



# NEW BEGINNINGS

A MAGAZINE FOR PARENTS OF  
BABIES WITH DOWN SYNDROME



DOWN SYNDROME  
INNOVATIONS



# FIRST THINGS PERSON FIRST

A baby is a baby first. When talking with family and friends use people first language such as “our daughter has Down syndrome” or “our baby was born with Down syndrome.” Saying things like “we have a Down’s baby” or “our baby is Downs” puts the diagnosis at the forefront and your baby is more like other babies than different.



## MISSION

Our life-changing support and services enable people with Down syndrome to live to their fullest potential.

## VISION

We serve as the expert resource and lead community mobilizer, sharing knowledge and creating solutions for people with Down syndrome.

## VALUES

**COMMUNITY:** We promote meaningful connections in everything we do

**INNOVATION:** We think broadly and boldly in pursuit of excellence

**INDIVIDUALITY:** We value the unique potential of every person

**PASSION:** We are deeply and personally committed to making a difference

**TRUST:** We work collaboratively to ensure mutually beneficial outcomes

### DOWN SYNDROME INNOVATIONS

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# CONGRATULATIONS!

## Dear New Parent,

You may be facing many emotions right now and Down Syndrome Innovations is here to be your lifespan partner.

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 What impressions you do have may be bleak, outdated or very inaccurate.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!



Down Syndrome Innovations 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 to visit with you and to provide you with a new parent welcome basket full of resources, books on Down syndrome and baby gifts to help celebrate your little one. Visit [kcdsi.org](http://kcdsi.org) to request a visit and basket.

Having a child with Down syndrome seems overwhelming right now. As you learn more, 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!

**DOWN SYNDROME INNOVATIONS 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 700 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, individuals with Down syndrome will lead fulfilling and productive lives.

# 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, challenges 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, 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 and a baby with Down syndrome automatically qualifies for services.

**Pediatric Physical Therapy (PT)** is the treatment of children with physical disabilities by a licensed professional physical therapist. 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.

**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. 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 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.

# WHERE TO START

## Infant-Toddler Services (ITS) and First steps (FS)

are federally funded early intervention programs. You will work with ITS or FS to determine the special needs of your child and how to address those needs through therapeutic interventions to help your baby meet developmental milestones as close to typically developing peers as possible.



## 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) 627-5500



[WWW.KSITS.ORG](http://WWW.KSITS.ORG)

## MISSOURI FIRST STEPS

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 & 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**



[WWW.MOFIRSTSTEPS.COM](http://WWW.MOFIRSTSTEPS.COM)

# HEALTH ISSUES

## TO ADDRESS AT THE HOSPITAL OR SOON AFTER BIRTH

Children with Down syndrome are often at increased risk for certain health issues. 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 helped people with Down syndrome live healthy and longer lives.

**We recommend the following medical issues be addressed at the hospital before you go home:**

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

Down Syndrome Innovations 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 to 3 months of life. Symptoms may present themselves as heart failure, difficulty breathing or failure to thrive. The symptoms



may not be apparent at first. Most hospitals have the capability to perform an echocardiogram. It is often most convenient to take care of this before leaving the hospital.

**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 experience a hearing loss. With new testing procedures this can be detected easily in newborns.

*Download a copy of the American Academy of Pediatrics approved healthcare guidelines for children with Down syndrome at [kcdsi.org/new-parents](http://kcdsi.org/new-parents).*

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

# BREASTFEEDING & 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. We can connect you to other parents who 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 & 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 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.

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 a 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.

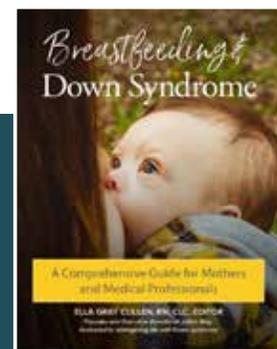
Sometimes mothers have trouble getting the baby’s tongue down from the roof of his mouth. To help with this concern, insert the tip of your finger between the roof of the baby’s mouth and the tongue in an upside- down position, then turn the finger over, to condition the sucking reflex. The procedure 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.

The rewards of nursing your baby are well worth the extra effort, so don’t be discouraged if you encounter problems.

