



down syndrome association
of greater cincinnati

*expecting an extraordinary life:
a new parent's guide to down syndrome*



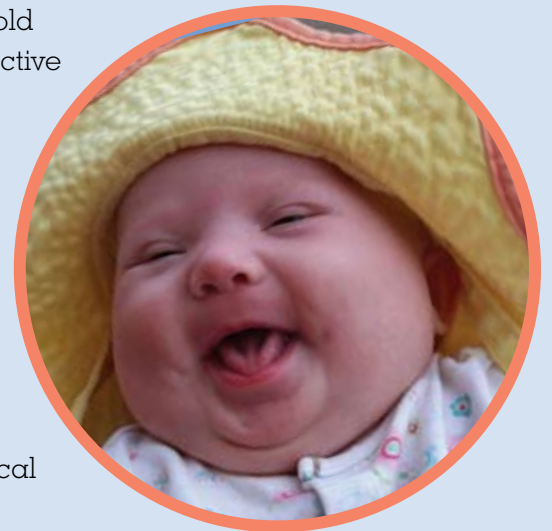
Congratulations on the birth of your new baby!

The Down Syndrome Association of Greater Cincinnati has been supporting families of children with Down syndrome since 1981. We, at the DSAGC, hope that the information in our *Expecting an Extraordinary Life: A New Parent's Guide to Down Syndrome* publication will help you to begin to understand Down syndrome and help you to see your baby's great potential.

The emotions that you are experiencing right now are probably intense. These emotions are very typical when you learn that your newborn is not what you had anticipated. Although the needs of your baby may seem overwhelming to you right now, let us reassure you that your baby is more like than unlike other babies. Your little one will bring you many happy moments and there will be many occasions for celebration.

You can count on us to help. We are here to offer you the information and support that will assist you during these early days. Based on your comfort level and individual request, we can:

- Introduce you to our Baby Matters Coordinator who has helped hundreds of families in your shoes.
- Connect you with other families with children 1-3 years old who can offer you the personal support from the perspective of someone who can easily recall the feelings and emotions that you may be experiencing.
- Be available 24 hours a day at our Support Line at 513.761.5400.
- Mail books to you from our Lending Library about your new baby free of charge.
- Connect you with other local agencies that can help you-including the Jane and Richard Thomas Center for Down Syndrome at Cincinnati Children's Hospital Medical Center, early intervention programs and others.
- Send you packets of information specific to grandparents, relatives, and a general packet about Down syndrome.
- Offer you classes that teach you about your baby.
- Send you our bimonthly newsletter, *ds press*.
- Visit you with a basket full of gifts for you and your baby.



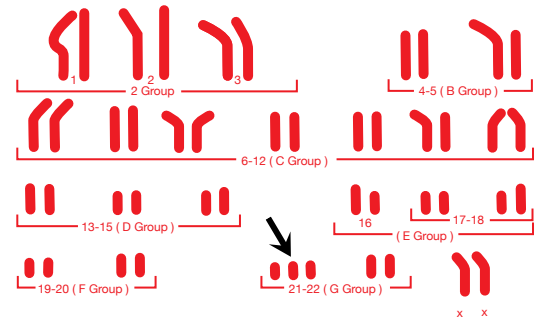
As one mother said, "The best phone call I ever made was to the DSAGC."

Please take a moment to mail or fax the enclosed Release Form so that we may contact you. Take time to get to know your baby. When you are ready, contact us. We can help.

What is Down Syndrome?

Down syndrome is a genetic condition, and is the most commonly occurring chromosomal abnormality. It occurs in 1 out of every 733 births and affects people of all races and economic levels. Typically, babies receive 23 chromosomes from their mother and 23 from their father. A baby with Down syndrome, for unknown reasons, will have three copies of the 21st chromosome instead of two. That is why Down syndrome is also called Trisomy 21. Every cell will contain 47 instead of the typical 46 chromosomes. This

extra genetic material will affect your baby's development, however, a baby has also inherited many physical and personality characteristics from you as well. A definitive diagnosis can only be made with a karyotype, which is a visual display of your baby's chromosomes. In the United States there are approximately 350,000 individuals living with Down syndrome. These individuals are active, vital members of their families and communities. A life with Down syndrome is a life well worth living.



Person First Language

A baby born with Down syndrome is not a "Down's child" or a "baby with Downs." When describing your child, it is preferred that you say, he/she is a baby with Down syndrome. Placing the person before the disability emphasizes the person first and the disability second. A child is much more than a label. Help to educate your family, friends and physicians about the preferred way to refer to your baby.



The DSAGC was formed in 1981 by a small group of parents who envisioned better opportunities and services for their children with Down syndrome. That vision expanded to become a commitment to assure that programs and services which support and educate families and professionals were offered in our community. Today the DSAGC provides over 20 programs and services to assist individuals with Down syndrome of all ages, support families and educate the community. All of our programs and services are provided free of charge.

The mission of the DSAGC is to empower individuals, educate families and enhance communities as together, we celebrate the extraordinary lives of people with Down syndrome.

DSAGC

644 Linn St. Suite 1128
Cincinnati, OH 45203
513.761.5400 • 513.761.5401 fax
toll free: 888.796.5504
www.dsagc.com

24 hour HelpLine: **513.761.5400**

Email: dsagc@dsagc.com

Hopeful Possibilities

By Zach Hart

Shortly after midnight, our beautiful boy, Isaac Matthew, was born. My wife, Tracy, had just endured a very fast breech birth. Our older son, Christopher, could hardly believe it when I announced that Isaac was here. Within minutes we were visiting as a newly expanded family.



