New Beginnings

A Magazine for Parents of Individuals with Down Syndrome

Developed by:
The Down Syndrome Guild of Greater Kansas City – a non-profit volunteer organization founded by parents of children with Down syndrome.
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
Dear New Parent,

As a parent of a child with Down syndrome, I want to introduce you to a non-profit volunteer organization founded by parents of children with Down syndrome. The Down Syndrome Guild of Greater Kansas City seeks to provide support and resources for individuals with Down syndrome and their families. As a fellow parent, I know that you are facing many emotions right now.

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!

The Guild 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!

Bridget Murphy
President, Down Syndrome Guild of Greater Kansas City
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 800-1,000 live births will result in a child with Down syndrome, representing approximately 5,000 births per year in the United States. There are approximately 350,000 individuals with Down syndrome in the United States today.

There is a wide variation in the abilities, physical development and behavior of individuals with Down syndrome. 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.
Children with Down syndrome are often at increased risk for certain health problems. Congenital heart defects, increased susceptibility to infection, respiratory problems and obstructed digestive tracts occur with greater frequency among children with Down syndrome. Fortunately, advances in medicine have rendered most of these health problems treatable.

As with all children, you must take an active role in ensuring the best health care for your child. Some steps 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.

For Down syndrome growth charts and healthcare guidelines, visit our website at 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 tryptophan (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 you can do 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 sometimes 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
On Father's Day, June 18th, our blessing came from above.
He weighed 6lbs. 14 ounces- what a bundle of love!!!
We knew he'd be special from all along.
And when we first saw him, we knew we weren't wrong.
Jack has Down syndrome, but please don't be sad.
Because he's our star and we're proud and glad-
That God chose us to be the family of Jack.
And we know love and attention are things he'll never lack.
We're excited that this gift will bring us so much joy.
Now our family is complete with this beautiful baby boy!

Love,
THE MELVIN
John, Joan, Lindsey, Jessica, and Christopher

Our lovely little girl is here!
Miss McKenna Ellen arrived February 15th at 2:55 am.
She weighed in at 7lbs 4oz and was 19 inches long.
Her eyes are becoming more blue so far and she has
dark hair which is thinning like her Daddy’s
(his said this first!). She has very fair skin but her
complexion is darker than mine, so maybe she
won’t sunburn as easily as me!
We of course think she is wonderful.

We also want to share that McKenna
was born with Down syndrome. We learned this the
morning after she was born. If you are not familiar
with this, it means that she will have some extra
challenges as she grows and may travel the
developmental path a bit more slowly than others.
We will consider each new milestone a blessing.
Please don’t apologize…there’s nothing to be
sorry for. She’s happy and healthy, and
we're just as proud as could be of
our beautiful baby girl.

McKenna’s Mom and Dad
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 is currently no fee for Early Intervention services.

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.

Is there an age limit to receiving Early Intervention services?
The age limit is newborn to three years.

PT, OT, and Speech Therapy

**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 motor 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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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.
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.
In February 2000, our fourth child, Alana Katheryn, 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
Expectant parents generally go through the same thought processes and range of emotions. Parents usually want the same things for their children; among the most important of these are health and happiness.

With our first child, everything about the pregnancy and birth of our son followed the textbooks. With our second child, I found out that we were going to have a girl and I thought, “I have everything a man could want, a loving wife, a son, and now a little girl.” Just like with my son, I had thoughts of what it would be like to have a daughter. I had thoughts of a pig-tailed girl running around saying “Daddy” a million times… watching a young lady grow up, go to the prom, and later; much later; walking my Little Princess down the aisle at her wedding. We planned to name our daughter Isabella (mainly so that every time I spoke to her, I could call her Bella…Beautiful).

Then for a brief moment, things changed. On the day my Little Princess was born, we learned that she had Down syndrome. My tears of joy suddenly came from another place. A child’s “birthday” is always filled with many emotions. This is especially true when you learn, on that day, that your baby is different. The desires for health and happiness are definitely still there; with health being paramount. But now, you also run through many new thoughts and feelings. Many of which are selfish and many of which you were unaware of hours before your child was born.

