



# NEW BEGINNINGS

**A Magazine for Parents of Individuals with Down Syndrome**

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The Down Syndrome Guild is a non-profit 501c3 organization whose mission is to provide support and resources for individuals with Down syndrome, their families, and the professionals who serve them.

The Guild seeks to provide the entire community with information and education to broaden awareness and foster positive attitudes regarding people with Down syndrome.

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## First Things – Person First

When describing your child's condition, you should say he/she has Down syndrome and not that he/she 'is a Downs child,' as parents sometimes do. Describe him/her as 'a child with Down syndrome,' rather than 'a Down syndrome child.' He/she is a child first and foremost. The fact that he/she has Down syndrome is of secondary importance.

Adopted from the book "Down Syndrome – The Facts"  
by Mark Selikowitz

# Congratulations!!!

## Dear New Parent,

The Down Syndrome Guild of Greater Kansas City (DSG) seeks to provide support and resources for individuals with Down syndrome and their families. You are facing many emotions right now and DSG is here to support you!

If you are like most new parents, you have little idea what Down syndrome will mean to your child and your family. What impressions you do have may be bleak or very inaccurate. You will be advised by the professionals that you encounter not to read anything about Down syndrome written more than five years ago, as new information and therapies are rapidly being discovered and refined. A large network of sophisticated services and specialists are available to assist your family and your child — most at no cost to you. Your child has a very bright future!

DSG has consolidated key information about Down syndrome in this magazine, including information on local services and resources available to you. We suggest that you read the section titled "Health Issues" while in the hospital. Select from the rest whenever you are ready.

Along with this magazine, we would like to offer you a complimentary copy of the book "Babies With Down Syndrome." The information in the book provides a current and comprehensive introduction to Down syndrome. Please contact our office to request your copy of "Babies With Down Syndrome". You can mail in the postcard on the back of this magazine to request additional information.

Having a child with Down syndrome seems overwhelming right now. As you learn more about Down syndrome, it will lose its place as a defining feature of your child — your wonderful, adorable, how-did-I-possibly-think-life-was-good-before-him child.

Congratulations on your new baby!

**DSG STAFF & BOARD OF DIRECTORS**







# What is Down Syndrome?

Down syndrome is the most commonly occurring genetic condition. Individuals with Down syndrome have an extra, critical portion of the number 21 chromosome present in all, or some, of their cells. 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 5,000 births per year in the United States. There are approximately 250,000 people living with Down syndrome in the United States and a few million people living with the condition worldwide.

There is a wide variation in the abilities, physical development and behavior of individuals with Down syndrome. Each individual has their own unique personality, capabilities and talents. One should always use “people first” language. For example: a newborn is a baby with Down syndrome, not a Down’s baby.

With appropriate education, therapy, social support and opportunity, the majority of individuals with Down syndrome will lead fulfilling and productive lives.

# Health Issues

## to Address at the Hospital or Soon After Birth

**C**hildren 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 that we recommend be taken soon after birth include:



- **Choose a pediatrician who has experience with children with Down syndrome or who is eager to learn.**

The Down Syndrome Guild does not endorse any health care provider. By contacting other parents, you can ask questions about how they selected a pediatrician for their child. You may also ask pediatricians for recommendations of colleagues with experience treating children with Down syndrome.

- **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, difficult 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.

- **Ensure that the diagnosis of Down syndrome is confirmed via chromosomal karyotyping.**

- **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.

- **If your child has any feeding difficulties, consult a feeding specialist.**

- **Obtain a hearing test before leaving the hospital.**

Some children with Down syndrome have a hearing loss. With new testing procedures this can be detected easily in newborns.

*Obtain a copy of the Down Syndrome Healthcare Guidelines which outline recommended screening tests for your child as he grows into adulthood. Copies are available on the DSG website – [www.kcdsg.org](http://www.kcdsg.org).*

*(Please note: This non-exclusive list is not meant to replace the care and advice of a qualified physician.)*

# Breast-feeding & Your Baby



The best advice your pediatrician can give you is to take your new baby home and shower him with love, warmth, security and personal attention that the family unit can provide. This helps your baby develop to his fullest potential. The majority of babies with Down syndrome are happy, playful, and a delight to the whole family. Though the child is developmentally delayed, he is capable of expressing his emotions. He responds readily to love, and returns it enthusiastically to those around him.

Please be aware that other mothers have gone through the emotions that you are feeling right now. You are not alone. These parents will be happy to share their experiences and the information they have gathered that will help you nurse your new baby successfully.

Can a baby with Down syndrome learn how to nurse and be strong enough to nurse successfully? The answer is YES! Sometimes it takes a little longer for the baby to learn how to suck well. It might take longer even for an experienced nursing mother to learn the particular "trick" to help your new baby with Down syndrome to nurse successfully.

Breastfeeding not only strengthens the maternal-infant bond, but it is also a major contributor to the baby's nutritional well being. The advantages of breastfeeding take on added significance for the baby with Down syndrome. They have a greater susceptibility to infection than other infants so the immune factors present in colostrum and breast milk are especially valuable. Recent research shows that breast milk contains lactoferrin and transferrin, which prevent the growth of harmful bacteria in the intestinal tract. The bifidus factor (contained in breast milk) also promotes the growth of friendly bacteria in the intestinal tract. Further protective action is gained from lysozyme found in breast milk that attack and break down bacteria. Antiviral factors, such as interferon, are also present in human milk. These are just a few examples of why breast milk is the best food for the baby. Of special interest is the high level of taurine (an amino acid) and lactose found in breast milk. These two nutrients have been found to be essential for growth in early infancy and especially for brain development.

Many pediatricians tell their new mothers that nursing is the very best thing for new infants with Down syndrome. It is the perfect food for their immature digestive systems and it provides good tongue thrust and jaw development.

When the baby is born with Down syndrome, there are varying degrees of concerns. The baby may be a little sleepier 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 learns.

Babies with Down syndrome are often more prone to respiratory infections and digestive upsets. Breastfeeding lessens the incidence of both of these problems and probably reduces the severity of them if they should occur. Babies with Down syndrome are often placid and sometimes have poor 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. To help with this concern, 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, the procedure could 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.

When you get home from the hospital it is important to remember to take care of yourself. You need to rest and to watch your nutrition, just as you did when you were pregnant. To assure yourself of these things, a mother's helper is a wonderful asset — someone to care for you while you care for your baby.

Of course you will be in close contact with your doctor who will continue to evaluate your baby's progress. Because some babies with Down syndrome don't gain weight as well as they should, doctors sometime suggest solids earlier than usual. Let your doctor's advice and the baby's needs be your guide. Many babies with Down syndrome are slow, leisurely nursers, so long feedings are to be anticipated. You'll both thrive on these quiet times; this can be a cozy, relaxing time.

The rewards of nursing your baby are well worth the extra effort, so don't be discouraged if you encounter problems. A good knowledge of breastfeeding is helpful. *The Womanly Art of Breastfeeding* can be obtained from the local La Leche League and can offer excellent information and encouragement. Lactation specialists are also available through most hospitals and WIC (Women Infants and Children) programs to offer encouragement and support and to help you and your new baby learn together the art of breast-feeding.

New parents often don't realize that children with Down syndrome can have nearly normal social and emotional development. Babies with Down syndrome thrive on the stimulation, attention, and the tender, loving care that all children need. They return love one-hundred fold.

Author - Unknown

# From the Darkness Came Light:

## Our Story of a Prenatal Diagnosis



### The Darkness

Nothing can describe the pure excitement of being pregnant with your first child. My husband and I were elated. The grandparents were beside themselves, as this would be the first grandchild on both sides of our family. We counted the days to our first OB appointment. We practically skipped into the doctor's office.

At that first appointment we had a scare... They didn't hear a strong heart beat and thought we should have an ultrasound. Fantastic, we get to see our baby!! The ultrasound was not fantastic. "There appears to be some issue with the baby's bowels, I can't tell you what exactly, but we will need you to see a perinatologist for the rest of the pregnancy." My husband took my hand and assured me that everything would be fine. It wasn't fine.

We went to the perinatologist for monthly ultrasounds. Here they discovered that our baby girl had a congenital heart defect along with duodenal atresia (blockage of the small intestine). The doctor said, "I am not telling you that your baby girl has Down syndrome, however these two congenital defects are common in babies with Down syndrome." My heart stopped. I was panicked beyond belief. This was not happening to us, it couldn't be.

After days of painful, tearful discussions about our baby girl, we elected to have an amniocentesis for a definitive diagnosis. One week after the amnio, we received the news. My husband and I rushed home from work to await the doctor's call and the test results. The phone rang and we put the doctor on

speaker phone..."Well...the test results came back positive for Trisomy 21. Do you have any questions?"

That was that. My husband dropped to his knees and sobbed in my lap. I was in complete shock and denial. I felt as if we were in the darkest place imaginable. What was going to become of this baby? What will our parents and friends say? What kind of life will this child have? What kind of life will my husband and I have? I spent the next three weeks drowning in heartbreak and a sadness I cannot even begin to describe. This darkness I was experiencing seemed to have no end. And then a glimmer of light came into our life...

