

a new parent's guide to
DOWN SYNDROME



Congratulations on your new baby!

A baby is a baby first.

The Down Syndrome Association of Greater Cincinnati has been supporting families of children with Down syndrome since 1981. Our hope is that the information in our ***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 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 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 Early Matters Coordinator who has helped hundreds of families in your shoes.
- Connect you with other families with children from birth - 5 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.
- 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 other state & county programs.
- Send you packets of information specific to grandparents, relatives, and a general packet about Down syndrome.
- Send you our monthly e-newsletter and quarterly magazine, Ds Press.
- Visit with you and bring a basket full of gifts for you and your baby.



"The best phone call I ever made was to the Down Syndrome Association of Greater Cincinnati."

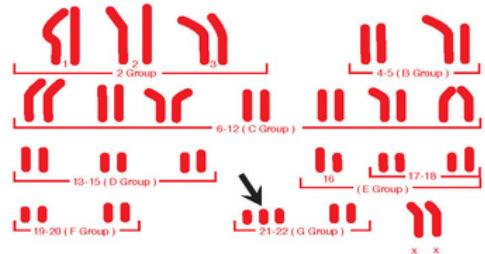
Parent

Take time to get to know your baby. When you are ready, contact us.

What is Down syndrome?

A baby with Down syndrome, for unknown reasons, will have three copies of the 21st chromosome instead of two.

Down syndrome is a genetic condition, and is the most commonly occurring chromosomal abnormality. It occurs in 1 out of every 691 births and affects people of all races and economic levels. Typically, babies receive 23 chromosomes from each biological parent. 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.



People-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". An example is: "Charlie has Down syndrome." NOT "Charlie is that Down's kid."

People-First Language emphasizes the person, not the disability. By placing the person first, the disability is no longer the primary, defining characteristic of an individual, but one of several aspects of the whole person. A child is much more than a label. People-First Language is an objective way of acknowledging, communicating, and reporting on disabilities. It eliminates generalizations and stereotypes by focusing on the person rather than the disability. People-First Language puts the person before the disability, and describes what a person has, not who a person is. Using a diagnosis as a defining characteristic reflects prejudice, and also robs the person of the opportunity to define him/herself.

Please help to educate your family, friends and physicians about the preferred way to refer to your baby.



My Sister Nora

By Rachel Donohue

My name is Rachel, and I am the big sister of Nora, who 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 four times, and three 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!



If you have other children and you are interested in receiving a "Sibling Packet", please request this from the Early Matters Coordinator. This packet will give you information about the appropriate steps and conversations to have with your other children about Down syndrome at the appropriate age. There is also information in this packet about books that may help reinforce the discussion.

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"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

I Can Do Anything

By Bob Effler

My name is Bob Effler. 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.**



Our Trinity

By The Wilson Family

Our daughter, Trinity, is 8 years old. When she enters a room, she will take all the attention! She is friendly, sweet, caring, funny, beautiful, and smart. We have been blessed to be part of the Down Syndrome Association of Greater Cincinnati since she was born. From day one, the DSAGC has been supportive and encouraging to all families - no matter what age, they've got you covered!

The DSAGC has been a huge influence on our family by educating and motivating us to advocate for our daughter in the community. Trinity can read, sing, swim, ride her scooter, play soccer, dance, participate in Girl Scouts, and so much more. The DSAGC programs have provided Trinity with countless social interactions and endless support for parents. The DSAGC Community Groups have provided us an opportunity to network with other families. We can share common interests, concerns, challenges, and information. At times, they have been a lifeline and provided with friendships for life.

Our hope for Trinity's future is to educate her family, friends, and our community about Down syndrome. We want to teach them to be open-minded, patient, respectful, and embrace differences. We want our daughter to continue being fearless and independent.

Trinity has changed our life for the better!



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 (513-761-5400). We can help you get started with early intervention services and get you connected with other families.
- Schedule an echocardiogram. This is usually performed at Children's Hospital.
- Schedule an appointment with your pediatrician to discuss any medical concerns and walk through the Health Guidelines in this book.
- Consider making an appointment with the Jane and Richard Thomas Center for Down Syndrome at Children's Hospital Medical Center for a developmental assessment (513-636-4611).
- Consider meeting with a genetic counselor to discuss chromosomal test results.
- Contact your Early Intervention Services (information in this book).
- For Ohio residents, apply for the Children with Medical Handicaps Program (CMH or BCMH).

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 today with Down syndrome.

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 50% 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 have provided the Healthcare Guidelines for Individuals with Down Syndrome in this book.

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 60 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.

Early Intervention Services

The first years of life are a critical time in a child's development. All young children go through the most rapid and developmentally significant changes during this time. During these early years, they achieve the basic physical, cognitive, language, social and self-help skills that lay the foundation for future progress, and these abilities are attained according to predictable developmental patterns.