This book offers advice on everything from preparing to breast- feed, to breastfeeding after heart surgery, to getting to the breast after tube feedings, and much more. Dozens of mothers’ stories are featured to help reassure you that babies with Down syndrome CAN and do breastfeed successfully. Download a free copy of the book here:

[downsyndromepregnancy.org/book/breastfeeding-and-down-syndrome](http://downsyndromepregnancy.org/book/breastfeeding-and-down-syndrome)



# PARENT TO PARENT PROGRAM

“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 others and shared the news.

Through Down Syndrome Innovations parent to parent program I was connected to other parents and it was nice to talk to someone else who had walked a similar journey. The parents I talked with focused on my baby and not his diagnosis and made me realize my baby had a positive future ahead.”

As new parents, you probably have many questions. One of your best resources for assistance is a fellow parent of a child with Down syndrome. Down Syndrome Innovations currently serves over 1,600 families who look to one another for support, resources and information.

If you would like to be matched to other parents contact our office at **913-384-4848** or **info@kcdsi.org**. You can also join our parent forum on Facebook where you can post questions and get real-time answers from other parents: **facebook.com/groups/kcdsi**.



# 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 Down Syndrome Innovations and what we do. Then we'll just talk." Walking into Down Syndrome Innovations that day was the beginning of hope for our family.

Amy spoke of all of the things that Down Syndrome Innovations 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 quarterly new parent gatherings. 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 gatherings 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, Down Syndrome Innovations, 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 those challenges. Ella greets every day 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"!

# 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?



*These kids are in love with their brother and he is their number one fan.*

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, explaining Down syndrome will be an on-going process. At first they just need to know that for the most part their sibling 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 Down syndrome 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.

# LITTLE PRINCESS

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.

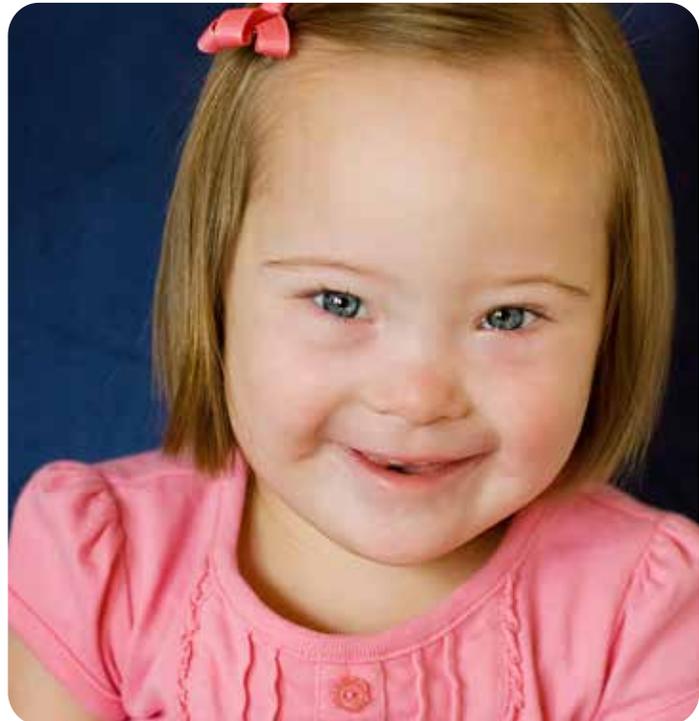
Fortunately, it is amazing how quickly thoughts can change and one can move thru the journey of acceptance. Suddenly, we knew that we couldn't live without our little angel, Lexi.

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 continues to amaze us with 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, and better people. Down Syndrome Innovations 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.



# A FATHER'S JOURNEY

I remember feeling an intense sense of calm after my wife gave birth to our son. 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 me 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 makes 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 son.