### Coming out of the Darkness

"Hi my name is Amy Allison. It is so nice to meet you two. Congratulations on your baby girl, I can't wait to meet her! Let me tell you about the DSG and what we do. Then we'll just talk." Walking into the DSG that day was the beginning of hope for our family.

Amy spoke of all of the things that the DSG does for individuals and families with Down syndrome. She said that she would put us in contact with other families that experienced the same congenital defects as our baby girl had. We learned of the New Parent breakfasts offered at the DSG. It was a lot of information to take in, but deep down I could feel a glimmer of hope.

We spoke with other parents that had babies with Down syndrome and listened to their stories, and in turn, they listened to ours. The New Parent breakfasts were instrumental to my husband and me. To be

surrounded by amazing families all going through the same thing brought us great comfort and peace. We were also able to become educated on what Down syndrome really is. And Down syndrome is nothing of what I had first envisioned.

### The Light

On November 22nd Ella came into our life. Due to the prenatal diagnosis, our team of doctors, the DSG, and supportive friends and family we were prepared for what was to come. Yes we tackled scary health issues and multiple surgeries, but it seems like a distant memory. We now have a healthy 4 year old girl that is our LIGHT. All of our previous thoughts of despair and darkness have lifted. We have a beautiful daughter. My husband and I have grown closer as a couple. We have an amazingly blessed life.

Having a child with Down syndrome can be challenging at times, but the rewards far outweigh these challenges. Ella greets everyday with a smile and a love for life. She has taught our family patience, joy, and love. Ella is a child first, not just a person with Down syndrome. She has amazing gifts and talents just like any child does. You may ask "Is this the life that you imagined?" Absolutely not, it is far greater and richer than I ever could have dreamed. So to new parents, I say congratulations to you. Congratulations on being chosen to raise your child with Down syndrome. Enjoy your gift, your "light"!

*Ella's Mom*



# Questions About Early Intervention

## **What is Early Intervention, and what is its purpose?**

The concept of “early intervention” is quite simple. If a child with a developmental delay receives proper help early on, problems in the future may be minimized. A child, his/her family, and the educational system will benefit by the reduced need for long-term intervention throughout the child’s school years.

## **How much does it cost?**

There may be fees associated with these services depending on which state you live in and your household income. Please ask your early intervention provider about fee schedules.

## **What kinds of things will my child with Down syndrome do in Early Intervention?**

Your child will participate in a variety of activities planned by licensed therapists, teachers, and nurses.

The setting for these activities—which are designed to provide physical, occupational, and speech therapies as needed—may include regularly scheduled home visits, play group activities, individual therapy at home, daycare or hospitals, or other combinations that work for your family. Your child’s record will be kept confidential.

## **Will I have any say regarding my child’s participation in any of these therapies?**

Absolutely! After eligibility is determined (and most children with Down syndrome usually qualify), the Individualized Family Services Plan (IFSP) is written with help from the parent(s) and services begin.

## **When should my child start Early Intervention Services?**

Some families choose to enjoy their babies and adjust to life with a new little one before jumping in. Others choose to start therapy right away. Ideally, a baby would start therapies within the first 8 weeks of life if that works in your family schedule.

## **Is there an age limit to receiving Early Intervention services?**

The age limit is newborn to three years.

## **PT, OT, and Speech**

**Pediatric Physical Therapy (PT)** is the treatment of children with physical disabilities by a licensed professional physical therapist who is educated and trained in the diagnosis and treatment of children with physical disabilities. The goal of PT is to improve care and provide a treatment program to obtain or restore the highest level of independence and function in quality of movement, walking, strength and endurance, gross motors skills, posture, positioning for functional skills, coordination, and mobility for the child with the disability.

**Pediatric Occupational Therapy (OT)** is the treatment of children with physical, emotional, and/or intellectual disabilities age birth to 21 by a licensed occupational therapist educated in a variety of diagnoses and therapies for such children. The goal of OT is to help make learning possible by helping children develop the underlying skills that will lead to independence in personal, social, academic, and vocational activities. This includes remediation of difficulties the child may

encounter with ADLs (Activities of Daily Living) such as dressing, grooming, feeding, etc.

**Pediatric Speech Therapy** addresses the child’s complete communicative needs. This often begins with the development of non-verbal communicative skills such as attending to the speaker and the activity, taking turns, and making appropriate eye contact. It is designed to help with speech disorder, 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. A speech-language pathologist is a specialist in the normal development of human communication. The Certificate of Clinical Competency (CCC) assures you that a speech-language pathologist has been qualified to provide clinical services by the American Speech-Language Hearing Association. (ASHA).



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# Where to Start

Infant-Toddler Services (ITS) and First Steps (FS) are federally funded programs and are your funding source to early intervention programs. You will work with ITS or FS to determine the special needs of your child.

## Infant-Toddler Services of Kansas

Infant-Toddler Services is a program established through the Individuals with Disabilities Education Act, Part C. This program serves children birth to 36 months of age who have special needs. Families are eligible for services if their child has a significant delay or concern in any one of the following areas: Health/nutrition, seeing, hearing, moving, thinking, communication, getting along with others, and doing things for themselves.

INFANT-TODDLER SERVICES OF JOHNSON COUNTY  
6400 Glenwood, Suite 205, Overland Park, KS 66202  
(913) 432-2900

WYANDOTTE COUNTY INFANT-TODDLER SERVICES  
4911 State Avenue, Kansas City, KS 66101  
(913) 627-5628



For all other counties contact  
MAKE A DIFFERENCE INFORMATION NETWORK  
1-800-332-6262

## First Steps Program of Missouri



The Missouri First Steps Program is a "family-centered" program offering early intervention services for children 0–36 months of age who have special needs. Participation in First Steps is voluntary and is intended to help families of children with disabilities:

- Understand their child's special needs
- Obtain the support and help they need to deal with situations that could interfere with their child's growth and development
- Provide the best conditions for their child's growth and development

First Steps is a collaborative effort of four state agencies – the Department of Elementary and Secondary Education, Health and Senior Services, Mental Health, and Social Services. First Steps is supported by federal and state funds from the four agencies and by other local and private agencies throughout Missouri.

Families can contact their county First Steps Office for more information by calling toll free 1-866-583-2392

# Parent-to-Parent



“After my child was born with Down syndrome, it became exhausting to deliver this news to my family and friends. I was very proud of my new baby, but felt like I had to stay extra upbeat when I talked to any of them.

Through the Parent-to-Parent program, I contacted another parent of a child with Down syndrome. It was nice to talk to someone else who had been in my shoes. He was able to talk to me with empathy, not sympathy. As a parent of a child with Down syndrome, he found it easy to focus on my new child as a child first and to convince me of the positive future for my child and my family.”

As new parents of a child with Down syndrome, you probably have many questions. One of your best resources for assistance is a fellow parent of a child with Down syndrome. The Down Syndrome Guild currently serves over 800 families who look to one another for support, this includes parents, siblings, grandparents, as well as aunts and uncles.

The Down Syndrome Guild has developed a Parent-to-Parent program. This program matches a family with similar experiences as your own. If you would like to be matched with a family, call the Down Syndrome Guild office at (913) 384-4848.



# How Do I Tell the Kids?

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?"

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.



These kids are in love with their sister and she is their number-one fan.





# Little Princess

It doesn't seem possible that it has almost been four years since our first baby, Alexa, was born. It is hard to think back on the sad and devastated parents we were at the very moment we first heard the words Down syndrome. Our earliest moments were filled with questions, sadness, fear and thoughts of how suddenly our lives were changed, presumably for the worse. We weren't sure we were going to be able to make it. I think it is fair to say that parents all have expectations of their babies... dreams, hopes and goals of what they will be like even before they enter the world. We are all hoping for a "perfect" child and when that expectation is not met, it is a huge shock.

Fortunately, it is amazing how quickly thoughts can change and one can move thru the journey of acceptance. Suddenly, we knew that we couldn't live without our little angel, Lexi.

Of course, we must admit that we fretted a little when it took Lexi longer to reach her milestones but looking back now, we don't even remember

the delays. We just remember how hard she worked to achieve each goal. We remember the overwhelming pride we felt as we celebrated each one.

Lexi has spent the last four years showing us all she is capable of. We couldn't be prouder of the little girl she has become. She is doing the same things that all kids do.... watching Barney, playing with dolls, swimming, eating pizza, taking dance lessons, laughing, attending preschool and playing outside with neighbor friends. She even spends a good deal of time tormenting her little brother and bossing him around. How very typical!

Lexi has blessed our lives with joy! She has given us the gift of perspective—helping us to become better parents, better people. The Down Syndrome Guild has provided our family with a wealth of resources and we have met many wonderful families who we are now fortunate to call our friends. We are happy because Lexi

is happy and healthy. She is "perfect" because our definition of perfection has changed.

Congratulations! Enjoy your new baby and take things day by day! God Bless you on your journey.

*Lexi's Mom and Dad*





# Journey



Our son, Morgan, was born on December 1, 2001. I remember feeling an intense sense of calm after his birth that we did not feel the first time around. This was our second child and everything people said about it being easier seemed to be true. It wasn't until the second day that life changed for us. While I was away preparing for my family's homecoming, the Doctor pulled my wife aside and informed her that Morgan could have Down syndrome.

For the next few days, I stayed the eternal optimist. While comforting my wife, I stayed strong. More than anything I wanted to fix it and that didn't seem to be possible. The day the test came back that our son did in fact have Trisomy 21, a social worker visited us.