Life always has turning points. One of the most important and positive in my life was the birth of my son. The day Isabella was born seemed, at first, to not be so positive. While everyone else was struggling to understand what this day meant, my father asked what was wrong and I explained. When he asked again, I thought he didn’t understand. I soon realized there was something I didn’t understand. Before I could explain again, he said “…then love her twice as much.” With those few words, the tears of joy were back!

It is very clear that all the hopes and dreams I had for my Little Princess are all still possible. The major difference is that I will now stop and cherish each step along the way. After all, Bella is the Little Princess that I had dreamed of all along.

Bella’s Dad
What
Caleb
Means to
Us

A few hours after our first child was born, a doctor came into our hospital room to tell us that our son had Down syndrome. We remember being in shock. We remember hoping that this was all a bad dream. We remember praying and asking God why he would do this to us. We just couldn’t imagine living our lives with a child who has a disability. After almost five years of being Caleb’s mom and dad, we know that when God gave us Caleb, he blessed us way beyond comprehension. We can’t imagine living our lives without him. - Mom and Dad

When Caleb entered our lives on April 28, 1994, he came as a complete surprise and has since opened up a new area of our world. An area of complete joy with no holds barred. The things we feared at his birth have long since disappeared. The term “Down syndrome” no longer brings a tear to our eye or a lump in our throat. Caleb is so happy and in turn makes us happy. His accomplishments are many and we rejoice with them all. He has taught us sign language. He has also shown us that Barney really does make good videos, and chips and pretzels are great treats. He has added so much to our lives that words can never explain. He makes our family complete. - Me-Me and Pop-Pop Brooks

Having a cousin with Down syndrome is not hard. He seems like a regular little kid to me. He is active and loving. Every time I see him I feel special to have him in my family. - Karlya, age 10
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
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.

It’s been ten months now and 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*
Love is like the blood that runs through our veins. If love does not exist, neither do we. Love can make us happy, love can make us suffer. Love has no color. Love is blind, but love can also change the way we see things. Love can make us a different person, because love has wonder.

When we love a child, we should love them regardless of who they are. Real love is unconditional. Trust me, the love of a child is so pure that it has no boundaries. A child can change your life for the better. My family and I are blessed to have such a wonderful little girl in our lives, Victoria. She has given us a whole new reason to be a family. I thank the Lord for giving us the opportunity to care for a child with a disability. A child is just a child not the title that they are given. Instead of asking God, “why me?” Say “thank you God for the opportunity of being part of this new life.” I say to you that the love for a special child is no different than the love you can give any other child. Love your child and you will see that love takes you to great places.

Right now you may be full of questions and be afraid. All of that will go away with time, and you will see that the light at the end of the tunnel is the love you have for your special child.

Victoria’s Mom
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 “Na Na” 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 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.

Our nickname for Abby was “Holly.” We ordered tulips for her.
The Down Syndrome Guild of Greater Kansas City (DSG) is a non-profit volunteer organization whose mission is to provide support and resources for individuals with Down syndrome and their families. The Guild seeks to provide the entire community with information and education to broaden awareness and foster positive attitudes regarding people with Down syndrome.

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

**24-Hour Phone Information Line** – Anyone in the community can dial into our phone information line at 913-384-9898 to access information about DSG events.

**Down Comforter** – Expectant Parent Packet provided to all local physicians who may provide a prenatal diagnosis of Down syndrome.

**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.

**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 2,000 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 200 titles readily available to families.

**Community Groups** – Monthly informational meetings for parents of children with Down syndrome. The meetings feature guest speakers or social activities. DSG currently supports twelve groups meeting in various locations in Greater Kansas City.

**Conferences, Seminars and Workshops** – DSG offers seminars and workshops throughout 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 Down syndrome.

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

**All Guild Social Events** – DSG hosts several events each year including the Easter Eggstravaganza, Annual Carnival 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.

**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.

**Adopt a Family Holiday Program** – DSG families can apply for assistance with a meal and gifts during the holiday season.