A few hours later a nurse said she was concerned about his oxygenation and floppiness. The doctor examined him, and proclaimed all was well. Tracy told Christopher and me to go home and get some rest.

By 9 am, everything changed. Tracy called in tears saying the doctor indicated Isaac may have Down syndrome and a heart condition. It was the beginning of the longest and perhaps scariest day of our life. A steady stream of doctors and nurses came to talk to us about genetic disorders and heart defects. We were devastated and overwhelmed, but I will never forget what one doctor told us that day, "The first year will be the toughest with the medical issues, but it will get better after that. My best piece of advice is to love him and take care of him just like you have with your older son."



Many new parents of a child with Down syndrome go through an experience similar to ours - a terrifying beginning followed by an intense learning process. At the same time, many parents must deal with medical issues that take precedence over the Down syndrome diagnosis. In our case, it was heart surgery at six months. The good news is that at some point, we all become families again and find that our child is a beautiful blessing. He has helped us to be better parents to both our sons.

Isaac, now 2 years old, has taught us to live each day as it comes as he enjoys flipping through books or roughhousing with his brother. Sure, challenges still occur, but they have become much easier to face when we see the joy of each day as Isaac does.

Raising any child is not easy, but raising a child with special needs enhances our strength of character and the quality of our parenting. At the same time, there is so much hope and possibility for children with Down syndrome today - that hope in possibilities will carry you through this journey. Enjoy every moment of watching your child grow up.

"All my friends wanted to help but my Parent Mentor really understood what I was going through."

A new parent

Welcome to Holland

By Emily Perl Kingsley

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

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. You must learn a whole new language. You will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. For the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very 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.



Getting To Know Zoe

By Jennie Mejan

Besides a Prince Charming of a husband, I've wanted a daughter since I was eleven years old. Twenty years and two sons later, my dearest wish was finally granted. The tremendous joy I felt turned out to be short lived. When my baby girl, Zoe, was eight hours old they gave me her diagnosis of Down syndrome. I was completely devastated. I truly believed that my family's lives were ruined, not just for the moment, but permanently.

It felt to me as if someone had died. I mourned the girl I had always imagined having. I kept wishing we could just try again and pictured a big bubble gum machine full of babies in pink and blue plastic balls. I wasn't the sort of mom it seemed this baby would need.

I'm sharing this with you because I've learned over the past three years that this is how a lot of new mothers feel when they hear the diagnosis of Down syndrome. It would have been priceless to me to have had a better understanding in those first weeks. Something to fuel the worries into hope and rekindle the excitement I had about nurturing a tiny life. Like myself, you may not even realize there is much more to your baby's life. Here are things I have learned while getting to know Zoe.

She can learn...a lot! I remember telling my boys that their new sister wouldn't be able to learn like they do. This is a common misconception about children with Down syndrome. Overall she is about a year behind in her abilities, but she has so many important skills. She can match shapes, use two word phrases, sing songs and pretend play with her dolls.

Children with Down syndrome go to school, read, have jobs, drive, and become valuable members of society. They are just like our typical kids. The difference I've seen with Zoe is that the pace is slower, but I feel like she is hitting all of the same key points that the boys accomplished and it is a thrill to succeed with her.

She was a real baby! Somehow I thought that Zoe was going to rob me of the joys of having a baby in the house. I learned that she was a 100% real baby! She was cuddly and good for long naps on the couch. She made delighted baby noises when she saw herself in her crib mirror. Great victories came in the form of her first turn over, her first crawl, and her first game of peek-a-boo. It was all there! Her low muscle tone made these milestones come slower than they did for my boys, but she made steady progress toward them until reaching them.

She is a best friend, not a burden. She is the lightest, pinkest joy in our house. She has an incredibly sharp sense of humor and a sweet magnetism that I've often wished I could copy in my own personality. She learns routines and has recently started feeding herself. She does empty her dresser drawers and pinch her brothers through the back of their dining room chairs, but I don't think this is due to her diagnosis!



She has not been made fun of or mistreated.

Zoe is a magnet. I am better connected to the world because of her power to draw people to her with a big smile on their face. She is friendly, but strongly independent, and I am sure she will handle conflicts as she develops in the same way that my boys do.

She has feelings! One idea I had was that Zoe wouldn't have the varied feelings that I have and I wouldn't be able to share with her on this level. I have been delighted with her proving me wrong. She lets me know when she is worried, afraid, hurt, tickled, or wants to be in front on a walk. She is definitely pleasurable company.

My goal is not to sell you on Down syndrome. I just want you to see a progression that I have experienced and heard from every parent I've met with a child with Down syndrome. It starts off being the most disappointing and petrifying news you've ever heard. It ends with a limitless love and appreciation for this fun and happy soul. When Zoe was one and a half, my then eight year old son asked me what the chances were that Zoe would have Down syndrome when she was born. I said that at my age the chances were 1 in 1000. With wide eyes he said, "Man! We sure got lucky!" I couldn't have said it better.



"The DSAGC inspired us to have faith in our child's ability and to look beyond the disability."

Parent of a nine-year-old daughter



People With Down Syndrome Offer Potential

By Violette Skavlem as imagined by her mother Melissa

My name is Violette Skavlem. Mommy and Daddy were concerned at first when the doctor said the words "Your daughter is beautiful, and wonderful and perfect, and she has Down syndrome."



