Susan Skallerup, 2008

Bloom by Kelle Hampton, 2013

Down Syndrome Parenting 101: Must-Have Advice for Making Your Life Easier by Natalie Hale, 2011

Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives by Kathryn Lynard Soper, Gifts 2, 2009

Going Solo While Raising Children with Disabilities quantity by Laura Marshak, Ph.D., 2015

My Heart Can't Even Believe It: A Story of Science, Love, and Down Syndrome quantity by Amy Silverman, 2016

Off to a Good Start: A Behaviorally Based Model for Teaching Children with Down Syndrome, Books 1 & 2 by Emily A. Jones, Ph.D., BCBA-D & Kathleen M. Feeley, Ph.D., 2019

Roadmap to Holland: How I Found My Way Through My Son's First Two Years with Down Syndrome by Jennifer Graf Groneberg, 2008

The Parent's Guide to Down Syndrome: Advice, Information, Inspiration, and Support for Raising Your Child from Diagnosis through Adulthood by Jennifer Jacob and Mardra Sikora, 2016

➡ Books for Siblings

Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters by Brian Skotko and Susan Levine, 2009

Oh Brother! Growing up with a Special Needs Sibling by Natalie Hale, 2004

The Sibling Slam Book: What It's Really Like to have a Brother or Sister with Special Needs by Donald Joseph Meyer and David Gallagher, 2005

Views from Our Shoes: Growing up with a Brother or Sister with Special Needs by Donald Joseph Meyer

We'll Paint the Octopus Red by Stephanie Stuve-Bodeen, 1998



7 An Extra Thanks

— for their contribution to this booklet —

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Beth Fetzer

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REFERENCES

Bull, M. J., & the Committee on Genetics. (2011). Health supervision for children with Down syndrome. *Pediatrics*, 128, 393–406.

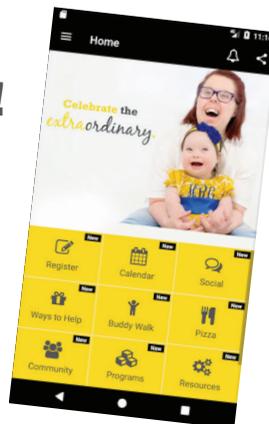
Skotko, B., Levine, S., Goldstein, R. (2011). Having a son or daughter with Down syndrome. *American Journal of Medical Genetics Part A*, 155 (10), 2335-2347.





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Down Syndrome Association of Middle Tennessee



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