

New Parents Guide

For Parents of Babies with Down Syndrome



Sponsored by the Down Syndrome Association
of Memphis and the Mid-South





Down Syndrome Association of Memphis & the Mid-South

To learn more, or to support DSAM,
please contact our office at 901.547.7588,
or e-mail us at admin@dsamemphis.org.

Down Syndrome Association
of Memphis and the Mid-South
2893 S. Mendenhall Road, Suite 3
Memphis, TN 38115
www.dsamemphis.org

Letter to New Parents

Congratulations! You have just become the parent of a remarkable little person. Like all newborns, your baby loves and needs you. In addition to the care that all newborn babies require, this little one has some special needs that may seem overwhelming to you right now. First and foremost, remember that your baby is a baby first.

If you are like most people, you have little idea what Down syndrome means. We would like to introduce you to the Down Syndrome Association of Memphis and the Mid-South (DSAM), an organization founded by parents of children with Down syndrome. DSAM supports and empowers individuals with Down syndrome and their families. Our organization provides this folder, which was written and assembled by parents of children with Down syndrome to consolidate all of the vital information that you will need. We recommend that you start by reading the "Health Issues: What Should I do First?" section. Read and use the other information whenever you are ready.

Along with this packet, we would like to give you a complimentary copy of the book, "Babies with Down Syndrome." The information contained in the book provides a current and comprehensive introduction to Down syndrome. If you have not received a copy, please contact our office at 901.547.7588 or admin@dsamemphis.org.



As the parent of a child with Down syndrome, we know you have many questions and lots of different emotions right now. Remember – you are not alone. There is a group of parents available to give you support and information.

Again, congratulations on your new baby! We look forward to meeting all of you.

Sincerely yours,

Down Syndrome Association of Memphis and the Mid-South

What is Down Syndrome?

Down syndrome is the most commonly occurring genetic condition. Individuals with Down syndrome have an extra copy of the number 21 chromosome present in all or some of their cells. The medical term for Down syndrome is Trisomy 21. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome. It is estimated that one in every 691 live births will result in a child with Down syndrome, representing approximately 6,000 births per year in the United States. There are approximately 400,000 individuals with Down syndrome in the United States today.

There is a wide variation in the abilities, physical development and behavior of individuals with Down syndrome. When describing your child, you should say he/she has Down syndrome. Your child should not be described as a Down's child or Down syndrome child. Your baby is a baby first and foremost. The fact that your baby has Down syndrome is of secondary importance. This is called "People First" or "People Centered" language.

With appropriate education, therapy, support, opportunity and love, individuals with Down syndrome can and will lead fulfilling and productive lives.

Health Issues

What Should I do First?

Children with Down syndrome are often at increased risk for certain health problems. Congenital heart defects, increased susceptibility to infection, respiratory problems and obstructed digestive tracts occur with greater frequency among children with Down syndrome. Fortunately, advances in medicine have rendered most of these health problems treatable. As with all children, you must take an active role in ensuring the best health care for your child. Some steps we recommend you take soon after birth include:

- 1. Talk to your pediatrician about their experience with children with Down syndrome.**

The Down Syndrome Association of Memphis and the Mid-South (DSAM) does not endorse any health care provider. DSAM can help you in contacting other parents, so you can ask questions about how they selected a pediatrician for their child. You may also ask pediatricians for recommendations of colleagues who have experience treating children with Down syndrome.

2. Obtain an echocardiogram.

It is important that all children born with Down syndrome, even those who have no symptoms of heart disease, have an echocardiogram in the first 2 or 3 months of life. Symptoms may present themselves as heart failure, difficulty breathing or failure to thrive. The symptoms may not be apparent at first. Most hospitals have the capability to perform an echocardiogram. It is often most convenient to take care of this before leaving the hospital.

3. Ensure that the diagnosis of Down syndrome is confirmed via chromosomal karyotyping. A genetic counselor can help explain the results.

