



BN^{EW} *Beginnings*

Created by:

*The Down Syndrome Guild of Greater Kansas City –
a non-profit volunteer organization founded by parents of
children with Down syndrome.*

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DSG DOWN SYNDROME GUILD of Greater Kansas City

The Down Syndrome Guild 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.

President Sarah Clayton

Executive Director Amy Allison

THE DOWN SYNDROME GUILD OF GREATER KANSAS

10000 W. 75th Street

Suite 220

Shawnee Mission, KS 66204

Phone (913) 384-4848

24-Hour Information Line

(913) 384-9898

www.kcdsg.org

kcdsg@sbcglobal.net

CONNECTIONS

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Call (913) 384-9898

to be added to the mailing list.



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.

From the book "Down Syndrome – The Facts"

by Mark Selikowitz

Congratulations!!!

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 fellow parents, we know that you are facing many emotions right now.



If you are like most people, you have little idea what Down syndrome will mean to your child and your family. What impressions you do have are probably bleak and very inaccurate. You will be advised by the professionals that you encounter not to read anything about Down syndrome that was 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 "First Things" while in the hospital. Select from the rest whenever you're ready.

Along with this magazine, we are including a copy of the book "Babies With Down Syndrome." The information in the book provides a current and comprehensive introduction to Down syndrome.

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

Sincerely,

Sarah Clayton
President, Down Syndrome Guild of Greater Kansas City



What is Down Syndrome?

Down syndrome affects people of all ages, races and economic levels. It is one of the most frequently occurring chromosomal abnormalities found in humans, occurring once in approximately every 800 to 1000 live births. Over 350,000 people in the United States, alone, are affected by Down syndrome.

All people 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 the syndrome.

Health Issues

to Address at the Hospital or Soon After Birth

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 who have Down syndrome. However, advances in medicine have rendered most of these health problems treatable.

Soon after birth, you must take an active role in ensuring the best health care for your child. Some steps that we recommend include:



- ▶ **Choosing 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. However, by contacting other parents, you can ask questions about how they selected a pediatrician for their child.
- ▶ **Have 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 of major heart defects may present themselves as heart failure, difficult breathing and failure to thrive in the newborn period. However, the defects may not be apparent at first. Most hospitals have the capability to perform an echocardiogram, and it is often more convenient to take care of this before leaving the hospital.
- ▶ **Ensure that the diagnosis of Down syndrome is confirmed via chromosomal karyotyping.**
- ▶ **Have the pediatrician check for gastrointestinal blockage.** Some signs of gastrointestinal blockage include vomiting or absence of stools.
- ▶ **If your child has any feeding difficulties,** ask for a consult with a feeding specialist. Most children with Down syndrome have success with breastfeeding.
- ▶ **Have 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.

These points are not meant to be exhaustive and are not meant to replace receiving care and advice from a qualified physician.

Breast-feeding

the Baby with Down Syndrome

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

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

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

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

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

When the baby is born with Down syndrome, there are varying degrees of concerns. The baby may be a little sleeper and have a poor sucking reflex, while others may have respiratory problems and more serious difficulties. If your baby is weak at birth, he may experience some difficulty in learning to suck and swallow, so you will need to be calm and patient while he learns.

Babies with Down syndrome are often more prone to respiratory infections and digestive upsets. Breastfeeding lessens the incidence of both of these problems and probably reduces the severity of them if they should occur. Babies with Down syndrome are often placid and sometimes have poor muscle tone and generalized weakness at birth. Therefore, the mother will have to learn to be a clock watcher, picking the baby up frequently and offering the breast, rather than waiting for him to cry to be fed. The baby should be encouraged to nurse about every two hours during the day and several times during the night.

Sometimes mothers have trouble getting the baby's tongue down from the roof of his mouth. To help with this concern, insert the tip of your finger between the roof of the baby's mouth and the tongue in an upside-down position, then turn the finger over, to condition the sucking reflex, the procedure could be repeated four or five times before each nursing, starting with the finger at the front of the baby's mouth and pushing it slowly into the baby's mouth so the baby will think he is drawing in.