When they grew up, conventional wisdom focused on the cognitive impairment that occurs with Down syndrome. People with Down syndrome were in the "special education" classes at schools, graduated to special homes far apart from the rest of society, and typically died young. Today the outlook for people like me with Down syndrome is much more optimistic.

Much research has been done into helping people with Down syndrome to speak, read, do mathematics and write; and I will do it. I won't learn the same way other people learn; but I will learn. I will go to a typical school; I will be in class with typical kids. In school, the kids will get to know me and they won't be afraid of my differences – the fact that I have Down syndrome will be just one aspect of the person they will know.

Mommy and Daddy are big believers that everyone who is able-bodied should hold a job and contribute to society. I have an able body, and thanks to many strides that have been made in treating people with Down syndrome, my life expectancy is well beyond my 50s. I will lead a productive life.

Mommy jokes that in the last several months she has gotten her "Masters Degree in Down syndrome," based on all the research she has done. She realizes how ignorant she was before she had me. My life will be one well worth living; though I may learn things and achieve things differently than other people, she and Daddy have great reason to be optimistic about my future.

The first generation of children with Down syndrome who have had the benefit of early intervention programs are doing wonderful things. Young people with Down syndrome going to college, owning homes, driving cars, holding jobs, getting married, using computers, becoming artists, swimming Lake Tahoe, traveling around the world and even skydiving! What happens when expectations are set high is amazing. I know no limits right now. I'm a small person, but I can and will make an impact. It may be big, it may be small, but I will make my own unique contribution to this world, the same as you.

"When Grace was born I didn't know where to turn. Although I was given tremendous support by my friends, family and church, they didn't know a thing about Down syndrome. I called the DSAGC and they made all the difference."

- A new father

My Sister Nora

By Rachel Donohue

My name is Rachel and I am 11 years old. My sister, Nora, is 2 years old and has Down syndrome. She's the cutest baby in the world. You always wonder, "What would we do without her?" She's the most playful baby. We sit around and make her car go, and she says, "Vroom, Vroom."

Nora loves to play with stuffed animals and to watch Barney. She can do the hand motions to the songs. I'm a cheerleader and when I say the cheer she moves her arms like me.

Nora has been sick about 4 times, and 3 of those times she was in the hospital. When Nora went to the hospital, I was so scared because she was only a baby. I knew it meant that she must be really sick. She's my baby sister and when you look at her you wonder what she feels like. When she was better, all I could do was hug and kiss her.

I would say that my relationship with Nora is awesome! I will do anything for her. When I feel sad or unhappy, Nora always will brighten my day. You look at her and just smile. When she was first born I wasn't sure what to think. When my Mom told me she had Down syndrome I thought, "OK. Kids at my school have it and it doesn't bother me." But it is totally different when your own sister has Down syndrome. I know sometimes people use the word "retarded" in a bad way. I get so angry when I hear that and I always tell people not to use that word. They usually don't mean it in a bad way, but it is still mean. I love my sister with all my heart and I wouldn't give her up for anything. Nora is the sweetest most beautiful person in the world!



"Siblings will be in the lives of their brothers and sisters who have disabilities longer than anyone. Their relationship may span 60-80 years. Because of this siblings will have an enormous influence on their brothers and sisters."

Don Meyer, Director, Sibling Support Project, Seattle



Parents report that children who have a sibling with Down syndrome generally grow up to be very caring individuals who are accepting and appreciative of differences in others. Many go on to choose helping professions in adulthood such as social services, education or healthcare due to the loving bond formed with their sibling.

A New Song

Parenting my son with Down syndrome isn't a trial; it's a joy

By Jennifer Graf Groneberg

I once read that coyotes howl and yelp to keep in touch with each other, and that their songs are a celebration. I am always surprised when I hear them, songs that are beautiful and chilling and sad and exhilarating all at once. The sound resonates deep within me. Coyote songs remind me of listening to opera — I don't understand it, but I do.

At the end of each summer, my friend Sarah throws a deck party. Early in the night, I find myself speaking with a woman I know only a little bit. She asks what I have been up to, and I tell her about Avery. As soon as I reach the part about Down syndrome she gets what I've come to think of as That Look. It's as if she slipped on a Halloween mask, behind which she retreats as she tries to think of something to say. The woman I was speaking with is gone, and in her place is the yellow smiley-face icon. I instantly feel bad for her. I see that she's struggling. I intervene. "It's okay," I say.

"You must worry," she says, after a moment. "I mean, every parent worries. You must worry."

Her comment is a new one, an observation I had not heard before. Usually it's "I'm sorry" or "You're so brave" or "I couldn't do what you do" or my least favorite, "God only gives those children to people who can handle them."

I dislike these remarks for reasons that are obvious to me — I am not sorry, I am not brave, and I don't do anything that any other parent wouldn't do. The last one, in particular, implies that my son is some sort of punishment, or a trial. I don't think of Avery as either. No. I am not worried about Avery.

I worry about my eldest son, Carter — he is gentle and sensitive, which are qualities that I respect but that cause me motherly concern. Sometimes I wish I could teach him to protect himself more, to take his heart from his sleeve and wear it inside, safely shielded by his rib cage. My youngest boy, Bennett, is fierce, and while I admire his daring, it also gives me pause — how will we make it through the teenage years? But Avery? I worry the least about Avery.