I felt that things were really geared towards my wife because by all appearances she was the one grieving. I think as a man and a father, you feel like you have to keep it together for everyone.

Over the next few months, I kept my feelings to myself but inside I was becoming angry. I blamed myself and then I blamed my wife. I thought, "She wanted to have another baby, let her deal with this." The truth was, it was I who needed to deal with things.

One day I finally told my wife about my feelings and that although I knew they were wrong, I felt them. Telling her was the best thing I ever did. I remember feeling such a sense of relief. I no longer felt angry or bitter and although those

feelings never made me love our son any less, keeping them inside was destroying our marriage. Allowing myself to talk about those feelings renewed our marriage.

I do not regret having Morgan for one second. He has brought more joy into our lives than I could have ever dreamed possible. Every single milestone is amazing. He has made me take stock in what's really important in life and I don't take as much for granted.

People will say, "God only gives special children to special people." Well, I'm not sure how special I am, but I'd like to thank God for giving me the chance to father such a wonderful little boy.

*Morgan's Dad*

# Joseph's Story



I think back to the emotions I dealt with five years ago when Joseph was born. I wish I could write something that would bring you to the beauty of having a child with Down syndrome right now, but I can't. I won't try to hurry what will certainly evolve. Instead, here are a few thoughts that may alleviate some anxiety.

Joseph is five years old and thoroughly enjoys life. He is a very involved family member with his own unique personality, just like the rest of us. He loves his family, horses, music, ice cream, people in general, and spending time with his grandparents. He and his brothers (ages four and two) are a unit. They play, fight, play, sleep and play together. I cannot imagine better relationships any children could have. That one of them has a disability isn't relevant to them.

When Joseph was five weeks old, he and I started attending the Lee Ann Britain Infant Development Center, a multi-disciplinary therapeutic/educational program all at one location. There he played with many adults-therapists,

teachers and classroom volunteers. From his point of view, school was a place to play with adults who liked him, had fun with him, and made a huge fuss about every little developmental accomplishment. He loved it and so did I. We have since had two other sons and would have liked for them to have the same experience with so many people who take such an interest in them.

Through Joseph's school and the Down Syndrome Guild, we met other families newly entering the world of disabilities. Not only has Joseph developed wonderful friendships but, so has my entire family. Somehow through Joseph, our old friendships and extended family relationships have also been enriched and strengthened.

Please realize that a profound joy will come from the birth of your child.

*Joseph's Mom*



# A Positive Transformation

In February 2000, our fourth child, Alana Kathryn, was born at Menorah Hospital in Overland Park, KS. The pregnancy was pretty normal with all the regular morning sickness, monthly check-ups and routine examinations. However, shortly after the delivery, I saw the nurses that were caring for our daughter giving each other strange looks as they cleaned her. After 2 –3 minutes they called the doctor who was caring for my wife over and continued to speak softly and point out my daughter's facial features, low muscle tone and other characteristics common for children with Down syndrome.

I knew something was wrong but I had been a part of three successful deliveries without any issues, so I figured I was due a short set back but never thought it would be Down syndrome. That's for "other people" to worry about, not us. I went through all the normal denial stages.

First was the "doctor will call to tell us they had made a mistake" stage, then the "why us" stage and the "God must

be mad at us" stage. I also wasn't as excited as I had been with the other three children. I didn't run to develop pictures to show all my neighbors, friends and co-workers. While I was devastated



my faith and trust in God pulled me through the initial shock that comes with having a child with Down syndrome. It took me a year or so to become comfortable with Alana's diagnosis.

Two years later, I actually feel kind of silly. How could I have had these

thoughts? Alana has been an absolute joy to our family. Everyone loves her and I wouldn't change one thing about her. She has given us more joy than I ever imagined you could get from one of your children. She has made us better parents, better citizens and most importantly better human beings. Our appreciation for the basic things in life has been transformed, our compassion for our fellow citizens has grown and I continue to develop a giving spirit.

Last Saturday, our family was in Wal-Mart when I noticed the family in line next to us didn't have enough money to pay for the school supplies in their shopping cart. I immediately asked the family if they would allow me to make up the \$40.00 shortfall and they agreed. The family was very appreciative and I was very happy to help.

Two years ago, I wouldn't have made that offer...but that's what a kid with Down syndrome will do to you.

*Alana's Dad*



# Nana's Boy

*Let me tell you about my Grandson...* his name is Isaac and he is such a smart, gorgeous little boy with a lot of energy, who goes in a run. He has a sparkle in his eye and is into everything. He is a typical two year old who is curious, hates naps and occasionally throws a fit. He loves going to the park, swinging, playing in his little car, and loves music. He has friends everywhere he goes.

Being a grandparent is wonderful, I had heard that but I could not have believed how it would change my life. On December 27, 2003, my first grandchild was born. Our daughter and son-in-law allowed me to be in the room when Isaac was born so I got the experience the miracle of his birth and hear his first cry.

The doctor and nurses where hurrying around after his birth. They put him in a warmer and began checking him. They mentioned that his fingers, the creases in his hands and neck looked as though he probably had Down syndrome. The nurse from the NICU checked him over very quickly and then a doctor came in and confirmed that he had Down syndrome. I could not see what they were talking about because all I could see was a beautiful baby boy with strawberry blond hair and a round little face.

I feel blessed to know that I had been prepared for Isaac's birth. When our daughter was a freshman in high school she did a project on siblings of children born with Down syndrome and I provided the transportation. We met wonderful families whose lives were enriched by having a child with Down syndrome. Tanya then sold the video to a national agency. We attended the National Down Syndrome Congress in

Memphis. Once again, learning more about children who happen to be born with Down syndrome.

I have been in education for the past 24 years, 14 of them as a principal. While I was a middle school principal we had a young man with Down syndrome and he became the delight of my life. I got to know Steve and his family quite well. He had many health issues and now is doing well in a group home setting. He currently is working as a file clerk in a Doctor's office. I feel that through knowing him I have learned some of the problems families experience educating children with special abilities.

I find that I spend more time educating teachers and other educators about children born with Down syndrome. I correct people who call children with Down syndrome, "Down syndrome children." My goal in life is to help Isaac and other children find caring, understanding and well prepared educators in their schools to best meet the needs of all children. It is not hard being an advocate for our grandchildren.

I hope that as a grandparent you will help your child(ren) find early intervention for the special baby they have been given. Help them learn all they can about their baby; you do the same and love the baby with all of your heart. God gave you this baby to love and help your child(ren) care for, understand and provide the best home possible. Be prepared to laugh and enjoy every moment. Isaac has decided to call me "Nana" and his grandpa "Damp." Have high expectations and then help your family achieve them. Congratulations on being chosen to have this little blessing as your grandchild!



# Welcome to Holland

by Emily Pearl Kingsley

I often am asked to describe the experience of raising a child – 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 guidebooks and make your wonderful plans. The Coliseum, Michaelangelo's 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 guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met otherwise.

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 Rembrandts.

And Holland has tulips.

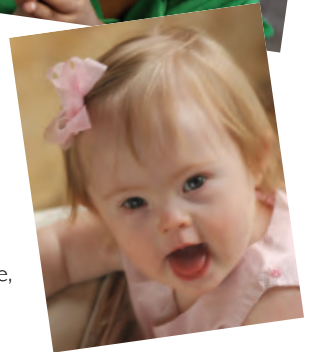
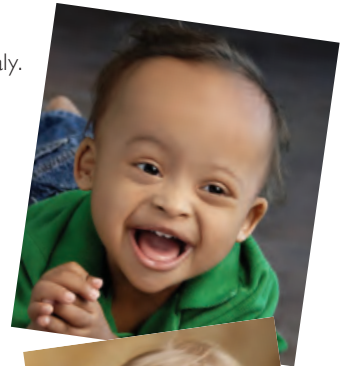
But everyone you know is busy coming and going from Italy, and they're all talking about what a wonderful time they had there.

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 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.

*Our nickname for Abby was "Holly." We ordered tulips for her.*



# An Unexpected Birth...

This is probably the hardest thing I've ever had to write in my entire life. The hardest and yet the most beautiful.

The story of our daughter's birth. I knew the minute I saw her that she had Down Syndrome and nobody else did. I held her and cried. Cried and panned the room to meet eyes with anyone that would tell me she didn't have it. I held her and looked at her like she wasn't my baby and tried to take it in. And all I can remember of these moments is her face. I will never forget my daughter in my arms, opening her eyes over and over. She locked eyes with mine, stared and bore holes into my soul.

She seemed to say love me, love me. I'm not what you expected, but oh, please love me. That was the most defining moment of my life. That was the beginning of my story. I don't remember a lot here. My friends have filled me in, but I feel like I was in a black hole. I know I held her. I know I kissed her. I know I begged every power in the world that this wasn't happening, that she was normal, but I knew in my soul exactly what this was.

She was scooped off my chest and taken to the warming bed where nurses nervously smiled as they checked her over. I wanted someone to tell me what was going on...I kept asking if she was okay, and they told me she was fine. She was crying and pink and just perfectly healthy. I wanted to say the words, but couldn't. I kept crying and asking, "Is there something you aren't telling me?" And they just kept smiling.