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

Of course you will be in close contact with your doctor who will continue to evaluate your baby's progress. Because some babies with Down syndrome don't gain weight as well as they should, doctors sometime suggest solids earlier than usual. Let your doctor's advice and the baby's need 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

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
600 Minnesota Avenue, Kansas City, KS 66101
(913) 627-5628

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

First Steps Program of Missouri



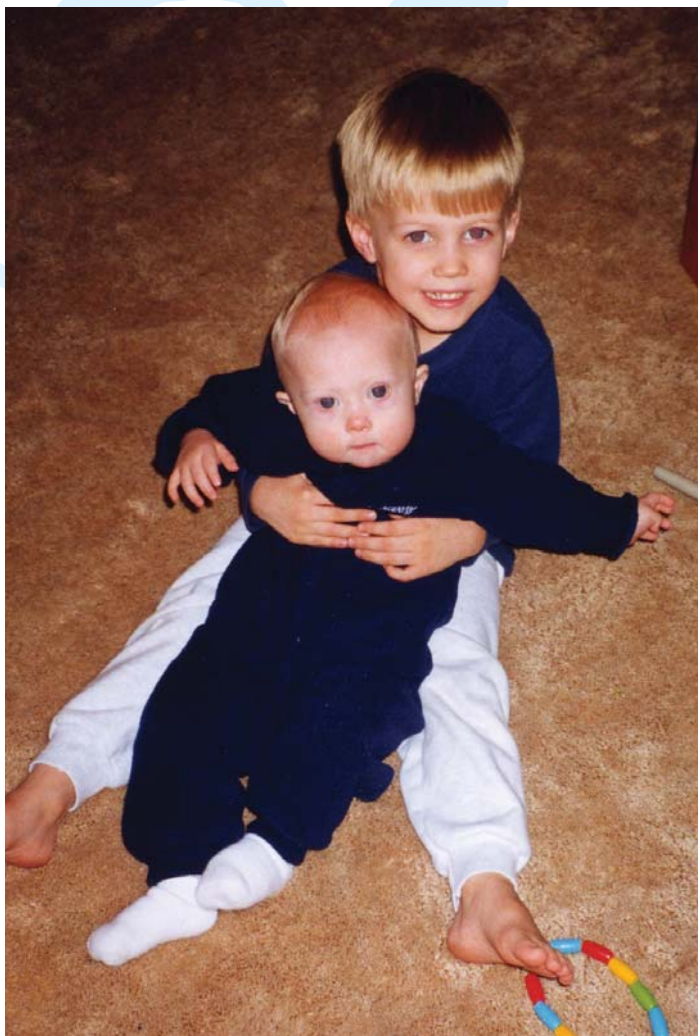
The Missouri First Steps Program is a "family-centered" program offering early intervention services for children 0 –36 months of age who have special needs. Participation in First Steps is voluntary and is intended to help families of children with disabilities:

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

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

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

Parent-to-Parent 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 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 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 Theresa DeBrevi at (913) 219-7863 or call the Down Syndrome Guild office at (913) 384-4848.

Birth Announcements

Jack Elliott Melvin

By L. Melvin



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 MELVINS

John, Joan, Lindsey, Jessica, and Christopher



MCKENNA ELLEN

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

(he 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

How Do I Tell the Kids?

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

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

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

more about you as you get older," I explained.

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

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

I have discovered that no matter how old your children are, telling them about Down syndrome is an on-going process. At first they just need to know that for the most part their baby is going to be like any other baby. She'll just need some extra help. As the kids mature, new experiences will invite further discussions. Maybe they notice some unique features and so we launch into a discussion about how each of us is made differently...hair, eyes, skin and so forth. Maybe a friend has a question and together we find the answer. As parents, we learn what we need to about DS each time we approach a new phase. It is exactly the same for our kids.