# DON'T FORGET TO BREATHE

I got up from the hospital bed gingerly and shuffled my way to the door to see my daughter Gabby. Our cardiologist had arrived at the hospital and was performing an echocardiogram in the nursery. As I entered the hallway, I saw balloons, an excited group of people, shouts of glee. They were going to the room next door. My heart clenched, and momentarily I was thrust back to the day we received the news at 18 weeks pregnancy that our baby had Down syndrome. The sadness, the fear, and the sense of disconnect all came rushing back at once. "Not for you," that voice in the back of my head said. This was irrational. My husband and I had moved on from those days. We'd learned about Down syndrome, acclimated, reclaimed joy. Meeting our daughter was a joyful experience. We had three delighted children who had already met their baby sister. Our extended family was welcoming, supportive, and loving. Our wonderful OB delivered the baby in a lively, joking atmosphere, just as we'd asked.



For a brief moment I'd let myself fall back into that trap of thinking the birth of Gabby was somehow "less than" or "other." Why did their joy throw me back emotionally? It was momentary, fleeting, but real, and intense. Feelings do not always make sense. Growth is not linear. And postpartum hormones are a catalyst for emotional variability. Perhaps it was their naive bliss, not tinged by worry or concern. They were balloons and stuffed animals; we were echocardiogram. Trying to squelch the unexpected reaction, I continued to the nursery. Through the window I saw my newborn. The doctor noticed me, smiled hugely, and showed a thumbs up. Within a few minutes, she was in the hall with me, happily congratulating me on the birth: "She's sooo beautiful!" Her warmth brought me back to center, back to the reality of the excitement of the newborn days.

For the most part, the peace after delivery is such a far cry from the worry of prenatal diagnosis anxiety. But sometimes, you may see or hear something that throws you back. You may find yourself responding to events or interactions with others: good news and supportive people center you, while unexpected medical news, unsupportive people, or even a glimpse of another family may trigger those feelings of uncertainty. It will pass! You will find your center, your steadiness. Anchor in the moment. Breathe in that intoxicating newborn smell. Hold your baby close, show her off, gaze at her, bond with her. Focus on a future of hugs, smiles, warmth, and giggles. The emotional blips are a separate thing, and they will fade. Enjoy and treasure this time.

# LIFE IS GOOD

“Missy, she’s beautiful, and she’s perfect and I’m quite certain she has Down syndrome.” With those words at Violette’s birth, my obstetrician changed the trajectory of my life as a parent. I liken it to the part of the Wizard of Oz where everything in Dorothy’s world goes from gloomy black and white to the vivid technicolor world over the rainbow. And, looking back 13 years later, in many ways I still feel that way. My life has been changed in having a child with an extra chromosome. But many of the fears I had initially about intellectual disability and her health have been unfounded, or at least misguided.

I felt things so intensely at first, and everything in my world, for a while, was clouded by a question of “how will Down syndrome impact” whatever situation I pondered. I never thought I would find a new acceptable normal, or a world that felt at all like the one I had before she was born. I had a lot of fears about the unknown - how would her extra chromosome impact our family? Would her sisters be “burdened” by her? I feared what school would be like for her, would she get picked on? Teased? Would she have friends? Would she be able to communicate with us? Would our family travel and dine out and do all of the things we loved to do before she and her extra chromosome came into our lives?

Today I look at those concerns through a new lens - one of experience. My life? Well, it feels pretty good, I have to say. The first year of her life was tough - I had a lot more on my plate working full time, parenting two other children and all the appointments and checkups (oh, and pumping breastmilk, that was a whole other never-ending job.) It was hard keeping things in my life harmonious, let alone keeping my house clean and picked up. The house actually didn’t get picked up, but things stayed mostly harmonious. But that was a period of time in my life, and as time passed, things got more manageable. I grew from dreading doctors’ visits and therapy appointments to mostly enjoy the one-on-one time with my daughter - I still do.

We have routines, games and habits that are part of our relationship that we share and look forward to during those appointments that are part of life with Down syndrome. My overwhelm turned into a familiar pattern. I learned the difference between worrying about everything that might happen to her vs. being chill in presuming that everything is ok, but alert to possible concerns. But, life as a full-time working mama who travels a lot for her job has stayed largely similar to what I expected before she was born.