When I think about this time later, I have cried and cried wondering what I did. Did she feel love? Did I kiss her? Did I hold her and tell her 'happy birthday' and smother her with happy tears? My friends in the room smile when I ask this and promise me I did. They said I couldn't stop kissing her. And while I held her, the room went on.

I remember feeling...nothing. As if I literally left my body for a bit. But they said I kissed her. They said I loved her. They said I was a mama. I remember my pediatrician suddenly walking in and my heart sank a bit I knew. "Why is she here?" I asked. And they told me she was just checking the baby out. Which she did. And then the room grew quiet and everyone was asked to leave. I started shaking. I knew it was coming. The tears. The twisting in my stomach that they were about to rock my world.

Brett stood behind me, stroking my hair and my nurse friends, Dot and Katie, stayed on either side of the bed. And it happened. My pediatrician snuggled Nella up in a blanket and handed her to me and she knelt next to my bed so that she could look up at me, not down, and she never took her eyes off mine. I need to tell you something...and I cried hard. "I know what you're going to say." She smiled again and squeezed my hand a little tighter. The first thing I'm going to tell you is that your daughter is beautiful and perfect...and I cried harder...but there are some features that lead me to believe she may have Down Syndrome.

Finally, someone said it. I felt hot tears stream down and fall on my baby's face. My beautiful, perfect daughter. I was scared to look up at Brett, so I didn't. I just kissed her. And then, Dr. Foley added.....but, Kelle....she is beautiful and perfect. The hallway was still filled with everyone who was waiting. I held my baby and told them all, crying, what we had been told. I knew there was a stream of friends ready to come and celebrate and I wanted them all to be told before they came in. I couldn't emotionally handle telling anyone and yet, strangely, I wanted people to know as soon as possible because I knew I needed the troops...I was falling, sliding, tunneling into a black hole and I needed as much love as possible to keep me up.

I just remember happiness. From everyone. All of the blessed souls in that room celebrated as if there was nothing but joy. Everyone knew...and there were a few puffy eyes, but mostly, it was pure happiness. More friends trickled in. More smiles. More toasts. And hugs with no words...hugs like I've never felt. And Brett, well, he never left our girl's side. He was quiet through this all, and I'm not sure I'll ever know what he felt, but I know the daddy of our babies, and I know he knows nothing but to love them with all his heart. And he did from the very start.

I remember arriving to our room and being told our older daughter, Lainey, was on her way. And I cried new tears... I hadn't even thought about how this would impact Lainey. What she would think...how her life would be different...how every beautiful vision I had of two sisters growing up together, grown-up phone calls, advice-giving, cooking together, shopping...everything would be different. Numbness started leaving my heart and sheer pain started settling in.

Don't cry. Don't cry. Don't cry when Lainey gets here and then I'll never forget her face...her cute outfit someone put her in, her eyes when she walked into that room, and the way she tried to hide her excitement with her shy smile. I will never forget the day my girl became a big sister. I will never forget the moment her little sister was placed in her arms. I watched in agony... in tears...in admiration as my little girl taught me how to love. She showed me what unconditional love looks like...what the absence of stereotypes feels like...she was....proud. That was one of the most beautiful moments of my life. I needed that.

As darkness set in that night and people started trickling out, I felt paranoid. So completely afraid because I knew with darkness, with the absence of everyone celebrating, the grief would come. I could feel it coming and it hurt so, so, so very bad. I think I cried for seven hours straight. It was gut-wrenching pain. I held Nella and I kissed her but I literally writhed in emotional pain on that bed in the dark with our candles and my friends by my side until the sun came up. I remember trying to sleep and then feeling it come on again and I'd start

shaking, and they'd both jump up and hug me from either side, Nella smooshed between the four of us.

I can't explain that evening. And I suppose it's horrible to say you spent the first night your daughter was born in that state of agony, but I know it was necessary for me to move on to where I am today. And, knowing where I am today and how much I love this soul, how much I know she was meant for me and I am meant for her, knowing the crazy way our souls have intertwined and grown into each other, I can say all this now. It's hard, but it's real, and we all have feelings. We live them, we breathe them, we go through them and soon they dissolve into new feelings.

I cried out that I wanted to leave her and run away.

I wanted to take Lainey and my perfect world and this perfect love I had built with my two-year old and our cupcake-baking days and our art projects and our beautiful bond and I wanted to run like hell. I wanted to be pregnant again. wanted to be pregnant so bad. I wanted it to be the morning she was born again when I was happy and excited. I wanted to go back. I moaned in pain and through it all, this little breath of heaven needed me. I cried while I nursed her, while I held her, while I pulled my nightgown off just so I could lie her body on my naked skin and pray that I felt a bond. I literally writhed in emotional pain for hours. And then morning came, and with it came hope.

Over the course of the next several days, things just became beautiful. I cried, yes, but they soon turned to tears of joy. I felt lucky. I felt happy. And so, we came home...happy. In fact, walking out of the hospital with our new baby girl and our proud new big girl, all crowned up, gripping the handle of the carseat with Daddy, it was just how I had imagined it.

Life moves on. And there have been lots of tears since. There will be. But, there is us. Our Family. We will embrace this beauty and make something of it. We will hold our precious gift and know that we are lucky. I feel lucky. I feel privileged. I feel there is a story so beautiful in store and we get to live it. Wow. The story has begun...



To read the full story visit: [www.kellehampton.com/2010/01/nella-cordelia-birth-story.html](http://www.kellehampton.com/2010/01/nella-cordelia-birth-story.html)

# THE DOWN SYNDROME GUILD

## of Greater Kansas City

The following is a comprehensive list of DSG programs and services:

### **New Parent Magazine**

"New Beginnings" magazine is designed to educate and comfort new parents of a child with Down syndrome. The magazine is filled with useful and accurate information with helpful lists of resources for families with individuals with Down syndrome. This resource is provided free to local hospitals to disseminate to new and expectant parents.

### **Quarterly Support Breakfasts**

Parents new to the diagnosis are invited to join us once a quarter for a networking and resource sharing breakfast.

### **Parent to Parent Network**

Experienced parents offer support, friendship and information to new parents upon receiving a diagnosis. The Guild also provides welcome packages with Down syndrome information and baby gifts.

### **Connections**

A bi-monthly newsletter, distributed to 2,800 recipients, with educational information, lists of current events, upcoming activities and programs and general information.

### **Resource Library**

Books, videos and brochures about Down syndrome available on loan at no cost. The Guild maintains approximately 300 titles readily available to families and professionals.

### **Meal Voucher Program**

DSG provides families whose loved one with Down syndrome is experiencing a hospital stay with meal vouchers to offset expenses incurred while staying in the hospital.

### **Conference Scholarships**

DSG offers financial funding for families to attend other local and national conferences that will benefit their family.

### **Community Groups**

Monthly informational meetings for parents of children with Down syndrome. The meetings feature guest speakers or social activities. DSG currently supports fifteen groups meeting in various locations in Greater Kansas City. (see listing)

### **Conferences, Seminars and Workshops**

DSG offers seminars and workshops through-out the year to educate DSG members and the community at large. Local and national speakers are invited to share pertinent information on best practices related to supporting individuals with Down syndrome.

### **All Guild Social Events**

DSG hosts several events each year including the BBQ, Farm Day and Family Holiday Party for all members to come together and share common interests and values. Families look forward to these events as an opportunity to network and share information and resources with one another.

### **Birthday Club Program**

Everyone loves to be remembered on their special day. DSG sends out a birthday greeting with a gift to each individual with Down syndrome in our database during their birthday month. It's our special way of reminding them how much DSG loves them.



### **STARS Teen Group**

This program offers a safe social environment for teenagers with Down syndrome to interact with each other and typical peer volunteers. Parents are not encouraged to attend so that the teenagers may develop independent skills.

### **3-21 Adult Group**

Gatherings for adults with Down syndrome. The group meets socially for dinner, movies, parties, and dances.

### **Counseling & Behavior Resources**

DSG provides families with up to six sessions with a licensed social worker or behavior analyst.

*For more information about the Down Syndrome Guild of Greater Kansas City contact our office at 913-384-4848, via email at [info@kcdsg.org](mailto:info@kcdsg.org), or visit our website at [www.kcdsg.org](http://www.kcdsg.org)*



# DSG Community Groups

DSG serves a large geographic area covering 37 counties in both Missouri and Kansas. In an effort to better serve our 1,500 member families, DSG funds and provides administrative support to community groups throughout the Greater Kansas City area. Community groups are lead by parent volunteers who work collaboratively with group members to host social and educational events pertinent to the group's individual needs. We encourage parents to get involved with all Guild events and with their local community group events as well.

## **African American Friends**

Serving all families of African American decent.

## **Northland Buddies**

Serving the area North of the Missouri River, including North Kansas City, Kansas City, Liberty, Gladstone, Platte City, Kearney, and Excelsior Springs.

## **Eastland Friends**

Serving families in the Eastern Kansas City, MO area, which includes Raytown, Blue Springs, Lee's Summit, Grandview, Peculiar, Warrensburg, and Oak Grove.

## **Dotte Friends**

Serving families in the Wyandotte County area, which includes Kansas City and Leavenworth.

## **Johnson County Friends**

Serving families in the Johnson County, KS area.