One evening, I am reading a book on the couch. Carter wants me to get him a glass of milk, which he can do himself, but he wants me to do it, to stop reading and pay attention to him. I mumble something about "in a minute," vaguely aware that I am raising children who are jealous of their mama's time with books. Bennett is next, also wanting milk, a copycat of his older brother. In fact, I suspect there might be collusion involved with this second request. "One moment," I say, holding up my index finger, still reading. I am aware that Avery has pulled up next to me. He sits beside me. I am still reading. He sits quietly. I am transfixed, carried away from my life by the sentences of another woman, in another place, at another time.



Carter and Bennett have moved on and forgotten about me, about the milk. Avery strokes my hair. He is there. Avery is still beside me. He is wiggling, or something. I am busy. He is wiggling again. I turn the page. He reaches up, places each of his two small hands on my face and gently turns it from the page toward him, so that we are eye to eye. Then he signs "Milk." He wants milk, too. Where the other boys have given up, Avery has stuck with it. In his single-mindedness, in his desire, in his knowledge of his desire, he has persevered. In his own way. In his own time. Which, as it turns out, is the right time. Time enough for me to lift my head out of my book and give my attention to my children, who, after all, have been very patient. Especially Avery. This is why I do not worry about him. Avery will find his way.

So I worry about a lot of things, but not Avery. I try to explain this realization to the woman, but the point is lost. Her genuine curiosity is gone and I am talking to the smiley-face again. It is a party, after all. The sun is warm and glowing and the stars are just beginning to come out.

The night is filled with the sound of women's voices, and laughter and music. In the midst of these women, I think of the coyotes. Calling to each other. Finding each other. Belonging. My song is the same as the other women's, mostly. But toward the end, there is a new part. It is a refrain in the key of Avery. I am not sorry. I am not afraid. I like it. It is strange and beautiful all at once, and if you let yourself listen, you might not think you understand it, but you will.

Babytalk,
September 2007



I Can Do Anything

By Bob Effler

My name is Bob Effler. I'm 31 years old. In a few years, I want to move out into an apartment by myself or with a roommate. I want to see if I can be more independent and do stuff on my own.

I work at a Medical Center in the therapy department and I am great at what I do. I straighten up the gym area and get ice and hot packs for patients. I like my job and I like working with the therapists and patients. In my spare time, I like to listen to country music. I even like to write stories about country music and make videos with my friends on my computer.

I look up lyrics and listen to clips of songs. I also look up biographies of actors and actresses. I collect DVDs of old TV shows and have over 300 country CDs.

On Sunday I go to church. We talk about gospel readings for upcoming services, so we understand what the priest is talking about.

I graduated from high school in 1995. I liked my school because it was a big school. I took both special education and regular classes, like drama, typing, and computer. I learned how to work with spreadsheets. My favorite subjects were English and History. In history we learned about things like deals with different presidents and black history.

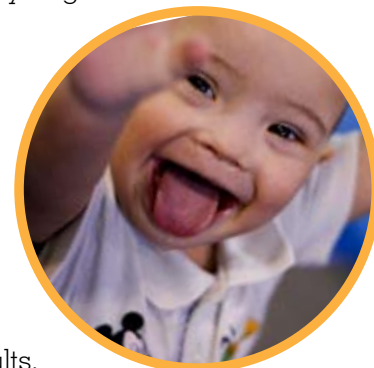
Let me tell you about some people in my life. Tracey is my best friend. We talk on the phone, hang out together and go out to eat. I have known her for 14 years through school. My friend Mike used to swim with me at Special Olympics. I also have a lot of friends at work.

I am passionate about society today and making a difference. I may not be fast but that's ok with me. I may do stuff a little slower but I don't mind. When my Mom had me in 1975, the doctor came in and told her I would never do much of anything. I proved him wrong, because I can do anything I want to.



Next Steps.... Where Do We Go From Here?

- Get to know your baby and welcome him/her into your family.
- Contact the Down Syndrome Association of Greater Cincinnati. We can help you get started with early intervention services and connected with other families.
- Make sure your baby has been scheduled for an echocardiogram. This is usually performed at Children's Hospital.
- Schedule an appointment with your pediatrician to discuss any medical concerns.
- Consider making an appointment with the Jane and Richard Thomas Down Syndrome at Children's Hospital Medical Center for a developmental assessment.
- You may want to meet with a genetic counselor to discuss chromosomal test results.



What Does the Future Hold For My Baby?

Since our organization was founded in 1981, tremendous advances have been made to improve the lives of our children in many areas including education, inclusion, social acceptance, healthcare, employment, housing and opportunities for a fulfilling life. While there is still much to be done, we are encouraged as we look to the bright future that lies ahead for babies born with Down syndrome today.

Improved Access to Medical Care - It is now routine for a baby born with Down syndrome to receive an echocardiogram shortly after birth. This painless procedure allows the doctor to determine if the baby's heart is functioning well. This is very important since 40% of babies born with Down syndrome will have a heart defect. The good news is that these defects are extremely treatable and the prognosis is very good. To assist your baby's doctor, we are happy to provide you with a Pediatrician Packet which contains the Healthcare Guidelines for Individuals with Down Syndrome. Simply contact our office and we can assist you.

Improved Educational Opportunities - In 1975, Congress enacted the Education for All Handicapped Children Act or Individuals with Disabilities Education Act (IDEA). Prior to that, schools were not legally responsible to educate our children. In addition, federal law mandates that all of our children have access to early intervention programs. Many of our children are educated alongside their typical peers within their public schools and provided with special education services. Students are graduating from high school and some are even pursuing post-secondary opportunities. The DSAGC is actively involved in assisting teachers in their efforts to maintain inclusive classrooms.