Our family and her sisters? Well, I can tell you there are a lot of laughs, and a lot of joy. The girls love each other, pick on each other, and enjoy each other. I had an impression

that having a child with Down syndrome would mean having a child who only takes from the family. But I was wrong - Violette gives a lot. She is great emotional support to her oldest sister. She and her middle sister tease each other and sass each other and get on each other’s nerves. And they also love each other. Having a sister with Down syndrome is what is normal to my older girls, and their friends. No stigma related to the extra chromosome that I can see exists for them. I think it helps that we have adopted a philosophy that a friend who has siblings with Down syndrome shared with me: My child with Down syndrome is a spoke on the wheel of our family, not the hub.

Finally, how is life for my girl? Well, she is a chatterbox. She learned to communicate quite a bit with sign language as a baby through Signing Time - we all did. That strong early communication signing skill turned into strong verbal communication skills for her. She is well understood (thank you speech therapists!). She has a wide range of friends. She plays Roblox with them, and FaceTime’s them. She is in an adaptive ballet program she enjoys. She has traveled the world with us - she’s been to Japan, Italy, Ireland, Hawaii, Alaska and all over the US I asked her what she thinks about her life with Down syndrome as I was writing this. Her answer? “Good. Spoiled. Happy.” And that basically sums up her life.

P.S. Everyone’s parenting experience is different, and I’ve found that to be equally true parenting a child with Down syndrome. I have a great big network of support when it comes to the Down syndrome parenting community. There is always someone to help me, support me and understand me. Reaching out and engaging in the community has been so helpful to me. Since she was born, I’ve leaned on the friends and organizations that are there to support me when something unexpected comes up.

I encourage you to find your people when it comes to raising your child. They are out there and those connections will be some of the closest you will have in your life. An unexpected gift of your child is how quickly your circle of support expands if you let it.



# I'LL MISS HIM WHEN HE MOVES OUT

I was 23-years-old when my son, Andy, was born with Down syndrome. He was whisked off to the NICU after he was born because he had trouble breathing, but I had no idea anything else was going on at the time. He was my first baby, so I didn't know what to expect. About 4 hours later, our pediatrician pulled us into a room outside of the NICU and explained that his almond shaped eyes, the wide gap between his toes, and the extra fold of skin on the back of his neck likely meant that he had Down syndrome. The doctor was pretty matter-of-fact about it and told us that we wouldn't know for certain until we received the results from the karyotype test. I felt so overwhelmed in that moment, and one of the best things my husband and I did was write down all the things that scared us so that we could talk through them with each other.

I remember I was really worried about whether other kids would be mean to him and how we would afford the extra expenses as recent college graduates. I also worried about him living with us forever, and I worried that my identity would be forever defined as the parent of a child with a disability. It's so strange now to think back on those fears because life has been much different than what I anticipated.

We were so comforted day after he was born when the parent support staff in the hospital walked in with a book about Down syndrome, a photo of her son with Down syndrome on a bike, and contact information for the local Early Intervention program. She showed us that life with Down syndrome could still be fun, and we learned right away that he could get speech, physical, and occupational therapy to help him reach his milestones. It may have taken a little more time, but Andy eventually learned to walk, talk, and ride a bike like his friends. We also have so much fun as a family—hiking, visiting state and national parks, jumping in waterfalls, and playing games. Andy was also so much cooler than I ever was in school. He has a vast network of friends who grew up with him and called him their brother, and he played high school lacrosse, worked on the high school yearbook, and earned his Eagle Scout award. Life is not perfect, and he still struggles with reading, math, and finances, but his strengths compensate for those challenges, and we're happy.

Andy's also had boxes packed to move out of the house since he was 13-years-old. My fear is no longer whether

he will live with us forever—my fear is how much I'll miss him when he does actually move out in the next couple of years. But I want that for him—I want him to be independent and follow his dreams. He is

now 21-years-old and is a talented photography, is currently serving as a missionary for our church at local food pantries, volunteers as a high school lacrosse coach, and works at our local grocery store. In fact, he got the job himself at 16 when he took off on his bike after school one day after seeing that some of his friends from school working at the store. I was cooking dinner, and I didn't realize that he'd left until I heard a message from Andy that he needed help from me to complete the application. I drove off to the grocery store in a panic, and my husband called to remind me, "Would you have every imagined when he was born that your fear at 16 would be that he took off on his own to get a job?"