## **Joplin Friends**

Serving families in the Joplin, MO area, including the surrounding cities.

## **Dads Appreciating Down Syndrome (DADS)**

Provides fellowship amongst dads, uncles and grand-fathers who have a loved one with Down syndrome.

## **Latino Group**

Serving all families of Hispanic decent.

## **Lawrence/Topeka Friends**

Serving families between the cities of Lawrence to Topeka, KS.

## **Rural Missouri Friends**

Serving families in the Northern Rural Missouri area, including such city as Brookfield, Rockport and Kirksville.

## **St. Joseph Friends**

Serving families in the St. Joseph, MO area, including Maryville and Savannah.

## **TRI-21 Group**

Serving families near the Grandview/Raymore area.

# First Downs

## for Down Syndrome:

### Gaining Ground for a Winning Cause

First Downs for Down Syndrome is a non-profit organization formed in 1992. In partnership with the Kansas City Chiefs offensive line, First Downs for Down Syndrome raises money to help those in the community with Down syndrome and their families.

Specifically, the funds raised by First Downs for Down Syndrome support two local organizations: the Down Syndrome Guild of Greater Kansas City, which provides education and support to individuals with Down syndrome and their families; and the Down Syndrome Clinic at Children's Mercy Hospital, a center that addresses the medical and therapeutic needs of children with Down syndrome from birth through adolescence.

There are over 1,500 families in the Greater Kansas City area with a child with Down syndrome. Without First Downs for Down Syndrome, these families would not have local access to vital medical, emotional, educational and support services.

Kansas City is home to the highest attended, highest grossing Down syndrome awareness walk in the world!

FDFDS hosts a variety of events throughout the year including a Private Cellar Wine Tasting and Auction, Huddle Time Sports Auction, First Downs Golf Classic and the Step Up for Down Syndrome Walk Festival. FDFDS also works with the local high schools to involve them in fundraising and awareness programs.

We would love for you to join us at any of these exciting events. If you would like to learn more about FDFDS, visit [www.fdfds.org](http://www.fdfds.org) or contact our office at 913-722-2499.



First Downs for Down Syndrome • 5960 Dearborn, Suite 100, Mission, KS 66202

Ph. 913-722-2499 • Fax 913-722-2466 • [www.fdfds.org](http://www.fdfds.org)

Amy Stoll – Executive Director

Tiffany Way – Event Coordinator

# Step Up for Down Syndrome Walk

The Kansas City Step Up for Down Syndrome Walk is one of the largest celebrations for people with Down syndrome in the world. The 2015 walk welcomed 340 teams, over 8,000 walkers, 400 volunteers and some great entertainers.

We are so proud to be the first Down syndrome walk in the world to raise over \$500,000!

DSG members are encouraged to create walk teams in honor of their loved one with Down syndrome. Be sure to invite your family, friends, co-workers and those who are in your circle of support so they will gain a better understanding of the joys of loving someone with Down syndrome.

The Step Up Walk takes place on a Saturday in September or October during a Chiefs home game weekend. The Chiefs join us after their Saturday morning practice to help us celebrate and mingle with our attendees.

Visit [www.fdfds.org](http://www.fdfds.org) for more information. Contact [stoll@fdfds.org](mailto:stoll@fdfds.org) for information on how to sponsor the walk or make a walk team.







**JUST LIKE YOU -- DOWN SYNDROME** - explores the life, hopes, challenges and dreams of three kids living with Down syndrome. Elyssa, Rachel and Sam share personal stories to help viewers better understand their condition and why they wish to be treated just like you. Each of our stars has their own talents, characteristics, strengths and challenges. Down syndrome is just one part of who they are and this film identifies how to handle and accommodate differences while celebrating the many similarities our friends with Down syndrome have with their peers.

We have had over 393,000 views on YouTube in just four years! Schools and Down syndrome organizations across the US are hosting screenings. The film is offered in Spanish, Portuguese and Icelandic. We also have requests to translate into Russian as well! We love reading feedback like this:

*"This is the very best video I've EVER seen explaining Down syndrome to ANYONE - it is appropriate to show children as young as Pre-k, Elementary, Middle School, High School - and yes even those ignorant adults we all know and sometimes love (some are friends, some are merely acquaintances, some are FAMILY members) . . . THEY ALL NEED TO WATCH THIS VIDEO!! "*

*"This film should be shown in every school around the world to help children and adults better understand what it means to live with Down syndrome and how you can provide respectful support."*

*"I watched this film with tears streaming down my face as I know it will open the doors to friendships. My 12 year old daughter with Down syndrome said, mom they have Down syndrome like me!"*

[WWW.JUSTLIKEYOU-DOWNSYNDROME.ORG](http://WWW.JUSTLIKEYOU-DOWNSYNDROME.ORG)

# Felicitaciones!!!

Querido Nuevo Padre,

Como padre de un niño con Síndrome de Down, quiero presentarle a una organización de voluntarios sin fines de lucro fundada por padres de niños con Síndrome de Down. El Down Syndrome Guild of Greater Kansas City busca proveer apoyo y recursos para individuos con Síndrome de Down y sus familias. Como un padre amigo, yo sé que está pasando por muchas emociones ahora mismo.



Si usted es como muchas personas, tiene un poco de idea de lo que el Síndrome de Down significará para su niño y su familia. Las impresiones que usted tiene han de ser probablemente sin esperanzas e inexactas. Usted será aconsejado por los profesionales que encuentra a no leer nada sobre Síndrome de Down escrito hace más de cinco años atrás, ya que nueva información y terapias están rápidamente siendo descubiertas y perfeccionadas. Una gran red de servicios sofisticados y especialistas están disponibles para ayudar a su niño y a su familia- la mayoría sin costo para usted. Su niño tiene un futuro muy brillante!

El Down Syndrome Guild ha consolidado informaciones precisas sobre el Síndrome de Down en esta revista, incluyendo información sobre servicios locales disponibles para usted. Le sugerimos que lea la sección titulada " Primeras cosas" mientras que esté en el hospital. Elija del resto en cualquier momento que esté listo.

Junto con esta revista, nos gustaría ofrecerle una copia complimentary del libro " Bebés con Síndrome de Down". La información en este libro provee una actual y clara introducción al Síndrome de Down. Por favor contacte nuestra oficina para pedir su copia gratis de este libro.

Tener un niño con Síndrome de Down parece abrumador en estos momentos. De todas maneras, a medida que usted vaya aprendiendo más y más sobre el Síndrome de Down, este llegará a ser una característica definida de su niño- su maravilloso, adorable, cómo-pensé-que-la-vida-era-buena-antes-de-él ...niño.

Felicitaciones por su nuevo bebé!

**DSG STAFF & BOARD OF DIRECTORS**



# Historia de la Familia

## Saenz Quintana

Mi nombre es Brenda V. Saenz, mi esposo es Abel Saenz y nuestros hijos son Daniela y Diego Saenz Quintana. Somos de México y nuestros niños nacieron en Kansas City, Missouri. En el tercer mes de mi segundo embarazo tuve un análisis de orina y los resultados confirmaron que mi niño podía tener Síndrome de Down. Recuerdo que me sentí muy triste y que lloré. Recuerdo a la enfermera diciéndome que yo necesitaba un ultrasonido para averiguar lo que estaba pasando.

Tuve que esperar por un mes para tener más detalles. Fue muy difícil esperar y tener tantas dudas. El ultrasonido mostró que íbamos a tener un niño. Estaba tan emocionada por mi esposo. ¡El bebé era un niño! Ya habíamos escogido un nombre, ¡él se iba a llamar Diego! También recuerdo que el doctor tomó mucho tiempo revisando al bebé. Me empecé a preocupar y él me explicó, "Su hijo tiene ciertos problemas; tal parece que él tiene Síndrome de Down e Hidrocefalia". La noticia fue un impacto para mí, estaba abrumada y solamente lloré. Yo estaba sola cuando recibí la información ya que mi esposo estaba atrasado debido a su trabajo. Cuando le dí la noticia él solamente me abrazó y me dijo que íbamos a amar mucho a nuestro niño y que lo íbamos a proteger. Ese día yo le pregunté a Dios, "¿Por qué nos está pasando esto a nosotros? ¿He hecho algo malo?".

Un mes después tuve otro ultrasonido y el doctor me informó que los pies de Diego estaban torcidos y que su intestino estaba obstruido, esto es común en niños con Síndrome de Down. La enfermera me dijo algo muy triste, "Es su decisión si quiere tener a su niño". Creo que ahí fue cuando me sentí más devastada. Empecé a leer todo lo que podía sobre el Síndrome de Down. Quería ver a niños y adultos con Síndrome de Down. Quería saberlo todo pero al mismo tiempo estaba deseando que los doctores estuvieran equivocados.

Cuando Diego nació examiné todo su cuerpecito, quería saber que todo estaba normal. Recuerdo que cuando ví sus bellas facciones no tuve dudas que mi hijo tenía Síndrome de Down. Ellos descartaron la Hidrocefalia y los pies de Diego eran perfectos. Una enfermera se llevó a mi niño y mi esposo se fue con ellos. Horas después me llevaron al cuarto de recuperación, un intérprete entró para decirme que todavía estaban examinando a mi hijo. Ella había sido mi intérprete antes y conocía el diagnóstico de mi hijo. Entonces ella me dijo, "usted sabe que hay una larga lista de espera para adoptar niños con

Síndrome de Down". Yo me enojé porque era la segunda vez que ellos me pedían que dejara a mi hijo. Sólo le contesté, "Quiero a mi niño y vamos a pelear por él".