4. Have your pediatrician check for gastrointestinal blockage. Some signs of gastrointestinal blockage include vomiting or absence of stools. Again, the symptoms may not present themselves for a period of time.

5. If your child has any feeding difficulties, consult a feeding specialist. Ask for a consult with a feeding specialist. Most children with Down syndrome have success with breastfeeding.

6. Obtain a hearing test before leaving the hospital. Some children with Down syndrome experience hearing loss. With new testing procedures, this can be detected easily in newborns.



For health care guidelines, visit our website at www.dsamemphis.org. Please note: This non-exclusive list is not meant to replace the care and advice of a qualified physician.

Early Intervention

The concept of early intervention is simple. If a child with a developmental delay such as Down syndrome receives proper help and supports early on in life, problems in the future may be minimized.

What is the cost?

At this time, Early Intervention services should be provided for no cost.

Is there an age limit to receive Early Intervention services?

The age limit to receive Early Intervention services is newborn to three years.

What kinds of things will my child do in Early Intervention?

After eligibility is determined (most children with Down syndrome qualify), an Individualized Family Services Plan (IFSP) will be developed. It is written with help from the parents and professionals (therapists, educators, medical professionals). Your child may participate in a variety of activities planned by licensed therapists, teachers, other medical professionals and most importantly, your family. The setting for these activities may include individual or group therapies, scheduled home visits or other activities in your home, day-care, hospital or clinic. You will be able to work out a plan that is appropriate for your child and your family. Your child's records will be kept confidential.

Early Intervention typically includes but is not limited to the following services:

Physical Therapy

Pediatric Physical Therapy (PT) concentrates on the development of gross motor (large muscles) skills such as crawling, sitting, walking, balance, and mobility. Children with Down syndrome may have low muscle tone and need physical therapy to condition muscles, build strength and improve movement.

Occupational Therapy

Pediatric Occupational Therapy (OT) focuses on the development of fine motor (small muscles) and self-help skills. The goal of OT is to help make learning possible by helping children to develop the underlying skills that will lead to independence in personal, social, academic or vocational activities. This includes difficulties a child may encounter with ADL's (Activities of Daily Living) such as dressing, grooming, and feeding.

Speech Language Therapy

Speech Language Therapy (SLT) addresses the child's communicative needs. This includes verbal and non-verbal communication. Often speech therapy incorporates non-verbal techniques such as sign language. SLT is designed to help with speech disorders often referred to as articulation or phonological disorders - problems with the way sounds are made or how sounds are sequenced to form words; oral motor problems resulting in difficulty producing speech sounds, and delays in feeding skills.

Resources

Resources in Tennessee

Tennessee Early Intervention System (TEIS)

TEIS is a program offered through the Department of Education for children from birth to age three. TEIS is funded by a federal grant under Part C of the Individuals with Disabilities Education Act (IDEA). The mission of TEIS is to empower families with a known disability or a condition that has a high probability of resulting in developmental delays; to promote and coordinate a comprehensive system of early intervention services to meet the needs of all eligible children and their families; and to implement strategies and procedures that ensure families and their children a smooth transition into, within, and out of early intervention services. Examples include special instruction and physical, occupational, and speech/language therapies, and support groups and services. TEIS is a system where parents and professionals work together to provide every possible advantage for children with special needs. TEIS is a system devoted to providing these advantages in the most natural environment, close to home, and within the family's community. TEIS can help you to determine which services your child may be eligible to receive, such as Children's Special Services (CSS) through the Tennessee Department of Health, and Supplemental Security Income (SSI) benefits through the Social Security Administration office, to include a few.

Tennessee's Early Intervention System
Perimeter Point Business Park
2175 Business Center Drive, Suite 11
Memphis, TN 38134
Phone 901-937-6738
www.state.tn.us/education/teis



Special Kids and Families, Inc.

Special Kids and Families is a family-centered Early Intervention program that serves children with developmental disabilities from birth to age three. SKF serves the needs of families and children through family training, a preschool program, therapies, transition, and advocacy training.

Special Kids and Families, Inc.