Children with Down syndrome typically face delays in certain areas of development, so early intervention is highly recommended. It can begin any time after birth, but the sooner it starts, the better. Early intervention is a free of charge service that works with children 0 – 3 years old. At age 3, a child is eligible to start pre-school through the local school district. The local school district is mandated by a law to provide free and appropriate public education.

What is Early Intervention?

Early intervention is a systematic program of therapy, exercises and activities designed to address developmental delays that may be experienced by children with Down syndrome or other disabilities. These services are mandated by a federal law called the Individuals with Disabilities Education Act (IDEA). The law requires that states provide early intervention services for all children who qualify, with the goal of enhancing the development of infants and toddlers and helping families understand and meet the needs of their children. The most common early intervention services for babies with Down syndrome are physical therapy, speech and language therapy, and occupational therapy.

How can Early Intervention be beneficial?

Development is a continuous process that begins at conception and proceeds stage by stage in an orderly sequence. There are specific milestones in each of the four areas of development (gross and fine motor abilities, language skills, social development and self-help skills) that serve as prerequisites for the stages that follow. Most children are expected to achieve each milestone at a designated time, also referred to as a "key age," which can be calculated in terms of weeks, months or years. Because of specific challenges associated with Down syndrome, babies will likely experience delays in certain areas of development.

However, they will achieve all of the same milestones as other children - just on their own timetable. In monitoring the development of a child with Down syndrome, it is more useful to look at the sequence of milestones achieved, rather than the age at which the milestone is reached.



Types of Early Intervention Therapy

Before birth and in the first months of life, physical development remains an underlying foundation for all future progress. Babies learn through interaction with their environment. In order to learn, therefore, an infant must have the ability to move freely and purposefully. An infant's ability to explore his or her surroundings, reach and grasp toys, turn his or her head while watching a moving object, roll over and crawl are all dependent upon both gross and fine motor development. These physical, interactive activities foster understanding and mastery of the environment, stimulating cognitive function, language and social development.

Physical Therapy

Physical therapy focuses on motor development. For example, during the first three to four months of life, an infant is expected to gain head control and the ability to pull to a sitting position (with help) with no head lags and enough strength in the upper torso to maintain an erect posture. Appropriate physical therapy may assist a baby with Down syndrome, who may have low muscle tone, in achieving this milestone. Another long-term benefit of physical therapy is that it helps prevent compensatory movement patterns that individuals with Down syndrome are prone to developing. Such patterns can lead to orthopedic and functional problems if not corrected.

Speech and Language Therapy

Speech and language therapy is a critical component of early intervention. Even though babies with Down syndrome may not say their first words until 2 or 3 years of age, there are many pre-speech and pre-language skills that they must acquire before they can learn to form words. These include the ability to imitate and echo sounds; turn taking skills (learned through games like "peek-a-boo"); visual skills (looking at the speaker and objects); auditory skills (listening to music, speech or speech sounds for lengthened periods of time); tactile skills (learning to touch, exploring objects in the mouth); oral motor skills (using the tongue, moving lips); and cognitive skills (understanding object permanence and cause and effect relationships).

Occupational Therapy

Occupational therapy helps children develop and master skills for independence. Occupational therapy can help with abilities such as opening and closing things, picking up and releasing toys of various sizes and shapes, stacking and building, manipulating knobs and buttons, experimenting with crayons, etc. Therapists also help children learn to feed and dress themselves and teach them skills for playing and interacting with other children. The overarching goal of early intervention programs is to enhance and accelerate development by building on a child's strengths and by strengthening those skills that are weaker in all areas of development.

How do I sign-up for Early Intervention?

Each state has its own set of laws governing early intervention services. Parents can get a referral from their baby's doctor or find a local agency by visiting www.nectac.org. Once a referral has been made, the program staff must schedule and complete an initial evaluation within a specified time. Once the assessment is done, a caseworker is assigned to coordinate the various services for which the baby and family qualify. Early intervention services are individualized to meet the specific needs of each individual baby. The caseworker, therapists and family will determine areas of focus and set goals based on developmental milestones. These will be recorded in a document called the Individualized Family Service Plan (IFSP).

Ohio

Adams County: 937-544-2574
Brown County: 937-378-4891
Butler County: 513-785-2800
Clermont County: 513-732-4832
Highland County: 937-393-4237
Clinton County: 937-382-7889
Warren County: 513-695-3010
Hamilton County: 513-794-3300

Indiana

Dearborn County: 812-283-1040

Kentucky

All Northern Kentucky Counties: 877-417-8377
chfs.firststeps@ky.gov

Health Guidelines

One of the main questions on the minds of many new and expectant parents is, "Will my baby be healthy?" It is important to note that many babies with Down syndrome are born without any health problems. However, it is true that newborns with Down syndrome are at a higher risk for certain complications. While your baby may not have any of these potential complications, it is important to be aware of them so you can catch them early if they do occur. This section discusses possible health concerns and useful tools for monitoring your child's health care.