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



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

A Positive Transformation

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



Little Princess

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

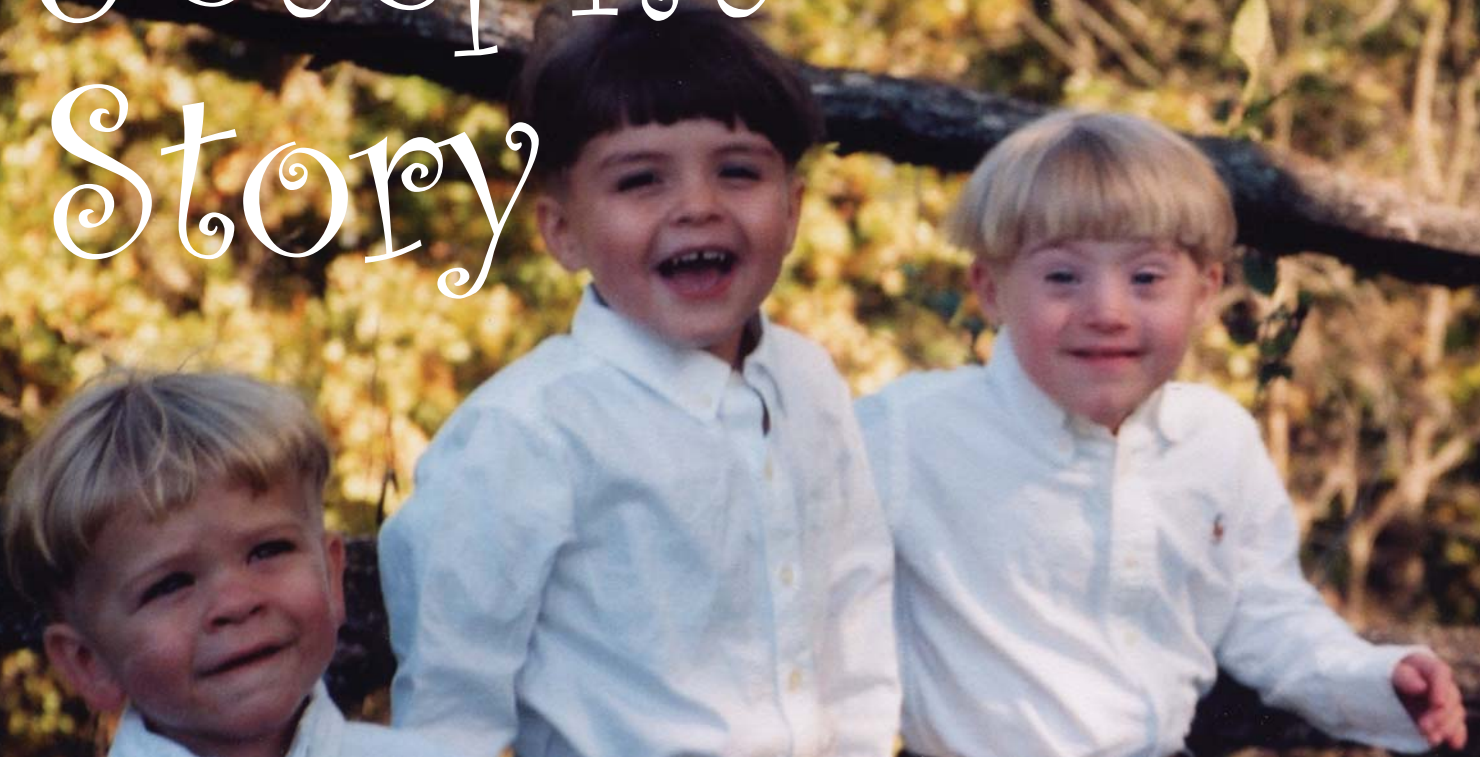


A few hours after our first child was born, a doctor came into our hospital room to tell us that our son had Down syndrome. We remember being in shock. We remember hoping that this was all a bad dream. We remember praying and asking God why he would do this to us. We just couldn't imagine living our 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**