**Birthday Club Program** – Everyone loves to be remembered on their special day. DSG sends out a birthday greeting with a treat 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.

**Infant/Preschool Group** – Playgroups and fieldtrips to provide socialization opportunities for children with Down syndrome and peer group support for their parents.

**Elementary Group** – Activities designed to educate, entertain and provide a healthy social environment for children with Down syndrome and their families. Scheduled group outings present opportunities for parents to work with their children on behavior management, inclusion and socialization.

**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.

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

For more information about the Down Syndrome Guild of Greater Kansas City contact our office at 913-384-4848 or visit our website at www.kcdsg.org
First Downs for Down Syndrome

First Downs for Down Syndrome, in partnership with the Kansas City Chiefs’ Offensive Line, is a non-profit, 501©3 organization that raises money with each first down scored per season to help those in the community with Down syndrome and their families.

Funds raised by FDFDS support two local organizations: The Down Syndrome Guild of Greater Kansas City and The Down Syndrome Clinic at Children’s Mercy Hospital. FDFDS also provides funding to Children’s Mercy to research the link between Down syndrome and leukemia.

FDFDS hosts a variety of events throughout the year including a private cellar wine tasting and auction, Huddle Time sports auction, Golf Classic, and Buddy Walk.

First Downs for Down Syndrome • 10000 West 75th Street, Suite 220 • Shawnee Mission, KS 66204
Ph. 913-722-2499 • www.fdfds.org

The Down Syndrome Buddy Walk

The Buddy Walk Festival is an event that raises awareness for Down syndrome and funds for the Down Syndrome Guild. It includes a one-mile walk around Arrowhead and Kauffman Stadiums with entertainment, raffles, food and more! There are over 250 Buddy Walks around the world and the Kansas City event is one of the largest in the nation! For more information on how to participate in the Buddy Walk visit our website at www.kcBuddyWalk.org
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, esto 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!

Sinceramente,
Bridget Murphy
Presidente de El Down Syndrome Guild of Greater Kansas City.
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...

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 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 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.
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 cromosa 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 rabillo 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 bebes 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 vertebraes del cuello. Esta condición causa que estos individuos sean más propensos a las heridas si participan en actividades durante los 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 Organizacion del syndrome de Down de Kansas City (DSG) ofrece programas y servicios con el fin de mejorar la calidad de vida de las personas con syndrome de down y sus familias. DSG sirve a mas de 750 familias en el area de Kansas City en los dos estados cuidando a sus amados miembros con syndrome de down. La siguiente es la lista de servicios del DSG.

**Linea de informacion las 24 horas** – Cualquier persona en la comunidad puede acceder a nuestra linea de informacion acerca de las reuniones de los grupos de apoyo en el area de Kansas City, programas, servicios, eventos, estudios de investigacion, patrocinadores, oportunidades para ser voluntarios, eventos especificos de acuerdo a las edades de las personas que tienen el syndrome de down.

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

**Revista Nuevo Padre** – La revista Nuevo Comenzar esta diseñada para educar y confortar los nuevos padres de un nino con syndrome de down. Esta revista ofrece informacion util y precisa y una valiosa lista de recursos para las familias con miembros de syndrome de down. Las familias pueden obtener durante las visitas entre padres o con una llamada telefonica una copia gratis del libros Bebes con syndrome de down y adicionar sus nombres a la lista de correo con solo devolver la tarjeta desprendible de los libros Wonderscope, el Pueblo Tunel, la musica terapia, Deanna Rose Farmstead y mucho mas.

**Red Padre a Padre** – Tan pronto como la Asociacion es informada de un Nuevo bebe con syndrome de down, un padre de la red contacta a los nuevos padres y ofrece su apoyo, amistad e informacion acerca de como recibir apoyo de la Asociacion y de otros recursos locales.

**Conexiones** – Una publicacion cada dos meses es distribuida a 1200 familias. Con informacion educative. La lista de eventos actuales y actividades que estan por venir e informacion general.