Increased Independence - The benefits of improved healthcare and enriching educational opportunities have resulted in people with Down syndrome leading full lives as contributing members of society. As a result, people born today with Down syndrome have a life expectancy of over 55 years. Many hold jobs, pay taxes and are active members of their communities. Today, the future is bright for your baby because of all the wonderful families and professionals who have helped pave the way.

No one can know for certain what the future holds for any baby, but the staff and families of the DSAGC are here to help your baby achieve his /her own unique potential every step of the way.



Breastfeeding

Breast milk helps protect your baby from infection as it provides immune protection not found in formula. It is also easier to digest making stool easy to pass which may be helpful if your baby has a bowel problem. It will stimulate mouth and tongue coordination which may improve speech skills.



However, it can also provide challenges due to your baby's low muscle tone, weaker reflexes and tendency to tire easily. Many mothers have successfully breastfed their infants with Down syndrome. If you find you are having difficulty we can connect you with another mother or professional who can assist you.

Feed often - 8 or more times in 24 hours including some during the night. You may need to wake baby to feed. Look for mouth or hand movement which usually means the infant is in a lighter sleep and will wake more easily. A baby with low muscle tone usually sucks better when the head and bottom are level, or close to it. Support your baby using pillows on your lap. If baby arches his body, try to hold the body flexed, with knees bent and spine rounded. Swaddling in a blanket in a flexed position can also help. Other helpful positions are modified cradle hold, football hold or dancer-hand position. Please refer to photos on website www.childrensmn.org and search for Down syndrome.

Here are some things to watch for in the first week after birth:

Days after birth	Wet diapers (at least this many in 24 hrs)	Stool color	Number of stools (at least this many in 24 hrs)
1st day	1	Greenish-black	
2nd day	2	Greenish-black	1- 2 stools
3rd day	3	Yellow, softer	2-4 stools
4th day	4	Yellow, softer	3-5 stools
5th day	5	Yellow, soft, seedy	3-5 stools



Take care of yourself. Patience is important. If you are comfortable and well supported physically and emotionally, you will have more energy for baby.

We value the right of every mother to choose which method of nursing is best for her and her baby whether it be breastfeeding, bottle feeding or pumping breast milk. The DSAGC is here to provide support and information to all mothers.

Adapted from information provided by Children's Hospitals and Clinics of MN, Minneapolis and St. Paul.

Early Intervention Services

All babies experience rapid development in the first three years of life. They achieve many milestones in the areas of physical, cognitive, language and social development. Every baby is unique, but typically, babies born with Down syndrome face delays in certain areas of development. Therefore, we believe it is very beneficial for babies to receive early intervention (EI) services so that some of these delays can be identified and addressed at a very early age.

The principle of early intervention is to provide appropriate therapies for children with disabilities, to minimize delays and maximize their development. The most common services for babies with Down syndrome are physical therapy (PT), speech and language therapy and occupational therapy (OT).

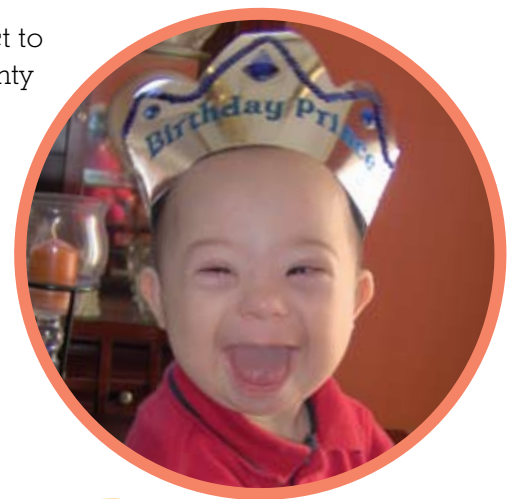
These services are provided by licensed therapists and teachers in your home, school or hospital setting. These professionals will help you create an Individual Family Services Plan (IFSP) which will outline the goals for your child.

The Early Matters Coordinator at the DSAGC can help you connect to the proper agency to help you begin this process. Each state and county has their own system of early intervention services.

“We encourage you to view your child as an individual and put no limits on the possibilities for his/her future.”

Dr. Bonnie Patterson, CCHMC

In Ohio you may receive EI services from Help Me Grow or PING. In Indiana and Kentucky this program is known as First Steps. Please contact our offices for more information.



DSAGC Programs for New Families

Baby Matters — This program was designed to meet the needs of our newest families - those with children from newborn to age three. We meet monthly in the evening and provide a guest speaker to address a topic relevant to your needs such as: speech and communication development, feeding issues, or gross motor development. These gatherings also provide a great opportunity for families to network and form relationships with one another. Please contact our offices for more information and to receive our schedule of upcoming meetings.

Parent Support Group — Four times a year you will have an opportunity to gather with other parents of young children with Down syndrome and enjoy a meal while sharing your thoughts on raising a child with a disability.

Parent To Parent Mentoring Program — As you begin caring for your new baby, you may find it helpful to be in contact with another family of a young child with Down syndrome. Having just experienced many of the emotions you are now facing, they may be able to offer a listening ear and kind words of support and understanding. Your parent mentor can also help you make connections within your community to other families. They can answer many of your questions and be a great resource for you. If you have not yet been matched with a parent mentor, please contact our offices at 513.761.5400.