Joseph's Story



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

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

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

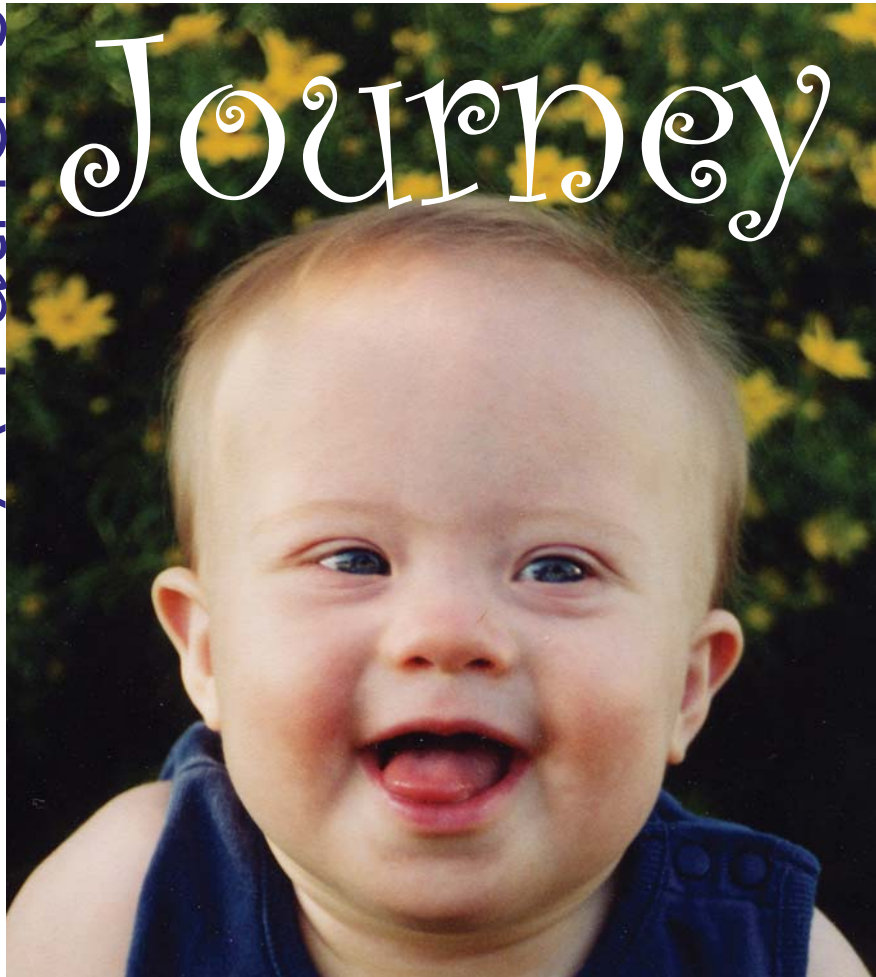
teachers and classroom volunteers. From his point of view, school was a place to play with adults who liked him, had fun with him, and made a huge fuss about every little developmental accomplishment. He loved it and so did I. We have since had two other sons and would have liked for them to have the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

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

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

Joseph's Mom

Journey



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

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

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

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

One day I finally told my wife about my feelings and that although I knew they were wrong, I felt them. Telling her was the best thing I ever did. I remember feeling such a sense of relief. I no longer felt angry or bitter and although those feelings never made me love our son

any less, keeping them inside was destroying our marriage. Allowing myself to talk about those feelings renewed our marriage.

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



El amor es como la sangre que corre por nuestras venas. Si el amor no existiera nosotros tampoco. El amor nos hace feliz. El amor nos hace sufrir. El amor no tiene color. El amor es ciego, pero el amor nos hace cambiar la manera de ver las cosas. El amor nos hace una persona diferente, porque el amor hace maravillas.

Cuando amamos un niño, debemos amarlo sin importarnos quien es. El amor verdadero es incondicional. Creámelo el amor de un niño es muy puro y no tiene límites. Un niño puede cambiar nuestras vidas para mejorar: Mi familia y yo estamos bendecidos de tener para ser una niña tan maravillosa en nuestras vidas: Victoria. Ella nos ha dado una razón nueva para ser una familia. Le doy gracias a Dios por darnos la oportunidad de cuidar de una niña con una necesidad especial. Un niño es solo un niño, no el nombre que la humanidad tiende a darles. En lugar de preguntarle a Dios, "¿por qué yo?" Den gracias a Dios por darnos la oportunidad de ser parte de esta nueva vida. El amor por un niño especial no es diferente del amor que se le da a otro niño, Ama a usted hijo y veras que el amor te lleva a lugares grandiosos.