2965 N. Germantown Rd., Suite 124
Bartlett, TN 38133
901.683.8787
www.specialkidsandfamilies.org

Resources. continued

The Harwood Center, Inc.

The Harwood Center is an early intervention program which provides services to children with developmental disabilities from birth to age three, and offers support to their families. Some of its programs include school for children with developmental delays, home-based services, speech/ language therapy, and behavioral services.

The Harwood Center, Inc.

711 Jefferson
Memphis, TN 38105
901.448.6580
www.harwoodcenter.org

Le Bonheur Early Intervention and Development (LEAD)

Designated as an Early Intervention Resource Agency by Tennessee's Department of Education, Le Bonheur Early Intervention and Development (LEAD) specializes in providing exceptional care to children age birth to three years. LEAD receives referrals from Tennessee Early Intervention System. More than 500 children and their families receive early intervention from LEAD each year.

Le Bonheur Children's Medical Center

50 N. Dunlap Street
Memphis, TN 38103
901.287.4900
www.lebonheur.org



The Department of Intellectual and Developmental Disabilities (DIDD)

DIDD is the state agency responsible for providing services and supports to Tennesseans with intellectual disabilities. DIDD provides services directly or through contracts with community providers in a variety of settings. These settings range from institutional care to individual supported living in the community.

The TN Family Support Program, under DIDD, is funded by state dollars and designed to assist individuals with severe disabilities and their families to remain together in their homes and communities. Family Support is not a substitute for more comprehensive services provided under other programs, including the Medicaid HCBS Waiver, TennCare, Medicare, or private insurance. SRVS currently has the Family Support contract for Shelby County.



West Tennessee Coordinator:
Susan Kurts-Acred
West Tennessee Regional Office
11437 Milton Wilson Road
Arlington, TN 38002
Phone: 901.745.7348
Fax: 901.745.7723
Email: Susan.Kurts-Acred@tn.gov

Support and Training for Exceptional Parents (STEP)

STEP is a statewide family-to-family program in Tennessee that provides trainings and information on special education for parents and caregivers, free of charge. The purpose of STEP is to support families by providing free information, advocacy training, and support services to parents of children eligible to receive special education services under the Individuals with Disabilities Education Act (IDEA) who reside in Tennessee. STEP services are available to any parent or family member of a special education student or a student who may need special help in school (birth through age 22).

West Tennessee Coordinator:
Name: Nancy Williams-Boyd
Phone: 901.726-4334
Email: nancy.boyd@tnstep.orgzzz
1-800-280-STEP | en español 1-800-975-2919 | www.tnstep.org

Resources in Mississippi

First Steps

The State of Mississippi provides early intervention services called First Steps, for qualified children from birth to three years of age at no cost to parents.

These services include evaluation/assessment, special instruction, speech therapy, occupational therapy, and/or physical therapy. The Early Intervention office will conduct an evaluation and assessment to identify your baby's strengths and to develop a plan for services. Early Intervention is a system designed to enhance families' abilities to help babies grow, develop, and learn. A Service Coordinator will help your family identify and use resources that will empower you to be a better advocate for your baby.

Your child can receive early intervention services in your home, day care, or other community setting. A team will work with your family to help decide what services your family will receive and where the services take place.

First Steps is administered through your local county health department. Contact your local health department or the Mississippi Department of Health Early Intervention program. Information, including a referral form, is available on their website.

Mississippi Department of Health, Early Intervention Program

Phone: 800.451.3903

Fax: 601.576.7540

www.msdh.state.ms.us/msdhsite/_static/41,0,74.html

Insurance and Medicaid

You can apply for Disabled Child Living at Home through the Division of Medicaid even if you have insurance and are employed. Medicaid may pay medical bills incurred on behalf of your child. Disabled Child Living at Home is NOT based on your income level; it is based on your child's disability.

Medicaid will pay for a variety of items and services that may not be included in your insurance plan, including co-pays, prescriptions, deductible, and limits on therapeutic services, etc. Medicaid will likely cover what your insurance doesn't cover. Medicaid will even provide diapers if your child needs them after age three. It is worth the time and investment to fill out the paperwork.