Medical Concerns in Newborns with Down Syndrome

Although babies born with Down syndrome may be as healthy as any newborn, they are at a higher risk for developing certain medical problems. Medical advances in the care of our babies have resulted in increased life expectancy while living full and active lives. Early detection and treatment of these medical problems can help your baby get off to a good start.

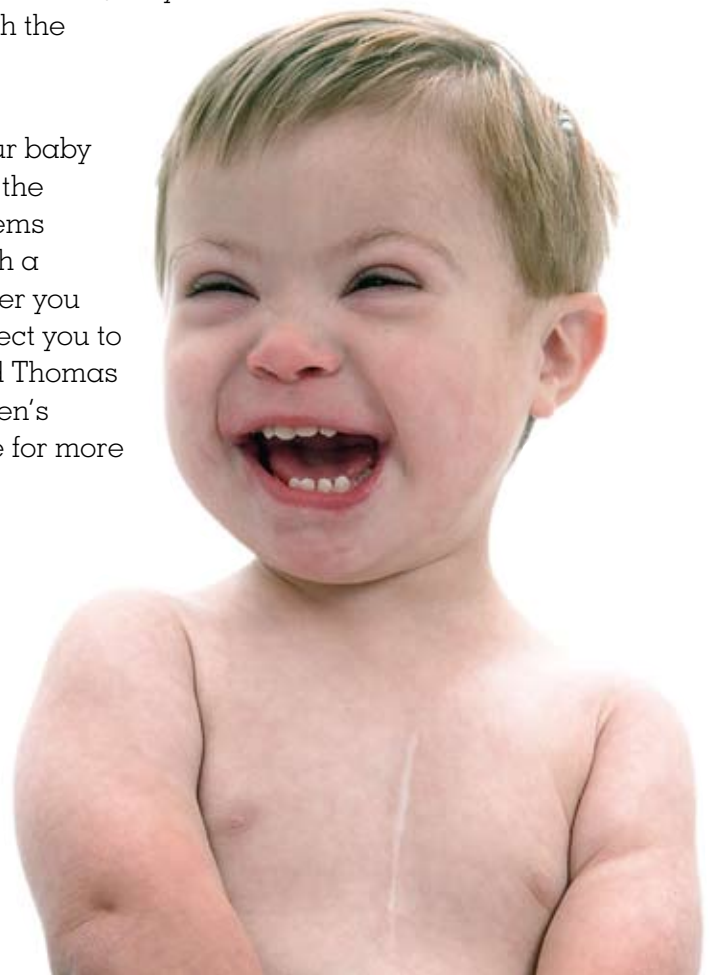
Heart defects - Almost 40% of babies with Down syndrome will be born with a congenital heart defect. Sometimes these problems will resolve on their own. In some cases, they may require surgery. Your pediatrician will examine your baby and refer you to a pediatric cardiologist if necessary. Today, the prognosis is very good for babies who are born with this condition.



Gastrointestinal problems - Babies born with Down syndrome have a 10 - 12% chance of having a congenital malformation of their digestive system. Symptoms of this type of problem include vomiting, poor feeding, swollen abdomen, lack of stool or pneumonia. These problems can be successfully treated surgically, however, it is important to recognize these symptoms promptly.

Respiratory problems - Your pediatrician will check your baby for signs of respiratory problems such as reflux, bronchitis, or pneumonia. Hypotonia, or low muscle tone, so often seen in infants with Down syndrome, may contribute to some of the problems associated with the respiratory system.

It is important to remember that not all babies experience these health concerns. However, if your baby has been diagnosed with any of these conditions, the DSAGC is here to help you. Although these problems may seem overwhelming, we can connect you with a parent who has been in your situation and can offer you reassurance and support. We can also help connect you to the medical professionals at the Jane and Richard Thomas Center for Down Syndrome and Cincinnati Children's Hospital Medical Center. Please contact our office for more information.



Thoughts from Grandparents

- Just as we did for his sister Hannah, all eight of us gathered in the hospital waiting room the night Ryan was born. Finally, my son came out to tell us that it was a boy. As my son gave us all the details, he began to weep as he told us that the doctors thought that Ryan had Down syndrome. Although I felt tremendous concern for my son and his wife, I also knew that this was another beautiful grandchild to love, care for and play with.
- When our grandson Drew was born, we knew nothing about Down syndrome. I called the Down Syndrome Association and talked to another grandmother who really helped us to get through those first difficult days. Although Drew did have some early health problems, he is now a happy and healthy little boy who loves to play with his twin brother and has become an accomplished swimmer. He has been such a positive addition to our lives and brought us so much joy.
- When Ryan was born, we all expected a healthy little baby boy. We were shocked to learn that not only did he have Down syndrome but he also had Hirschsprungs disease and a heart defect. That first year was very difficult for all of us. But eventually, as each of Ryan's health issues were treated, my daughter and her husband found they could go on with their lives and just do things a little differently with Ryan. Today, he is a happy little boy in every sense of the word and enjoys all the things that every little boy enjoys.



Grandparent Support

Both parents and grandparents share similar reactions to a diagnosis of Down syndrome. The grandparent's reaction, however, can be doubled - they are concerned not only for their newborn grandchild but also for their own child as well. Many families have told us how helpful our Grandparent Group was in the early days following the birth. Contact our offices to be connected to another grandparent in your area. In addition, we have two groups of grandparents who meet quarterly to enjoy a dinner and share photos, joys and experiences of grandparenting a baby with Down syndrome.