Being Andy's mom has changed my life and defined me in the most profound ways. It's an honor to be his mom and not because of the milestones he's accomplished but because of who he is as a person. The time I was most proud of him, which had nothing to do with a milestone, was when his little sister smacked her head on the floor during a basketball game, and he leaped to the floor to scoop her up before anyone could even respond. His first instinct was to help and show love to his sister, and that made me more proud than any award or achievement. Because of Andy's influence in my life, my career has also shifted to creating programs and advocating for people with disabilities, and I've had the most amazing opportunities to travel all over the US and to Russia and Japan to teach about Down syndrome. I also have my own incredible network of friends because of that extra chromosome, and I'm incredibly grateful for the opportunity I've had to live this life alongside my son.





# WELCOME TO HOLLAND

by Emily Pearl Kingsley

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

When you're going to have a baby, it's like planning a fabulous vacation trip to Italy. You buy a bunch of 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.

## GET CONNECTED!

Learning that your baby has Down syndrome can be an overwhelming time. Down Syndrome Innovations has been supporting families as they learn of a diagnosis for nearly four decades. We are here to answer any questions you may have. We can connect you with resources and will provide a parent-to-parent match if you would like to visit with other parents and learn more about their experiences.

We would love to learn more about your family, so we know how to best support you. Visit [mykcdisi.org](http://mykcdisi.org) to get connected and register your family to receive our e-newsletters, as well as vital resources and information at every age and stage as your child grows and thrives.

# PHILANTHROPY AND FUNDRAISING

When you make a gift to Down Syndrome Innovations through donating, attending an event, or participating in one of our fundraisers such as our Step Up For Down Syndrome Walk—you are directly supporting our mission and the families we serve. Your support helps fund scholarships for families who are unable to afford our fee-for-service programs, supplement our free educational programs for all age levels and our free educational seminars for caregivers, educators, and medical professionals. Your generosity directly impacts our ability to deliver our mission!

## HOW YOUR SUPPORT HELPS US DELIVER OUR MISSION:

Down Syndrome Innovations creates tools and connects people that offer people with Down syndrome the best resources to achieve success. For nearly four decades, we've pioneered best practices that educate and support the people we serve. We are an expert resource helping communities and families better serve and create new opportunities for people with Down syndrome. Everyone benefits.

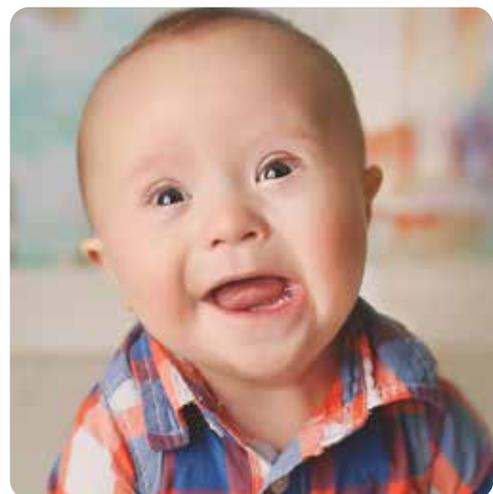
The Step Up for Down Syndrome Golf Tournament is held bi-annually. The first tournament is held in Columbia, MO at the Country Club of Missouri each Spring and the second tournament is held in the Fall at Shadow Glen Golf Club in Olathe, KS. Both tournaments include not only a fun day of golf at these beautiful and prestigious clubs, but each golfer enjoys shopping in the gift salon featuring top golf and lifestyle brands, food on the course, specialty drinks, fabulous prizes for each golfer and a chance to win a car! Golfers also have the opportunity to meet and play against local celebrity golfers, and special golfers with Down syndrome.

The Step Up for Down Syndrome Walk and Festival is also held bi-annually. Both events are held in the Fall. The first event is held in Columbia, MO and the second at Arrowhead Stadium in Kansas City. Both events are family-friendly with family activities (bounce houses, live music, carnival games, lunch, treats, etc.) and festivities for every age group. Both events feature a one-mile ceremonial walk in celebration of their loved one or friend with Down syndrome.

Down Syndrome Innovations also seeks and welcomes gifts from public and private grantors as well as memorials, honorariums, corporate matching gifts and planned giving/estate planning.