En este momento usted puede estar lleno de preguntas y asustado. Todo esto pasara con el tiempo, y usted vera que la luz al final del túnel es el amor que usted tieno por su hijo especial.

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 can make us change. 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



THE DOWN SYNDROME GUILD of Greater Kansas City

PROGRAMS

The Down Syndrome Guild of Greater Kansas City provides monthly programs and services for individuals with Down syndrome and their families.

The programs are divided into five separate categories: Parents, Infants & Toddlers, Elementary, Teen, Adult.

DSG members are welcome to attend any and all activities and meetings. Calendars listing each group activity are mailed to DSG members with pertinent details. Activity schedules are also listed in the bi-monthly *Connections* newsletter.

PARENT GROUP for parents of children of all ages

Parent information, social and support meetings are held monthly. This program provides a valuable opportunity for parents to network with each other in order to discuss common issues and inquire from parents of older children about their own child's future stages.

Meeting topics and speakers are decided upon by parents involved in this program. Topics include: behavior issues, safety, sexuality, transitions, inclusion, service providers, wills and trusts, potty training, etc.

Children are welcome to attend. Free baby-sitting is provided whenever possible.

INFANT-TODDLER GROUP for children birth to age 3

A variety of play groups for infants, toddlers and parents are held in a variety of locations and at various times.

This group provides an opportunity for children and parents to interact with each other. Families are encouraged to bring friends/ buddies and siblings.

Activities include Gymboree, music therapy and field trips. The playgroup is for socialization, stimulation and overall development of infants and toddlers.

ELEMENTARY GROUP for children ages 7-12 (approximately)

Activities for children and their parents at a variety of locations and different dates are offered.

This group provides an opportunity for children and parents to interact with each other. Families are encouraged to bring friends/buddies and siblings.

Coordinated activities include: Tunnel Town, the KC ZOO, Kaleidoscope, Horse Back Riding, Swimming, Bowling, Roller Skating, and much more.



TEEN GROUP for individuals ages 13-18 (approximately)

Opportunities for teenagers to meet independently to work on social skills and enjoy socializing with friends are offered. Activities are held at various locations and on different dates.

This group provides an opportunity for teenagers to gather without their parents. Volunteer chaperones/mentors are always present, parents are encouraged NOT to attend. Teens are encouraged to bring friends/ buddies and siblings.

Coordinated activities include: Halloween Dance, the KC ZOO, Horse Back Riding, Bowling, Roller Skating, Pottery Painting, Movie & Pizza Parties, Dance Lessons, Spring Formals and much more.

ADULT GROUP for individuals 19 years and older

Opportunities are offered for adults to meet independently in order to work on social skills and enjoy a time for socializing with friends. Activities are held at various locations and on different dates.

This group provides an opportunity for adults to gather without their parents. Volunteer chaperones/mentors are always present, parents are encouraged NOT to attend. Individuals are encouraged to bring friends/ buddies and siblings.

Coordinated activities include: Lunch & A Movie, Halloween Dance, KC ZOO, Horse Back Riding, Bowling, Roller Skating, Pottery Painting, Movie & Pizza Parties, Dance Lessons, Spring Formals and much more.

The Down Syndrome Buddy Walk



The Buddy Walk started in 1996 to provide an opportunity for the entire community to celebrate individuals with Down syndrome and their families. The mile walk and Festival take place at Arrowhead Stadium each October with members of the Chiefs' Offensive Line at hand to pass out awards and encourage walkers. The community is invited to participate in a wide array of activities, to form "Buddy Teams" and raise money in honor of an individual with Down syndrome. For information about the Buddy Walk, contact the FDFDS office at (816) 237-1200 or visit on-line at www.kcbuddywalk.org.

First Downs

for Down Syndrome



In partnership with the Kansas City Chiefs Offensive Line, First Downs for Down Syndrome raises money to help those in the community with Down syndrome. Many fundraising events are held each year including an auction, golf tournament, motorcycle ride and walk. These events, in addition to the significant generosity of area corporate sponsors, ensure consistent funding of two specific organizations, the Down Syndrome Guild and the Down Syndrome Clinic at Children's Mercy Hospital. For information about First Downs for Down Syndrome or fundraising events, contact the FDFDS office at (816) 237-1200 or visit on-line at www.fdfds.org.