Resources

Books

All of the following resources are available in our Lending Library. We continually update our collection of books to provide you with the most current and accurate information. Please visit our website at www.dsagc.com for more information. Use our search box to find the information you are looking for or contact us for assistance.

A Parent's Guide to Down Syndrome: Toward a Brighter Future

Sigfried Pueschel (2000)

This book discusses a wide range of topics for parents including IDEA, new developments in the biomedical field, what to expect as your child grows, what to hope for in terms of health, schooling, and life in the community.

Babies with Down Syndrome: A New Parent's Guide

Karen Stray-Gundersen (1995)

Thousands of new parents and professionals have turned to this book for their first source of information on Down syndrome.

Also available in Español

A free copy of this book is given to all new parents in the DSAGC area.

Common Threads: Celebrating Life with Down Syndrome

Cynthia Kidder and Brian Skotko (2001)

This book is an essay and photographic celebration of inspirational accomplishments of people of all ages with Down syndrome. Throughout the book there is a common thread - the thread of belief that similarities outweigh the differences between children with Down syndrome and their peers.

Early Communication Skills for Children with Down Syndrome

Libby Kumin (2003)

Dr. Kumin shares her expertise with parents and speech-language pathologists to help them maximize the communication development of young children. It focuses on speech and language development from birth through the stage of making 3-word phrases.

Expecting Adam: A True Story of Birth, Rebirth and Everyday Magic

Martha Beck (1999)

By the time Adam was born, Martha and John were propelled into a world in which they were forced to redefine everything of value to them, put all their faith in miracles, and trust that they could fly without a net. And it worked.

Gifts

Karen Lynard Soper (Ed) (2007)

In this candid and poignant collection of personal stories, sixty-three mothers describe the gifts of respect, strength, delight, perspective, and love which their child with Down syndrome has brought into their lives. Their diverse experiences point to a common truth: the life of a child with Down syndrome is something to celebrate.

Living with a Brother or Sister with Down Syndrome

Don Meyer (1996)

This book focuses on the intensity of emotions that brothers and sisters may experience when they have a sibling with special needs. This book is for parents and siblings as well as professionals.

Married with Special Needs Children

Laura Marshak and Fran Pollock Prezant (2007)

This book is for parents to examine the stress that is often placed upon a marriage when a couple has a child with a disability. In this practical, supportive guide, the authors draw on their experience in marital counseling and feedback from hundreds of parents who share their solutions and secrets for a healthy relationship.

Medical and Surgical Care for Children with Down Syndrome: A Guide for Parents

D.C. Van Dyke, P. Mattheis, S.S. Eberly, & J. Williams (Eds) (1995)

This book is designed to give parents a complete and easy-to-understand overview of specific medical conditions that are more common among children with Down syndrome. This guide also includes sections on preventative care, anesthesia and surgical concerns, planning for health care in adulthood, and a resource guide for resilient families.

Road Map to Holland

Jennifer Graf Groneberg (2008)

Personal account of a mother's journey following the birth of twin sons, one of whom has Down syndrome.

Uncommon Fathers: Reflections on Raising a Child with a Disability

Don Meyer (Ed) (1995)

A collection of essays by fathers who were asked to reflect and write about the life-altering experience of having a child with a disability. Nineteen fathers have taken an introspective and honest look at this deeply emotional subject, offering a seldom-heard perspective on raising children with special needs.

Understanding Down Syndrome: An Introduction for Parents

Cliff Cunningham (1996)

Also available in Español

A comprehensive book for parents of babies and young children. The author provides answers to the countless questions directed to him during his twenty years' involvement with individuals with Down syndrome and their families.

You Will Dream New Dreams

Stanley D. Klein, Ph.D. and Kim Schive (2001)

Real-life fathers and mothers of children with special needs speak from the heart on how they mourned for the child of their dreams, experienced the disappointment of letting go of certain expectations and found the unexpected joy of discovering new dreams.

Books for Siblings

The Best Worst Brother

Stephanie Stuve-Bodeen

An endearing and realistic look at how a relationship evolves between a typically developing older sister and her younger brother with a developmental disability. It also shows how sign language can help a child that acquires speech more slowly. As Emma is pleased to discover, Isaac can learn to sign, he just learns when he's ready.

Reading Level Ages 4-8

We'll Paint the Octopus Red

Stephanie Stuve-Bodeen

When baby Isaac is born, the family is confronted with the fact that he has Down syndrome. Father explains that Isaac will still be able to do all of the things that big sister Emma has thought of; he will just do them at a slower pace. The story ends on a high note with an excited Emma and her father visiting Isaac and her mother in the hospital.

Reading Level Ages 4-8

Our Brother Has Down Syndrome

Shelley Cairo

Tara and Jasmine tell about their little brother Jai, who has Down syndrome. The text stresses the ways in which he is like all children, although he needs extra help to walk, use a spoon, stack blocks, etc.

Reading Level Ages 4-8

Big Brother Dustin

Alden Carter

Dustin, a young boy with Down syndrome, is excited when he learns that his mother is going to have a baby.

Reading Level Ages 4-8

Living With a Brother or Sister with Special Needs

Don Meyer

This book lends the voice of hope, confidence and clarity to the experiences of many siblings of people with special needs. It not only sheds light on many questions that often crop up, it also provides a safe forum to explore any and all sibling related issues.