### Additional philanthropic and fundraising activities include:

- First Downs High School Football Fundraiser
- Virtual Wine Auction
- Social media fundraising



# DOWN SYNDROME INNOVATIONS

Through comprehensive, community-driven services and programs, we enable brighter futures for people of all ages with Down syndrome. We're your trusted partner for every step of the journey.

## OUR PROMISE

Down Syndrome Innovations is your trusted source for **life-changing services** for people with Down syndrome, their families, and communities. Our expert resources, comprehensive support, and partnership with families empower and enable individuals with Down syndrome to live to their **fullest potential**.

## OUR UNIQUE APPROACH

Our **singular focus** on building brighter futures for individuals with Down syndrome gives us a comprehensive understanding of what it takes to realize that vision. For nearly four decades, **we've pioneered best practices** that educate and support the people we serve. We are an expert resource helping communities and families better serve and create new opportunities for people with Down syndrome. **Everyone benefits.**



**Services & Support**  
for people with  
Down syndrome and  
their families



**Educational Resources**  
for educators, healthcare  
professionals, and  
community members



**Advocacy**  
on issues that affect  
the lives of people with  
Down syndrome

## HERE FOR YOU AT EVERY STAGE OF THE JOURNEY



**EXPECTANT PARENTS**  
Resources and support  
after a diagnosis of  
Down syndrome



**NEW PARENTS**  
Connection &  
information for healthy,  
happy beginnings



**CHILDHOOD**  
Programs and support for  
developmental progress  
and social success

Lifespan therapeutic and educational services and community connection for enhanced wellbeing

# OUR LIFESPAN SERVICES

Wherever you are on your journey, our expert Lifespan Service Team is with you, continually finding new ways to offer **innovative services for every age and season of life.**

## Therapy Services

Our transformational therapeutic services equip the person with Down syndrome and his/her caregivers with skill-building strategies and individualized supports within the home and community.

## Expectant & New Parent Support

We offer diagnosis support and education, family support gatherings, referrals; and resources every step of the way.

## Playgroups for Young Children

Designed by our therapy team, playgroups promote the development and learning of children 6 years old and younger, and provide education to caregivers to support positive life trajectories.

## Social Programs for School-Age Children

Our programs for 6-12 year olds provide inclusive and fun opportunities to learn and practice essential social and communication skills, participate in meaningful movement activities, explore new leisure activities, and make friends.

## Educational Programs for Teens

Our programs for 12-18 year olds focus on building independence and confidence, practicing essential social skills, empowering self-advocacy and preparing for a meaningful and productive life after high school.

## Adult Services

Our programs for adults 18 years and older focus on maximizing independence, increasing productivity, integrating in the community, preparing for employment, and learning essential social skills.



\*Teletherapy and virtual options are available for many of our services. Inquire about virtual options for the services above.



### EXPECTANT PARENTS

Resources and support after a diagnosis of Down of syndrome



### NEW PARENTS

Connection & information for healthy, happy beginnings



### CHILDHOOD

Programs and support for developmental progress and social success

# 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. Down Syndrome Innovations 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!

Down Syndrome Innovations 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!

**DOWN SYNDROME INNOVATIONS STAFF & BOARD OF DIRECTORS**



# HISTORIA DE LA FAMILIA SAENZ QUINTANA

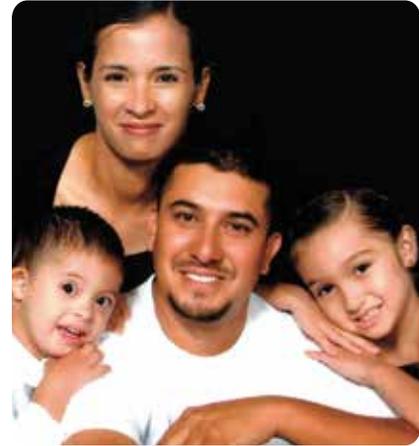
Mi nombre es Brenda V. Saenz, mi esposo es Abel Saenz y nuestros hijos son Daniela y Diego Saenz Quintana. Somos de México y nuestros niños nacieron en Kansas City, Missouri. En el tercer mes de mi segundo embarazo tuve un análisis de orina y los resultados confirmaron que mi niño podía tener Síndrome 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, dejenme decirles que es algo parecido a lo siguiente...**

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, dejenme 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 Angel, 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 yendo 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 perdida 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.