MR/DD Medicaid Waiver

If you qualify for Medicaid for Disabled Child Living at Home, you are eligible to apply for the MR/DD Medicaid Waiver program. This program provides an approved number of hours of attendant care or respite care free of charge in your home to allow you to work and take care of your family's other needs. MR/DD Waiver can also provide Community Care, which would provide free care for your child at a Medicaid-approved facility.

Mississippi Division of Medicaid

Senatobia Regional Office (Counties served: DeSoto, Panola, and Tate)

2776 Highway 51 South

Senatobia, MS 38668-9403

Phone: 662.562.0147

Fax: 662.562.7897

www.medicaid.ms.gov



Resources in Arkansas

First Connections, Arkansas Infant and Toddler Program

The First Connections Program is a statewide system of services to assist infants and toddlers and their families. Children grow, learn, and develop at different rates and in different ways. Just as children are all individuals, families also have different abilities and needs. The First Connections Program works with families on an individualized basis to assist in locating and coordination services and assistance to enhance not only the child's abilities but those of the family to assist their child.

The First Connections Program is authorized and funded through Part C of the Individuals With Disabilities Education Act. The Department of Human Services (DHS) is the Lead Agency for the Program. The Division of Developmental Disabilities Services (DDS) is the division within DHS, which has administrative responsibility for implementation of the program.

Family help and information line: 1-800-643-8258

Website: <http://humanservices.arkansas.gov/ddds/Pages/FirstConnectionsProgram.aspx>

Studlein Learning Center is a non-profit, developmental disabilities service center. Our mission is to work with children who have been diagnosed with developmental disabilities. We serve children from birth to five years old. Our focus is for each child to increase developmental skill level and education in order to transition into the general curriculum of preschool, daycare or school. We believe that it is necessary to provide a strong curriculum for children; one that will address each child's needs and at the same time, is developmentally appropriate with engaging, hands on, multisensory activities. Our services include evaluation/assessment, early intervention, and special instruction in a structured classroom environment, as well as, physical, occupational and speech/language therapy. It is our goal to teach children and help them reach a level of skill that will enable them to be successful as they reach kindergarten and school.

Studlein Learning Center

207 Balfour

West Memphis, AR 72301

(870) 733-9950

Breastfeeding

Can a baby with Down syndrome learn how to nurse and be strong enough to nurse successfully? It may take a little longer for the baby to learn how to suck well, or for an experienced nursing mother to learn the particular “trick,” but with a little patience, and lots of love, it can be done!

A child born with Down syndrome may be a little sleeper and have a poor sucking reflex, while others may have respiratory problems and more serious difficulties. If your baby is weak at birth, he may experience some difficulty in learning to suck and swallow, so you will need to be calm and patient while he/she learns.



Babies with Down syndrome may be placid and sometimes have low muscle tone and generalized weakness at birth. Therefore, the mother will have to learn to be a clock watcher, picking the baby up frequently and offering the breast, rather than waiting for him to cry to be fed. The baby should be encouraged to nurse about every two hours during the day and several times during the night. Sometimes mothers have trouble getting the baby's tongue down from the roof of his mouth. If this happens, insert the tip of your finger between the roof of the baby's mouth and the tongue in an upside down position, then turn the finger over, to condition the sucking reflex.

This procedure can be repeated four or five times before each nursing, starting with the finger at the front of the baby's mouth and pushing it slowly into the baby's mouth so the baby will think he is drawing in.

Stay in close contact with your doctor so that he/she can continue to evaluate your baby's progress. Let your doctor's advice and your baby's needs be your guide. Many babies with Down syndrome are slow, leisurely nursers, so long feedings are to be anticipated.

Myths and Truths

Myth: Down syndrome is a rare genetic disorder.

Truth: Down syndrome is the most commonly occurring genetic condition. One in every 691 live births is a child with Down syndrome, representing approximately 6,000 births per year in the United States alone. Today, Down syndrome affects more than 400,000 people in the United States.