Reading Level Ages 4-8

Views From Our Shoes – Growing Up with a Brother or Sister with Special Needs

Donald Meyer

A collection of 45 brief essays by children and young adults who have a sibling with special needs, ranging from mental retardation through a number of rare syndromes. The writings are arranged in chronological order, from that of a 4 year old to an 18 year old.

Reading Level Ages 8 through Young Adult

DVD

Emma's Gifts

Endless Horizon Productions (2006)

This documentary follows one family's journey through the preschool years and illustrates the importance of advocating for your child's rights and the importance of early intervention.

Down Syndrome - The First 18 Months

Will Schermerhorn (2003)

Heartwarming footage of young children with Down syndrome is interspersed with interviews with parents and experts. Veteran parents share their joys and concerns on raising a baby with Down syndrome. An inspiring and educational video for parents who want to know more, and an excellent tool for support groups, medical professionals, and libraries to support families.

Discovery - Pathways to Better Speech for Children with Down Syndrome

Will Schermerhorn (2005)

This invaluable resource offers practical advice, examples, and expertise for parents and professionals to follow as they help children with Down syndrome from infancy to age seven become the best talkers they can be.

What Did You Say? A Guide to Speech Intelligibility

Libby Kumin (2006)

This informative film looks at the importance of speech intelligibility (clear speech) for people with Down syndrome. Featuring Dr. Kumin and dozens of children and young adults, it explains the various factors underlying speech intelligibility problems common in Down syndrome. It helps parents and SLP's pinpoint specific problem areas, allowing them to devise a more effective therapy plan for clear, understandable speech.

Websites

www.ds-health.com — Created by pediatrician and parent of a child with Down syndrome, Dr. Len Leshin.

www.ndss.org — The National Down Syndrome Society was founded in 1979 to promote a greater understanding of the scientific, medical and developmental aspects of Down syndrome.

www.ndscenter.org — The National Down Syndrome Congress was formed in 1972 to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

www.peakparent.org — The mission of PEAK Parent Center is to provide training, information and technical assistance to equip families of children birth through twenty-six including all disability conditions with strategies to advocate successfully for their children.

www.cchmc.org — Cincinnati Children's Hospital Medical Center is dedicated to providing the highest level of pediatric care. As Greater Cincinnati's only pediatric hospital, Cincinnati Children's is committed to bringing the very best medical care to children in our community.

CCHMC is also home to the Jane and Richard Thomas Center for Down Syndrome <http://www.cincinnatichildrens.org/svc/alpha/d/disabilities/clinical/down-syndrome-center.htm> which offers interdisciplinary evaluations and interventions for infants, children, adolescents and young adults.

Formulario Para Referir A Futuros Padres de Familia a DSAGC

Me gustaría recibir una llamada telefónica de DSAGC Si No

Me gustaría recibir una visita de DSAGC y una canasta de bienvenida Si No

Me gustaría recibir información sobre el síndrome de Down Si No

Favor incluir a nuestra familia en las listas de correo de DSAGC Si No

Nombre: _____

Fecha prevista para el nacimiento: _____

Dirección: _____

Ciudad, Estado, Código Postal: _____

Teléfono de la Casa: _____ Celular: _____

Teléfono del trabajo: _____ Otro teléfono: _____

Correo electrónico: _____

Autorizo _____

(Nombre del hospital o centro médico) para entregar esta información a DSAGC

Firma: _____

Fecha: _____

New and Expectant Parent Referral Form

I would welcome a phone call from the DSAGC	Yes	No
I would welcome a visit from the DSAGC along with a welcome basket	Yes	No
Please send me Information Pockets	Yes	No
Please include our family on the DSAGC mailing list and email list	Yes	No

Name: _____

Due Date or Child's Date of Birth: _____

Address: _____

City, State and Zip: _____

Home Phone: _____ Call Phone: _____

Work Phone: _____ Other: _____

Email Address: _____

I grant permission to _____
(Name of hospital or physician's office) to release this information to the DSAGC.

Signature: _____ Date: _____



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644 Linn Street • Suite 1128 • Cincinnati, OH 45203
P: 513.761.5400 • F: 513.761.5401
EMail: dsagc@dsagc.com • Web Site: www.dsagc.com

The Down Syndrome Association of Greater Cincinnati

We are happy to offer new parents and baby the following gifts at no charge:

"Babies with Down Syndrome: A New Parent's Guide"

Praised as the finest book ever written for parents of a baby with Down syndrome. This book contains current, complete and compassionate information written by professionals and parents.

"The Journey Ahead...Consider the Possibilities"

A DVD for new parents created by the Down Syndrome Association of Greater Cincinnati as our gift to you.

"I Can, Can You?"

A board book containing photos of children with Down syndrome for your baby.



In addition, we offer packets of information for Friends/Relatives as well as Grandparents.

Our Early Matters Coordinator is available to meet with you and help you get started making connections within the community. Please contact our office at 513.761.5400 or by email at dsagc@dsagc.com.

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**"Their children will do everything.
Perhaps not quickly. Perhaps not by
the book...What if they kept their
expectations but erased the time line?
What harm could it do? Why not try?"**

Memory Keeper's Daughter by Kim Edwards



down syndrome association
of greater cincinnati

644 Linn Street • Suite 1128 • Cincinnati, OH 45203

P: 513.761.5400 • F: 513.761.5401

Email: dsagc@dsagc.com • Web Site: www.dsagc.com

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