Después que él fue dado de alta empezamos el proceso de la terapia. Había tanta información que algunos días me sentía deprimida y confundida, pero teníamos que ser fuertes, él era tan pequeñito y sólo nosotros, sus padres, podíamos ayudarlo a salir adelante. Empecé a disfrutar todas sus terapias. Quería que Diego tuviera todo. Y él lo tuvo, un terapeuta excelente, una intérprete maravillosa, los doctores, éramos el equipo perfecto trabajando a favor de Diego.



Queremos que Diego sea lo más independiente posible y que su vida sea lo más normal que se pueda. Tomamos en cuenta su discapacidad pero no lo tratamos como si fuera incapacitado. Nosotros lo incluimos en todas las actividades familiares, su hermana Daniela es una ayuda increíble para él.

Diego trata de copiar todo lo que lo rodea. Esto lo ha ayudado en su desarrollo. Su hermana lo quiere, ella está orgullosa de su hermanito. El siempre está incluido. Las reglas del hogar son las mismas para ambos. Le enseñamos todo lo que podemos, Diego ha sido una gran bendición y le damos gracias a Dios por la alegría que Diego nos ha brindado.

Diego nos ha enseñado que en la vida todo es posible si es hecho con amor y determinación. Mi esposo Abel, mi hija Daniela y yo queremos agradecer a todas las personas que nos han ayudado, que han compartido su tiempo para enseñarnos acerca de las necesidades especiales.

# Bienvenidos a Holanda

por Emily Pearl Kingsley

A menudo me piden que describa lo que es la experiencia de criar a un niño con una discapacidad. Para ayudar a entender lo que esta experiencia única significa, a aquellos que nunca la han tenido; para poder imaginar lo que se siente, déjenme decirles que es algo parecido a lo siguiente...

Cuando se va a tener un bebé es como planificar un viaje de vacaciones fabulosas a Italia. Se compran un montón de guías turísticas y se hacen planes maravillosos: el Coliseo, el David de Miguel Ángel, las Góndolas de Venecia.

Uno se prepara incluso para aprender algunas palabras en italiano.

Es muy emocionante.

Luego que se han pasado meses en expectativa, finalmente llega el esperado día. Horas más tarde, el avión aterriza. La aeromoza se acerca y anuncia: "Bienvenidos a Holanda".

"Holanda?!" se pregunta uno. "Como que Holanda?!" Mi vuelo era para Italia! Se supone que debía estar en Italia. Toda mi vida he soñado con ir a Italia.

Pero, ha habido un cambio en el plan de vuelo. El avión aterrizó en Holanda y debe quedarse aquí.

Lo importante es que no le han llevado a un lugar horrible, desagradable y sucio, lleno de pestilencia, hambre y enfermedad. Es sólo un lugar diferente.

Así es que usted debe salir a hacer compras y adquirir nuevos mapas y guías. Y debe aprender un nuevo idioma. Y conocerá a un montón de gente que nunca habría conocido.

Sólo que es un lugar diferente. Con un ritmo un poco menos ajetreado que el de Italia, menos bullicioso y aparatoso. Pero, luego de estar allí por un tiempo, una vez que la agitación ha pasado, usted mira a su alrededor y comienza a darse cuenta que Holanda tiene los molinos de viento, y Holanda tiene los tulipanes. Holanda incluso tiene los Rembrandts!

Pero todo el mundo está muy ocupado iendo y viniendo de Italia, y todos se ufanan de las maravillosas vacaciones que han pasado allí. Y por el resto de su vida, usted se dirá "Si, allí es donde yo debía haber ido. Eso es lo que tenía planeado".

Y ese dolor nunca, nunca jamás se irá, pues la pérdida de ese sueño es una pérdida muy significativa.

Pero, si usted se pasa la vida lamentando el hecho que no llegó a Italia, nunca tendrá el espíritu libre para disfrutar lo más especial, lo más precioso de Holanda.



# El Síndrome de Down

## DEFINICIÓN

El síndrome de Down es la más común y fácil de reconocer de todas las condiciones asociadas con el retraso mental. Esta condición (antes conocida como mongolismo) es el resultado de una anomalía de los cromosomas: por alguna razón inexplicable una desviación en el desarrollo de las células resulta en la producción de 47 cromosomas en lugar de las 46 que se consideran normales. El cromosoma adicional cambia totalmente el desarrollo ordenado del cuerpo y cerebro. En la mayor parte de los casos, el diagnóstico del síndrome de Down se hace de acuerdo a los resultados de una prueba de cromosomas que es suministrada poco después del nacimiento del niño.

## INCIDENCIA

Cada año en los Estados Unidos, nacen aproximadamente 4,000 niños con síndrome de Down. Se podría decir que uno en cada 800 a 1,000 niños nace con esta condición. Los padres de cualquier edad pueden tener un niño con síndrome de Down. Aunque no importa si los padres sean jóvenes o mayores, la incidencia es mayor entre las mujeres sobre los 35 años de edad. Las formas más comunes del síndrome generalmente no ocurren más de una sola vez por familia.



## CARACTERÍSTICAS

A pesar de que hay más de 50 síntomas reconocidos del síndrome de Down, es raro encontrar una persona con todos o una gran cantidad de éstos. Algunas características incluyen:

1. Falta de tono muscular
2. Ojos alargados, con el cutis pliegado en el raballo del ojo
3. Hiperflexibilidad (la habilidad de extender excesivamente las coyunturas)
4. Manos chicas y anchas con una sola arruga en la palma de una o ambas manos
5. Pies anchos con los dedos cortos;
6. El puente de la nariz plano
7. Orejas pequeñas, en la parte inferior de la cabeza
8. Cuello corto
9. Cabeza pequeña
10. Cavidad oral pequeña
11. Llantos cortos y chillones durante la infancia

Los individuos con síndrome de Down típicamente son más pequeños que sus

compañeros normales, y su desarrollo físico e intelectual es más lento.

Aparte de un distintivo aspecto físico, los niños con síndrome de Down frecuentemente experimentan problemas relacionados a la salud. Por causa de la baja resistencia, estos niños son más propensos a los problemas respiratorios. Los problemas visuales, tales como los ojos cruzados y la miopía, son comunes en los niños con síndrome de Down, al igual que la deficiencia del habla y del oído.

Aproximadamente una tercera parte de los bebés que tienen síndrome de Down tienen además defectos en el corazón, la mayoría de los cuales pueden ser corregidos. Algunos individuos nacen con problemas gastro intestinales que también pueden ser corregidos, por medio de la intervención quirúrgica.

Algunas personas con síndrome de Down también pueden tener una condición conocida como Inestabilidad Atlantoaxial (Atlantoaxial Instability),

una desalineación de las primeras dos vértebras del cuello. Esta condición causa que estos individuos sean más propensos a las heridas si participan en actividades durante las cuales pueden extender demasiado o encorvar el cuello. A los padres se les pide una examinación médica en este respecto, para determinar si al niño se le debe prohibir los deportes y actividades que puedan dañar el cuello. A pesar de que esta desalineación puede ser una condición seria, un diagnóstico correcto podría ayudar en la prevención de las heridas serias.

En muchos casos los niños con síndrome de Down son propensos a subir de peso con el tiempo. Además de las implicaciones sociales negativas, este aumento de peso amenaza la salud y longevidad de estos individuos. Una dieta controlada y un programa de ejercicio podrían presentar una solución a este problema.



# LA ORGANIZACION DEL SYNDROME DE DOWN de Kansas City

La Organización del síndrome de Down de Kansas City (DSG) ofrece programas y servicios con el fin de mejorar la calidad de vida de las personas con síndrome de down y sus familias. DSG sirve a más de 750 familias en el área de Kansas City en los dos estados cuidando a sus amados miembros con síndrome de down. La siguiente es la lista de servicios del DSG.

**Apoyo Down** – El Paquete para los padres que esperan un bebé con down syndrome, es entregado a todos los doctores que hacen este tipo de diagnóstico. El paquete contiene información precisa y positiva acerca del síndrome de down como también sugerencias de materiales de lectura y los recursos para adopción. Otras personas también pueden comunicarse con la oficina del DSG para solicitar copias de este paquete.

**Revista Nuevo Padre** – La revista Nuevo Comenzar está diseñada para educar y confortar a los nuevos padres de un niño con síndrome de down. Esta revista ofrece información útil y precisa y una valiosa lista de recursos para las familias con miembros con síndrome de down. Las familias pueden obtener durante las visitas entre padres o con una llamada telefónica una copia gratis de los libros Bebes con síndrome de down y adicionar sus nombres a la lista de correo con solo devolver la tarjeta desprendible de la revista con sus datos. Nuevo Comenzar es presentada a los padres lo más temprano posible y sin ningún costo. DSG trabaja en cooperación con los hospitales y médicos y distribuye aproximadamente 100 revistas cada año.