Myth: Most children with Down syndrome are born to older parents.

Truth: Eighty percent of children born with Down syndrome are born to women younger than 35-years-old. However, the incidence of births of children with Down syndrome increases with the age of the mother.



Myth: People with Down syndrome have severe cognitive delays.

Truth: Most people with Down syndrome have IQs that fall in the mild to moderate range of cognitive delays. Children with Down syndrome are eager to learn and educators and researchers are still discovering the full educational potential of people with Down syndrome.

Myth: Most people with Down syndrome are institutionalized.

Truth: Today people with Down syndrome grow up at home with their families and are active participants in the educational, vocational, social, and recreational activities of the community. They are integrated into the regular education system, take part in sports, camping, music, art programs, socialize with people with and without disabilities, and as adults obtain employment and are able to live in independent housing arrangements.

Myth: Parents will not find community support in bringing up their child with Down syndrome.

Truth: In almost every community of the United States there are parent support groups and other community organizations directly involved in providing services to families of individuals with Down syndrome.

Myth: People with Down syndrome are always happy.

Truth: People with Down syndrome have feelings just like everyone else in the population. They respond to positive expressions of friendship and they are hurt and upset by inconsiderate behavior.

Myth: Children with Down syndrome must be placed in segregated special education programs.

Truth: Children with Down syndrome have been included in regular academic classrooms in schools across the country. In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The degree of mainstreaming is based in the abilities of the individual; but the trend is for full inclusion in the social and educational life of the community.

Myth: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.

Truth: People with Down syndrome date, socialize and form ongoing relationships. Some are beginning to marry. Women with Down syndrome can and do have children, but there is a 50 percent chance that their child will have Down syndrome. Men with Down syndrome are believed to be sterile, with only one documented instance of a male with Down syndrome who has fathered a child.

“Having Down syndrome is like being born normal. I am just like you and you are just like me. We are all born in different ways, that is the way I can describe it. I have a normal life.”

- Chris Burke, Actor with Down syndrome

Welcome to Holland

By Emily Pearl 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 to understand it, 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. And you must learn a whole new language. And 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....and 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. And 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, 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.

How do I tell the other Kids?

Greg & Karen Embry, Leawood, Kansas

It was actually easier to tell my children that their new baby sister had Down syndrome than it was to tell other family and friends. Adults have preconceived ideas or remember old stereotypes. Their first instinct was to be sad. I spent a lot of time comforting them, and explaining that times have changed and that our child has a promising future.

Children, however, are so accepting and if they are already in school, they have probably had more experience with people with special needs than most adults. Their new sibling is either the best new playmate they could ever ask for, or she's an intruder that is demanding a lot more of mom's time than they are willing to give up. Well, what newborn doesn't fall into one of those two categories?

I've always told my children that what makes them different is what makes them special. They understood this long before we brought home their new sister. "Oh, so Kathryn is special because she has Down syndrome. Well, I'm special because I'm the fastest runner in my class," my older daughter simply stated. "Yeah, and I'm super special because I am the only brother in our family," added my son. "That is true, and as Kathryn gets older we'll learn more about her special talents and gifts just as we learn more about you as you get older," I explained.

Of course how much your child understands about Down syndrome depends on their age and sometimes their personality. My six-year-old daughter wanted to know all about therapy.

Most kids play house or doctor. Mine played therapist. She became an authority on the subject among her school friends and enjoyed educating them about her "special" sister and the best teaching techniques. My four-year-old son, on the other hand, just wanted to know when she would be ready to wrestle. As far as he was concerned, telling him his sister has Down syndrome was like telling him she has blue eyes. "Yeah, yeah, yeah. But does she like Spiderman better, or Batman?"

"Having Down syndrome means nothing to me, I'm special like everyone else. I do not let people judge me for having Down syndrome. The important thing is how I feel about myself. On the inside, I feel beautiful."