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.



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 motors skills, posture, positioning for functional skills, coordination, and mobility for the child with the disability.

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

Pediatric Speech Therapy addresses the child’s complete communicative needs. This often begins with the development of non-verbal communicative skills such as attending to the speaker and the activity, taking turns, and making appropriate eye contact. It is designed to help with speech disorder, often referred to as articulation or phonological disorders—problems with the way sounds are made or how sounds are sequenced to form words; oral-motor problems resulting in difficulty producing speech sounds; and delays in feeding skills. A speech-language pathologist is a specialist in the normal development of human communication. The Certificate of Clinical Competency (CCC) assures you that a speech-language pathologist has been qualified to provide clinical services by the American Speech-Language Hearing Association. (ASHA).

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National Down Syndrome Resources



Education. Research. Advocacy.

The National Down Syndrome Society, a not-for-profit organization, was established in 1979 to promote a greater understanding of the scientific, medical, and developmental aspects of Down syndrome. Since that time, the NDSS has grown into the largest non-governmental supporter of Down syndrome-specific research in the United States. Today, the NDSS continues forward with its mission of increasing public awareness about, and discovering the underlying causes of Down syndrome through education, research, and advocacy.

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, an organization of parents and professionals, works at the national and local levels to promote the rights of and opportunities for persons with Down syndrome. It is the purpose of the NDSC to create a national climate in which all persons will recognize and embrace the value and dignity of persons with Down syndrome.

MISSION

It is the mission of the National Down Syndrome Congress to be the national advocacy organization for Down syndrome and to provide leadership in all areas of concern related to persons with Down syndrome. In that capacity, NDSC will function as a major source of support and empowerment to persons with Down syndrome and their families.

For more information, contact:

NATIONAL DOWN SYNDROME CONGRESS

1370 Center Drive, Suite 102
Atlanta, Georgia 30338
Tel. (800) 232-NDSC
www.NDSCcenter.org

The Lee Ann Britain Infant Development Center



The Lee Ann Britain Infant Development Center is a community outreach program of Shawnee Mission Medical Center. Dedicated to serving children with developmental disabilities from birth to six years of age, the Center provides a unique program that involves families in the process of therapy and education. Individualized programs are shaped for each child and family by a team of physical, occupational, and speech therapists, a developmental pediatrician, early childhood special education teachers and a music therapist.

The Britain Center staff work hand-in-hand with parents. Together they create a program to meet the individual needs of their child and family. With parents as partners, they create an environment which enables each child to become the very best they can be. They work as a team to integrate the child's goals in a multi-disciplinary therapeutic/educational framework.

Receiving children from all over the Kansas City area, the Center provides services to any child and family in need of the program regardless of their ability to pay. Children in the Britain Center are challenged by a wide range of developmental disabilities.

Services include:

- Parent Involved Infant Stimulation and Toddler Classes
- Preschool and PreKindergarten Classes with Typically Developing Peer Models
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Music Therapy
- Parent Support Groups
- Parent Education
- Collaboration with a Developmental Pediatrician
- Full Team Evaluations and Parent Conferences

LEE ANN BRITAIN INFANT DEVELOPMENT CENTER

Life Dynamics Building
Shawnee Mission Medical Center
9100 West 74th Street
Shawnee Mission, KS 66204
(913) 676-2253

The Children's SPOT



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

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

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

What families say about The Children's SPOT:

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

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

THE CHILDREN'S SPOT

4232 Wornall Road
Kansas City, MO 64111
(816) 932-3832

Children's TLC

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

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

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



CHILDREN'S TLC

3101 Main

Kansas City, MO 64111

(816) 756-0780

Northland Early Education Center

The Northland Early Education Center is a unique private not-for-profit preschool that provides a curriculum for children from birth to five to achieve their highest level of potential and independence through individualized programming for each child. This specialized programming was developed from the principal that all children have special needs and special strengths whether or not diagnosed with a disability.

The Northland Early Education Center is a very special place where every child can come to learn. Certified teachers and caretakers are assigned to age-specific groups where a low teacher-to-child ratio ensures that every child will benefit from individualized education.