**Libreria de Recursos** – Libros, videos y panfletos acerca del syndrome de down estan disponibles para ser prestados a ningun costo. La Asociacion mantiene aproximadamente 100 titulos disponibles par alas familias.

**Lista de Recursos** – Listas de los recursos disponibles por las familias que tienen nicos con syndrome de down. Nuestro personal mantiene informacion actualizada y precisa acerca de los recursos.

**Grupo de Apoyo para Padres** – Mensualmente se hacen reuniones de informacion para padres de nicos con syndrome de down. A estas reuniones tambien son invitadas personas expertas para hablar sobre diferentes temas y en algunas ocasiones un padre lidera las conversaciones sobre asuntos relacionados con salud, educacion, mentiras y verdades, manejo de comportamientos, derech os legales, programas de transicion, y entreamiento para uso del bajo. DSG actualmente apoya 7 grupos que se reúnen en varias localidades de Kansas City.

**Conferencia Annual** – Es un orgullo para el DSG organizar anualmente una conferencia educacional que reune expertos del area para discutir las mejores practicas para las personas con el syndrome 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 a;o seminarios y talleres requeridos por los miembros. Eventos pasados incluyen el Seminario “Dandole un significado a su matrimonio” donde las parejas fueron asesoradas por consejeros profesionales y terapistas que les ayudaron a disminuir los niveles de estres dentro de sus matrimonios. Otro seminario fue IDEA101 donde las familias aprendieron a manejar la sistema de educacion para individuos con discapacidades y el seminario: Herramientas para la comunicacion oral/motora y terapia del lenguaje donde los padres y los terapistas aprendieron como conectar el habla en los individuos con syndrome de down.

**Programas de Animacion** – Algunas de nuestras familias estarán durante un periodo mayor de lo normal en el Hospital cuando su nino(a) tengan complicaciones medicas. El DSG provee vale para ayudar con los gastos de alimentacion de la familia mientras esta en el Hospital. Las familias podrian estar recibiendo visitas de otro miembro de la familia Guild durante su estadia en el Hospital.

**Programa del Club de Cumpleanos** – Cada persona le gusta ser recordado en su dia especial. El DSG envia una tarjeta de cumpleanos con un pequeo regalo a todos sus miembros con el syndrome durante su mes de cumpleanos. Es una manera especial de recordarles a todos cuanto los amamos.

**Grupo de Ninos de Edad Pre-escolar** – Grupos para juntarse y para salir a pasear dan a los nicos con el syndrome de down la oportunidad de socializar y a sus padres de formar relaciones de ayuda. Las actividades incluyen el Gymboree, el Pueblo Tunel, la musica terapia, Deanna Rose Farmstead y mucho mas.

**Grupo de Ninos de Edad Escolar** – Actividades organizadas para educar, entretenear y proveer un saludable ambiente social para los ninos con el syndrome de down y sus familias. Se organizan grupos para que los padres puedan trabajar con sus nicos en manejo de comportamientos, inclusion y socializacion. Actividades como el Museo para Wonderscope, el paseo a caballo, el puebulo tunel, el calidoscopio, el zoologico de Kansas City y mas.

Para mas informacion acerca del Syndrome de Down Guild de Kansas City por favor connete nuestras oficinas al 913-384-4848 o visite nuestra pagina web en www.kcdsg.org
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.
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.”

“With the help of the talented doctors and therapists, 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
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

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 for 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.

MPACT
Parent Training and Information
8301 State Line Road
Suite 204
Kansas City, MO 64114
(816) 531-7070
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, a 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.

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

MISSION

The mission of the National Down Syndrome Society is to benefit people with Down syndrome and their families through national leadership in education, research and advocacy.

For more information, contact:

THE NATIONAL DOWN SYNDROME SOCIETY
666 Broadway
New York, NY 10012-2317
Tel. (800) 221-4602
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
1370 Center Drive, Suite 102
Atlanta, Georgia 30338
Tel. (800) 232-NDSC
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 recivir cada dos meses el Períodico Connections y folletos de actividad.

Favor de contactarme para poner una cita de padres a padres.

Favor que el líder 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