**-Edward Barbanell,
Actor with Down
syndrome**

I frequently point out to my children other individuals with Down syndrome. They learn a lot from observing, asking me questions, or talking with the person. It is comforting for them to see that the world is full of some pretty great people who just happen to have

Down syndrome. I have discovered that no matter how old your children are, telling them about Down syndrome is an on-going process. At first they just need to know that for the most part their baby is going to be like any other baby. She'll just need some extra help.

As the kids mature, new experiences will invite further discussions. Maybe they notice some unique features and so we launch into a discussion about how each of us is made differently...hair, eyes, skin and so forth. Maybe a friend has a question and together we find the answer. As parents, we learn what we need to about DS each time we approach a new phase. It is exactly the same for our kids.

You'll be amazed how much your children figure out for themselves and can even teach you.



A Parent's Perspective

My Work Out Buddy - By Steve Baucum



A few summers ago, I became frustrated when arthritis in my knee kept me from being able to jog, and I decided to undergo surgery. After finishing physical therapy, I resumed my previous workout schedule at the YMCA. My son, Wesley, asked to join me. He walked in a 5K race the previous spring, and wanted to start training for the next year's 5K!

I think back on how we felt fifteen years ago, when Wesley was born. Wesley arrived about two weeks ahead of schedule, following an uneventful pregnancy. Wesley was our first child, and his having Down syndrome was not in the forecast. Carol had to be given general anesthesia for the delivery, as he was delivered via an emergency C-section. The

neonatologist hinted to me that she would like a genetic consult, even though Wesley's Apgar scores were good. She showed me the single crease in his palms, the folds in his eyelids, and the low muscle tone. The genetic testing confirmed Trisomy 21.

Although we were shocked and saddened by the news, we were blessed that two parents of children with Down syndrome came to visit us before we left the hospital. By the time we left, we heard positive stories from both parents about their child with Down syndrome. Since their stories were very similar, we left the hospital with a vision of where Wesley would be five years down the road.

Back to the present... during our workouts Wesley puts on his Walk Man, and huffs and puffs for thirty-five or forty minutes on the treadmill. Wesley learned how to adjust the speed of the treadmill belt, stop and start it, and follow the safety procedures. I have had some great father and son bonding times along the way. Wesley shaved 20 minutes off his previous 5K time, and learned that hard work pays off!

After the initial feelings we had to deal with on the news of Wesley's diagnosis of Down syndrome, we are seeing Wesley mature beyond our wildest dreams. And thanks to my work out buddy Wesley, my knee feels a whole lot better now!

Ben - By Becky and Joel Halvorson

Amid splashing and sounds of laughter, giggling and chattering could be heard as a young woman and a little boy carried on a conversation. They were making the most of the pool on a warm spring day. Vacationing in Arizona, we were lounging behind them and could see how much they were enjoying each other. In a little while, they came over to us. The young woman told us how much fun she was having with this little boy because he reminded her of her younger brother who wasn't vacationing with her. I knew what was coming...she said her younger brother, Derek, has Down syndrome. You see, so does our son, Ben...the little boy with whom she had been chatting.



We had a pleasant conversation before the young woman left the pool. We didn't get her name, but she is just one of many people with whom we have had a special encounter because we parent a child with Down syndrome. Because of Ben, almost daily we interact with someone who otherwise would not have noticed us. Our life's tapestry is woven with smiles and handshakes, hugs and high fives...often from complete strangers. Ben has the power to break down barriers between age, gender, race and disability. In the face of this sweet boy, people seem to see hope.