**Red Padre a Padre** – Tan pronto como la Asociación es informada de un Nuevo bebé con síndrome de down, un padre de la red contacta a los nuevos padres y ofrece su apoyo, amistad e información acerca de cómo recibir apoyo de la Asociación y de otros recursos locales.

**Conexiones** – Una publicación cada dos meses es distribuida a 1200 familias. Con información educativa. La lista de eventos actuales y actividades que están por venir e información general.

**Librería de Recursos** – Libros, videos y panfletos acerca del síndrome de down están disponibles para ser prestados a ningún costo. La Asociación mantiene aproximadamente 100 títulos disponibles para las familias.

**Lista de Recursos** – Listas de los recursos disponibles para las familias que tienen niños

con síndrome de down. Nuestro personal mantiene información actualizada y precisa acerca de los recursos.

**Grupo de Apoyo para Padres** – Mensualmente se hacen reuniones de información para padres de niños con síndrome de down. A estas reuniones también son invitadas personas expertas para hablar sobre diferentes temas y en algunas ocasiones otro padre lidera las conversaciones sobre asuntos relacionados con salud, educación, mentiras y verdades, manejo de comportamientos, derechos legales, programas de transición, y entrenamiento para uso del baño. DSG actualmente apoya 15 grupos que se reúnen en varias localidades de Kansas City.

**Conferencia Anual** – Es un orgullo para el DSG organizar anualmente una conferencia educativa que reúne expertos del área para discutir las mejores prácticas para las personas con el síndrome de down.

**Becas para Conferencias** – DSG ofrece ayuda financiera a las familias que desean atender conferencias locales y/o nacionales que vayan a beneficiarlas.

**Seminarios y Talleres** – DSG organiza durante el año seminarios y talleres requeridos por los miembros. Eventos pasados incluyen el Seminario "Dándole un significado a su matrimonio" donde las parejas fueron asesoradas por consejeros profesionales y terapeutas que les ayudaron a disminuir los niveles de estrés dentro de sus matrimonios. Otro seminario fue IDEA101 donde las familias aprendieron a manejar el sistema de educación para individuos con discapacidades y el seminario: Herramientas para la comunicación oral/motora y terapia del lenguaje donde los padres y los terapeutas aprendieron cómo conectar el habla en los individuos con síndrome de down.

## Otros Eventos Sociales de la Asociación

– DSG organiza varios eventos casa a casa que todos sus miembros se reúnan y compartan sus valores e intereses. Entre otros están: El Eastern Eggstravaganza, cazando los Conejos de Pascua, el Picnic Annual, las Fiestas de Navidad y el Rodeo Real Americano. Las

familias esperan todos estos eventos como una oportunidad para conectarse y compartir información y recursos entre ellos.

**Programa de Vale para Alimentación** – Algunas de nuestras familias estarán durante un periodo mayor de lo normal en el Hospital cuando su niño(a) tengan complicaciones médicas. El DSG provee vales para ayudar con los gastos de alimentación de la familia mientras está en el Hospital. Las familias podrían estar recibiendo visitas de otro miembro de la familia Guild durante su estadía en el Hospital.

## Programa del Club de Cumpleaños

– Cada persona le gusta ser recordado en su día especial. El DSG envía una tarjeta de cumpleaños con un pequeño regalito a todos sus miembros con el síndrome de down su mes de cumpleaños. Es una manera especial de recordarles a todos cuánto los amamos.

**Grupo de Niños de Edad Pre-escolar** – Grupos para jugar y para salir a pasear dan a los niños con el síndrome de down la oportunidad de socializar y a sus padres de formar relaciones de ayuda. Las actividades incluyen el Gymboree, el Pueblo Tunnel, la música terapia, Deanna Rose Farmstead y mucho más.

**Grupo de Niños de Edad Escolar** – Actividades organizadas para educar, entretener y proveer un saludable ambiente social para los niños con el síndrome de down y sus familias. Se organizan grupos para que los padres puedan trabajar con sus niños en manejo de comportamientos, inclusión y socialización. Actividades como el Museo para niños Wonderscope, el paseo a caballo, el pueblo tunnel, el calidoscopio, el zoológico de Kansas City y más.

*Para más información acerca del Síndrome de Down Guild de Kansas City por favor contacte nuestras oficinas al 913-384-4848 o visite nuestra página web en [www.kcdsg.org](http://www.kcdsg.org)*

# The Lee Ann Britain Infant Development Center



The Lee Ann Britain Infant Development Center at Shawnee Mission Medical Center serves children with developmental disabilities from birth to age six. Founded by the late Lee Ann Britain, a speech therapist, the Center is a parent-involved program.

From the beginning, Britain felt therapy wasn't as effective if it didn't involve parents and siblings. Today, the Britain Center program carries her vision forward, not only offering advanced therapy techniques to children, but also providing support for the whole family.

Individualized programs are shaped for each child and family by a team of physical, occupational and speech therapists, early childhood special education teachers and a music therapist. With parents as partners, they create an environment which enables each child to become the very best they can be.

Receiving children from all of the Kansas City area, the Center provides services to any child and family in need of the program, regardless of their ability to pay.

Services include:

- Parent Involved Infant Stimulation and Toddler Classes
- Preschool Classes with Typically Developing Peer Models
- Physical Therapy
- Occupational Therapy
- Aquatic Therapy
- Speech therapy
- Music Therapy
- Parent Support Groups
- Parent Education
- Full Team Evaluations and Parent Conferences

## LEE ANN BRITAIN INFANT DEVELOPMENT CENTER

Life Dynamics Building  
Shawnee Mission Medical Center  
9100 West 74th Street  
Shawnee Mission, KS 66204  
(913) 676-2253  
[www.BritainCenter.org](http://www.BritainCenter.org)

# The Children's SPOT



## Saint Luke's Hospital (Speech, Physical, Occupational Therapy)

Children come to The Children's SPOT (an acronym for Speech, Physical and Occupational Therapy) with a wide variety of diagnoses: from autism, Down syndrome, cerebral palsy, or premature birth, to those with general or minor developmental delays. Intensive therapy-based services are provided in a family-centered environment. Programs include 1) the Developmental Pre-school where children as young as one year of age are provided a stimulating environment for therapy, learning and developing basic socialization skills; 2) the Intensive Care Nursery Follow-up clinic where development is monitored in a series of screenings; 3) Multidisciplinary Evaluations for infants and toddlers with suspected developmental delays; 4) Individual Therapy sessions in speech, physical and/or occupational therapy.

All direct service staff members are certified therapists who have a great love of children and families. Their warmth and guidance help children develop appropriate academic, behavior and social skills. Their principal goal is to increase each child's functional independence and quality of life regardless of his or her family's ability to pay.

What families say about The Children's SPOT:

*"His face beams with pride at his accomplishments! The therapists have a way with the kids that is amazing."*

*Our daughter has Down syndrome and is part of a number of children who are redefining what those with disabilities can achieve. We give full credit to the early and aggressive intervention therapy she received at the SPOT."*

## THE CHILDREN'S SPOT

4333 Pennsylvania  
Kansas City, MO 64111  
(816) 932-3832

## Children's TLC

For many years, Children's TLC has been a place where children with developmental disabilities and special health-care needs, along with their families, can find the help and support they're looking for.

Our staff consists of full and part-time employees with the highest levels of educational and professional certification, totaling many collective years of teacher/therapist experience.

Our center-based program is equipped to serve preschool-age children with a variety of disabilities. We provide therapy classrooms, a warm water pool for aquatic therapy, a lunchroom and play area. In addition, we have a home-based program for children ages three and under who benefit by remaining in their familiar home or childcare environment.



### **CHILDREN'S TLC**

3101 Main

Kansas City, MO 64111

(816) 756-0780

## Northland Early Education Center

The Northland Early Education Center is a unique 501 C (3) nonprofit preschool that shapes the future of children through quality early education and therapeutic intervention, while teaching compassion for diversity. The Northland Early Education Center serves children aged birth to five in a preschool environment that organizes its classrooms into chronologically aged peer groups, regardless of a child's individual developmental level, so that all children can learn and play together in age-appropriate activities.

Certified by the National Association for the Education of Young Children and the Commission on the Accreditation of Rehabilitation Facilities, the Northland Early Education Center offers its' students the opportunity to learn in a highly specialized environment. Qualified lead teachers staff each classroom and, for those children who need it, there is also the opportunity to work with one of the preschool's three therapists or special instructor. The Northland Early Education Center is in the community to provide the services and care that young children and their families need to be prepared to enter kindergarten, primed for success and ready to learn.

### **NORTHLAND EARLY EDUCATION CENTER**

8630 North Oak Trafficway

Kansas City, MO 64155

(913) 420-9005



# Families Together, Inc



Families Together, Inc. is a statewide organization that assists parents and their sons and daughters with any form of disability. This program's mission is to encourage, educate and empower families to be effective advocates for their own children.

Families Together, Inc. is dedicated to a society that includes and values all people. They offer families the security of belonging to a support network of other parents that face similar goals, challenges and needs.

## **FAMILIES TOGETHER, INC.**

Kansas City Parent Center  
6811 W. 63rd Street  
Suite 117  
Overland Park, KS 66202  
(913) 384-6783

# MPACT Mission

***MPACT's mission is to ensure that all children with special needs receive an education which allows them to achieve their goals.***

## **MPACT** provides:

**PARENT MENTOR PROGRAM** – Parent Mentors provide support and guidance to parents of children with disabilities throughout the IEP process. Their goal is to help the parent build a collaborative partnership with the district so that their child may receive an appropriate education.