## ¿Por qué son importantes los servicios para bebés-niños?

Comenzar con una relación entre padres y profesionales en esta etapa temprana ayuda al niño, a la familia y a la comunidad como un conjunto. **Esta relación puede ayudar a:** Mejorar la capacidad de las familias para satisfacer las necesidades de sus hijos; Ayudar a los bebés y niños a alcanzar niveles de desarrollo adecuados a su edad; Maximizar el desarrollo signi\*cativo que tiene lugar durante los primeros tres años de vida del niño; Reducir los sentimientos de aislamiento, estrés y frustración que pueden experimentar las familias; Reducir los costos de educación a largo plazo para la sociedad minimizando la necesidad de educación especial y servicios relacionados en la etapa escolar; y Ayudar a los niños a convertirse en individuos productivos e independientes.

## ¿Quién es elegible para la ayuda?

Las familias de Kansas con bebés o niños (desde su nacimiento hasta los tres años de edad) con retrasos en el desarrollo/ discapacidades tienen derecho a servicios de intervención temprana. La elegibilidad para los servicios se determina utilizando un informe de los padres, una opinión clínica, y una evaluación y mediciones de valoración.

**Su programa local para Bebés-Niños tiny-k puede hacer una evaluación:**

**Física:** Incluyendo una evaluación motora, sensorial, de salud, nutricional, visual y de audición

**Cognitiva:** Resolución de Problemas

**De Comunicación:** Lenguaje Social/Emocional/ Comportamiento Adaptación/Auto-Ayuda

# 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 rabllo 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 gastrointestinales 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.

## 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 Dietitian, an Audiologist, a Speech Pathologist, an Occupational Therapist, Behavioral Psychologist, and a Parent Coordinator/Advocate.

**For more information or to schedule an appointment with the Down Syndrome Clinic at Children's Mercy Hospital please call (816) 960-2856.**



## DOWN SYNDROME HEALTHCARE GUIDELINES

Specialized health care guidelines for children with Down syndrome have been published by the American Academy of Pediatrics. The guidelines cover prenatal care through age 21 and help families and physicians understand and screen for conditions that are more commonly found in patients with Down syndrome. The information in these guidelines has grown with the help of families, Down syndrome clinics, and doctors around the world. Most of the information is easy to follow. Many tests only need to be done once. Some areas might need to be looked at again, or even many times, as the child grows to an adult. Some tests or pediatric specialists might be needed that are not available in your area. Your doctor can help to sort out the best next steps when something can't be done quickly or nearby.

**Download a copy of the guidelines by visiting: [kcdsi.org/new-parents/](http://kcdsi.org/new-parents/)**

## 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.

**[ssa.gov/benefits/ssi](http://ssa.gov/benefits/ssi)**

## NATIONAL DOWN SYNDROME SOCIETY

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.



## NATIONAL DOWN SYNDROME CONGRESS

The National Down Syndrome Congress is the country's oldest national organization of self-advocates, their families, and the professionals who work with them. 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.

The Global Down Syndrome Foundation is a 501c 3 non-profit organization dedicated to significantly improving the lives of people with Down syndrome through research, medical care, education and advocacy.

### MISSION

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



[www.NDSCcenter.org](http://www.NDSCcenter.org)

*Down Syndrome Innovations is proud to be affiliated with both national Down Syndrome organizations.*

## GLOBAL DOWN SYNDROME FOUNDATION

The Global Down Syndrome Foundation is a 501c 3 non-profit organization dedicated to significantly improving the lives of people with Down syndrome through research, medical care, education and advocacy.

[globaldownsyndrome.org](http://globaldownsyndrome.org)

## LUMIND IDSC RESEARCH FOUNDATION

LuMind accelerates Down syndrome research to increase availability of therapeutic, diagnostic and medical care options and empowers families through education, connections and support.

[lumindidsc.org](http://lumindidsc.org)



# DOWN SYNDROME INNOVATIONS

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