Eleven years ago, we mourned when we learned, prior to his birth, that our baby would have Down syndrome. While that is a natural and necessary process, we soon rejoiced for the marvelous baby boy born into our family and for the young child he would become. That young boy is now entering fifth grade. He reads and does math, has a green belt in taekwondo, and participates on the basketball and swim teams. He works hard for every achievement, and our family is proud of each one. However, Ben's greatest accomplishment is how he changes people and how he has taught us to see the world differently and to be more compassionate. While we don't pretend to understand the reasons people are born with disabilities, we do know that their lives have great value, and they bring tremendous joy and meaning to others. They impact the world and change hearts. Our 14-year-old daughter, Olivia, once said that she wished everyone in the world would accept people who are different. She said that the people who don't take the time to get to know Ben are really missing out on something wonderful. Olivia is 100% correct. Ben is a treasure, and your new baby is as well. Allow yourself to grieve for this diagnosis of Down syndrome. More importantly, allow yourself to rejoice for the precious child you have been given...he or she will bless you and your family more than you can ever imagine.

Perspective Continued

Precious - By Larry and Marie Dodson

Hello, we are the parents of a beautiful young lady with Down syndrome. When she was born, we were only eighteen and nineteen years old. She was our first-born.

At birth, the doctor hesitated to let us know that our baby had Down syndrome. Instead, he called in another pediatrician who compassionately revealed to us that our daughter was born with more chromosomes than normal. She continued to explain that the extra chromosomes resulted in Down syndrome. We cried, "Why me Lord?" So much went through our minds that tested our faith in God. Accepting that our child had Down syndrome was difficult because we had such big plans for her, and we thought they had ended.

The healing process began when Larry named our daughter Precious, and we accepted God's will. We did not want to spend our lives mourning God's blessing. Having Down syndrome is what makes Precious different, and is what makes her special.

Larry and I became like "The Little Engines that Could" by meeting each challenge head-on. As the little choo choo would say, "We know we can, we know we can!"

Note: Precious Dodson is now in her late thirties. She leads an active social life, and holds a full-time job.



Information about DSAM

The Down Syndrome Association of Memphis and the Mid-South (DSAM)

DSAM's mission is to support and empower people with Down syndrome and their families. DSAM is a volunteer driven organization which

- Sponsors social, educational, advocacy and networking events throughout the year
- Hosts a website, www.dsamemphis.org
- Publishes regular newsletters, DSAM Insights and STEP UP for Down Syndrome
- Maintains a weekly email distribution with subjects of interest to people with Down syndrome and their families

If you would like be on our mailing list to learn more about the events and activities and hosted by DSAM, please call 901.547.7588 or email us at admin@dsamemphis.org.

STEP UP for Down Syndrome (SUDS)

SUDS is hosted by DSAM, and is the largest disability awareness event in the Mid-South. Held on a Sunday afternoon in October, the goal of SUDS is to promote the awareness and inclusion of individuals with Down syndrome in the community.

Annually, SUDS brings together families, educators, community leaders, the business community, and other disability organizations to celebrate the ABILITIES of individuals with Down syndrome.



Additional Resources

The Arc, Mid-South

The Arc, Mid-South is a non-profit, United Way agency that is dedicated to empowering people with disabilities to achieve their full potential. The Arc offers a wide variety of programs and services for individuals with developmental and intellectual disabilities.

The Arc, Mid-South

3485 Poplar Ave., Suite 210

Memphis, TN 38111

901.327.2473

www.thearcmissouth.net

National Down Syndrome Congress

The National Down Syndrome Congress is the country's oldest national organization of self-advocates, their families, and the professionals who work with them. NDSC has become known for its advocacy in promoting the rights of and opportunities for individuals with Down syndrome. Additionally, the Congress is recognized for the personalized care it gives to families.

National Down Syndrome Congress

1370 Center Drive, Suite 102
Atlanta, Georgia 30338
800.232.6372
www.ndsccenter.org

National Down Syndrome Society

Education. Research. Advocacy. The National Down Syndrome Society, a not-for-profit organization, was established in 1979 to benefit people with Down syndrome through education, research and advocacy. Since that time, the NDSS has grown into one of the largest non-governmental supporters of Down syndrome-specific research in the United States. Today, the NDSS continues its commitment to enhancing the quality of life and realizing the potential of all people with Down syndrome.

National Down Syndrome Society

666 Broadway, 8th floor
New York, NY 10012
800.221.4602
www.ndss.org