**TRAINING WORKSHOPS** – Monthly Training workshops develop parents' understandings and skills on special education process, effective advocacy, behavior support and bullying.

**RESOURCE LIBRARY** – The MPACT resource library is housed in the Kansas City office. Over 1300 books, videos and CDs on special education or disability information are available to browse and check out.

**MPACT** is a parent training and information center that serves families of children with special needs in Missouri by providing education, direct assistance, disability resources and referrals.



8301 State Line Road  
Suite 204  
Kansas City, MO 64114  
(816) 531-7070  
[www.ptimpact.com](http://www.ptimpact.com)

# The Down Syndrome Center at Children's Mercy Hospital

The mission of the Down Syndrome Center is to improve the quality of life of individuals with Down syndrome by providing a thorough, coordinated program that addresses the medical and therapeutic needs of these individuals as well as offering support and education to their families..

The most vital part of the center is the Down Syndrome Clinic. This specialty clinic serves as a consultative service and screening mechanism for children with Down syndrome from birth through adolescence, following established Healthcare Guidelines created by the National Network of Medical Clinics for Children with Down syndrome. the clinic is comprehensive, and an experienced team of professionals with an expertise and interest in Down syndrome hold clinics twice a month (usually on Wednesdays) to evaluate the specific needs of each child scheduled. Together, they problem solve and strive to improve the quality of life for the child and the family.

the team consists of a Pediatric Geneticist, a Nurse Practitioner, a Genetic Counselor, a Registered Dietician, an Audiologist, a Speech Pathologist, an Occupational Therapist, Behavioral Psychologist, and a Parent Coordinator/Advocate.

For more information about the Down Syndrome Clinic at Children's Mercy Hospital, please call (816) 234-3784, or to schedule an appointment please call (816) 234-3490.



## **CHILDREN'S MERCY HOSPITAL**

Department of Clinical Genetics  
2401 Gillham Road  
Kansas City, MO 64108  
(816) 234-3290

# The Sunshine Center

The Sunshine Center offers families a comprehensive array of services to meet the need of their children age birth to five. Sunshine serves children with disabilities – developmental, physical and medical, children who are at risk and children who are typically developing in inclusive, natural classroom environments. Services offered include: occupational, speech and physical therapy; special instruction; early childhood education; and childcare.



## **SUNSHINE CENTER SCHOOL**

607 West Lexington Avenue  
Independence, MO 64050  
phone (816) 833-2088  
fax (816) 833-1105  
sunshine@sunshinecenter.org  
www.sunshinecenter.org

# Marian Hope Center

Marian Hope Center was born of a vision for enhancing the lives of children with special needs through integrative, holistic programs. The center was founded by licensed speech-language pathologist, Angie Knight, M.A., CCC-SLP, and Karen Embry, parent of a child with special needs. Staffed by multifunctional therapists and paraprofessionals that are highly talented and nurturing, Marian Hope Center is growing and gaining recognition among health care, academic, and child advocacy professionals for its unique functional approach and phenomenal successes in treatment, instruction, and complete care for children and their families. Our student-to-therapist/paraprofessional ratios and “whole child” programs set us apart and make the difference in your child’s success.

Marian Hope Center offers intensive, individualized, therapeutic classes for children ages 2-16. These classes focus on play skills, handwriting, language enrichment, feeding, apraxia, motor development, and reading. In addition to the therapeutic classes, Marian Hope Center offers a free nutritional management support to families who are interested in making healthy food choices for their families. Marian Hope Center is also working with the community in order to integrate children with special needs successfully into community programs such as karate, dance, Sunday schools, and gymnastics.



**MARIAN HOPE CENTER**

FOR CHILDREN'S THERAPY

## **MARIAN HOPE CENTER FOR CHILDREN'S THERAPY**

14820 E. 42nd Street  
Independence, MO 64055  
[www.marianhopecenter.org](http://www.marianhopecenter.org)  
phone (816) 695-1255  
fax (816) 478-7762

# Social Security and Supplemental Security Income Programs

**The Social Security and Supplemental Security Income** disability programs are the largest of several Federal programs that provide assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify for benefits under either program.

Social Security Disability Insurance pays benefits to you and certain members of your family if you are “insured,” meaning that you worked long enough and paid Social Security taxes.

Supplemental Security Income pays benefits based on financial need. SSI makes monthly payments to people with low income who are disabled. Your child may qualify if your family income falls within a certain range.

When you apply for either program, Social Security will collect medical and other information from you about your child and make a decision about whether he meets Social Security’s definition of disability. These are income based programs so your household income and work history of parents will be taken into consideration.

Learn more and apply here: [www.ssa.gov/disability/](http://www.ssa.gov/disability/)



# National Down Syndrome Resources



Founded by a parent of a child with Down syndrome in 1979, the National Down Syndrome Society (NDSS) gradually expanded to become one of the largest organizations in America focusing on intellectual disabilities. The mission of NDSS is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.

- The NDSS National Policy Center strives to protect the rights and remove barriers for all individuals with Down syndrome. The policy center works with Congress and federal agencies to develop and improve legislation.
- NDSS leads a national network of over 330 affiliate groups across the country, consisting of local parent support groups and other organizations.
- The Goodwin Family Information and Referral Center offers a toll-free helpline and e-mail service that can be accessed in over 150 languages. The NDSS website, [www.ndss.org](http://www.ndss.org) is a comprehensive and up to date resource for families, professionals, affiliates and others and includes extensive Spanish translation.
- NDSS created the Buddy Walk®, a national program that promotes acceptance and inclusion of people with Down syndrome and raises funds for local and national initiatives that support people with Down syndrome and their families.
- Through public awareness, NDSS works to ignite a new way of thinking about people with Down syndrome. NDSS proactively reaches out to national media to secure editorial content and monitors all forms of media, 365 days a year. The My Great Story campaign honors and celebrates the great stories of the 400,000 Americans living with Down syndrome by showcasing these stories in a beautiful online storybook. NDSS has turned two stories into a national public service announcement which has been featured in national and local media outlets across the country.

For more information, contact:

## **THE NATIONAL DOWN SYNDROME SOCIETY**

8 E. 41st Street, 8th Floor  
New York, NY 10017  
Tel. (800) 221-4602  
[www.ndss.org](http://www.ndss.org)



The National Down Syndrome Congress is the country's oldest national organization of self-advocates, their families, and the professionals who work with them. Over the years, the NDSC has become known for its unflinching 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. Each year, the NDSC National convention brings together speakers and participants from throughout the United States and the World to learn and share in a giant "family reunion" setting.

## **MISSION**

The Mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down Syndrome.

For more information, contact:

## **NATIONAL DOWN SYNDROME CONGRESS**

30 Mansell Court, Suite 108  
Roswell, GA 30076  
Tel. (800) 232-NDSC  
[www.NDSCcenter.org](http://www.NDSCcenter.org)

*The Down Syndrome Guild of Greater Kansas City is proud to be affiliated with both national Down Syndrome organizations.*

- ☐ Please send me a complimentary copy of the book "Babies with Down Syndrome" to the address below.
- ☐ Please add my name to the Down Syndrome Guild Mailing List so I can begin receiving the bi-monthly *Connections Newsletters* and activity flyers.
- ☐ Please contact me to schedule a parent-to-parent visit.
- ☐ Please have a support group leader contact me so I can learn more about meetings that take place in my area.

PARENT'S NAME \_\_\_\_\_

CHILD'S NAME \_\_\_\_\_

CHILD'S BIRTHDATE \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY, STATE, ZIP \_\_\_\_\_

PHONE \_\_\_\_\_

E-MAIL \_\_\_\_\_

- ☐ Favor de incluir a nuestra familia al base de datos de Down Syndrome Guild!
- ☐ Favor de incluir mi nombre a la Lista de Correo de Down Syndrome Guild para que yo pueda comenzar a recibir cada dos meses el Periodico Connections y folletos de actividad.
- ☐ Favor de contactarme para poner una cita de padres a padres.
- ☐ Favor que el lider del grupo Latino de apoyo se contacte conmigo para que yo pueda prender sobre reuniones que se llevan acabo para apoyar a familias hispanoparlantes.

NOMBRE DE PADRES \_\_\_\_\_

NOMBRE DE NINO \_\_\_\_\_

FECHA DE NACIMIENTO \_\_\_\_\_

DIRECCION \_\_\_\_\_

CIUDAD, ESTADO, CÓDIGO POSTAL \_\_\_\_\_

TELÉFONO \_\_\_\_\_

CORRERO ELECTRÓNICO \_\_\_\_\_

**THE DOWN SYNDROME GUILD OF GREATER KANSAS**

5960 Dearborn, Suite 100 • Mission, KS 66202

Phone (913) 384-4848 • Fax (913) 384-4949

[www.kcdsg.org](http://www.kcdsg.org) • [info@kcdsg.org](mailto:info@kcdsg.org)

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5960 DEARBORN, SUITE 100  
MISSION, KS 66202

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5960 DEARBORN, SUITE 100  
MISSION, KS 66202

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