NORTHLAND EARLY EDUCATION CENTER

5742 N. Broadway

Kansas City, MO 64118

(816) 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

To ensure that all children with special needs receive an education which allows them to achieve their personal goals.

MPACT is a statewide parent training, information center serving all disabilities and all ages.

- Do you have a child with special needs or a disability?
- Do you sometimes need support to cope with being a parent of a child with a disability?
- Have you ever felt alone or helpless at your child's individual education plan meeting?
- Is your child in special education?
- Do you have questions about your child's school programs?

MPACT Can help you...

- Help you talk with the schools.
- Give information on special education laws and disability resources.
- Help you be informed effective advocates for your children.
- Support from parents of children with disabilities.

Parent Support Groups are provided with technical assistance. Individual Assistance helps parents with I.E.P. development, problem solving and accessing community resources. Parent-to-Parent Networking provides emotional and moral support to families.

Volunteer Program provides the opportunity for parents to be involved in the MPACT parent center.



One West Armour Boulevard
Suite 302
Kansas City, MO 64111
(816) 531-7070

The Down Syndrome Center at Children's Mercy Hospital

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

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

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

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

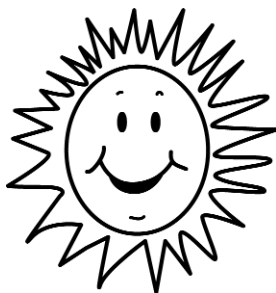


CHILDREN'S MERCY HOSPITAL

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

The Sunshine Center

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



SUNSHINE CENTER SCHOOL

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

Down Syndrome Guild Reference Library

TITLE

AUTHOR

A Parent's Guide to Down Syndrome - Toward a Brighter Future	Siegfried M. Pueschel
After the Tears	Robin Simons
An Introductory Guide for Parents - Babies With Down Syndrome	Karen Stray-Gunderson
Bittersweet BabyJolie Kanat Cara: Growing with a Retarded Child	Martha Moraghan Jablow
Charlsie's Chuckle (2 books)	Clara Widess Berkus
Children with Special Needs - Circles of Friends	Robert Perske
Communication Skills in Children with Down Syndrome	Libby Kumin, Ph.D.
Differences in Common	Marilyn Trainer
Early Use of Total Communication	B. Gibbs and A. Springer
ExtraOrdinary Children, Ordinary Lives	Reef Martin, J.D.
From the Heart	Jayne D.B. Marsh
Games to Play with Babies	Ms. Jackie Weissman
Going to the Potty	Fred Rogers
Growing up Proud	James E. Lindemann, Ph.D.
Honor Thy Son	Lou Shaw
Hope for the Families (2 books)	Robert Perske
Journey Through Grief	Elizabeth B. Farnsworth
Living with a Brother or Sister with Special Needs	Donald J. Meyer and Patricia F. Vadasy
Medical & Surgical Care for Children w/ Down Syndrome	D.C. Van Dyke, M.D.
My Brother, Matthew	Mary Thompson
New Perspectives on Down Syndrome	Siegfried M. Pueschel
On Becoming a Special Parent	Marcia Routburg
Our Brother has Down Syndrome	Shelley Cairo
Parents are Important Teachers	Annette Dollins Burkart
Raising a Handicapped Child	Charlotte Thompson, M.D.
Retarded isn't Stupid, Mom!	Sandra Z. Kaufman
Sibshops: Workshops for Siblings	Donald J. Meyer and Patricia F. Vadasy
Some Just Clap Their Hands	Margaret Mantle
Special Kids Make Special Friends	Debra Buchbinder Shalom
The Language of Toys	Sue Schwartz, Ph.D.
The Summer of the Swans	Betsy Byars
The Young Person with Down Syndrome	Siegfried M. Pueschel
Together We Can Make a Difference (.....	1995 NDSC Convention)
Uncommon Fathers	Donald J. Meyer
Where's Chimpy?	Bernice Rabe
Your Child Has a Disability	Mark L. Batshaw, M.D.

Additional items are being added to the library, so for the most current list, please contact the office @ 913-384-4848