The DSAGC strongly recommends that you use these guidelines on your first pediatric appointment as what to expect, as well as what to request of your pediatrician if any of the concerns listed below are not discussed. Requesting that your pediatrician uses these guidelines and staying informed ahead does not make you an overbearing parent, but an advocate for your child. And while your pediatrician may be a wonderful physician, he or she may not be familiar with the most current guidelines.

Health Care Information: Birth - 1 month

- Genetic Testing:** If the physical examination after birth raises the possibility of Down syndrome, testing by rapid (FISH) confirmation and a complete chromosome analysis are needed. The rapid analysis results are typically available within 48 hours, whereas the complete analysis might take 35 days for the results. A complete chromosome analysis is needed to provide full information, but to ensure prompt results, both should be obtained unless the complete analysis can be done as quickly as the rapid analysis.
- Counseling:** The prenatal or newborn diagnosis of Down syndrome can cause many concerns for parents. Talking with a medical genetics team (medical geneticist and genetic counselor) or others recommended by your child's doctor may be helpful.
- Feeding:** Infants with Down syndrome sometimes have low muscle control, which can cause feeding problems. For this reason, infants should be closely watched for slow feeding or choking and for appropriate weight gain. If breastfeeding, extra attention may need to be given to positioning and keeping the baby awake or alert.
If you choose to breastfeed and are having difficulty, be sure to ask for a lactation consultant to assist.
- Car Seat Evaluations:** Your baby should be evaluated for apnea, bradycardia, and oxygen desaturation with the infant in a car seat. A car safety seat screen should be conducted before hospital discharge.
- Heart:** An echocardiogram (an ultrasound picture of the heart) is needed to check for any evidence of heart defect. This should be done even if a prenatal echocardiogram was done. If issues exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.
- Duodenal atresia or anorectal atresia/stenosis:** This is a condition in which the first part of the small bowel has not developed properly or where a normal anal opening is absent at birth. Other conditions your pediatrician will evaluate for are **constipation, gastroesophageal reflux, stridor, wheezing, or noisy breathing.**
- Hearing:** An audiology assessment will be done and appropriate referrals will be made if any concerns arise. A hearing re-evaluation will be done at 6 months of age if the infant passed the newborn screening for confirmation.
- Vision:** Infants with Down syndrome are at risk for sensory issues, such as eye problems leading to vision loss. Cataracts at birth will be assessed by looking for a red reflex. Within the first 6 months of life, referral to a pediatric ophthalmologist or ophthalmologist will be done.
- Thyroid:** Thyroid hormone levels can be too low in newborns and need to be checked (a TSH test). Thyroid hormone imbalance can cause a variety of problems that might not be easy to detect without a blood test. Repeat thyroid tests will need to be done at 6 and 12 months of age and then on annually.
- Blood test:** After birth, white and red blood cell counts can be unusually high in infants with Down syndrome. These blood counts need to be checked to monitor for anemia and/or other abnormalities.
- Infection:** Because of an increased risk of infections (especially respiratory infections), infants should be protected from any unnecessary exposures to sick siblings, relatives, or others. It is also recommended to get checked quickly when any infection is suspected.
- Developmental Services:** It is not too early in the first month of life to start to look for the developmental services (sometimes called "Early Intervention") that will be very important in early childhood.

Health Care Information: 1 month - 1 year

Follow up on known problems with specialists and be sure that reports are sent to your child's primary doctor.

- Regular wellness visits:** (check-ups) While infants with Down syndrome might need multiple special visits to their doctor and specialty physicians, it is very important that they get regular wellness visits (check-ups). These visits will include checking your child's health, yearly bloodwork, giving immunizations (shots), and building the relationships between the doctor and the family. Developing these relationships will help support the medical and other needs of the child and the family.
- Monitor growth:** It is important to check growth at every visit. Measurements include height, weight, weight for height, and head circumference. Discuss your child's diet, activity level, bowel and urine patterns, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.
- Immunizations (shots):** Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It is important that your child gets their regular standard vaccines of infancy and childhood as required to optimize their health. It is important to note that children with DS are susceptible to recurrent and prolonged infections, making recommended vaccines twice essential.
- Heart:** If there are any signs of heart defects in the first month of life, heart monitoring will be continued at all well-child visits. Heart problems could still worsen or new ones could arise. If concerns exist, it is very important to act early.
- Hearing:** Hearing should be tested at birth and again at 6 months in early childhood to be sure that the baby's hearing is the best possible. A behavioral audiogram will be attempted at 1 year of age – if unable to complete, additional testing should be performed.
- Vision:** The eyes should be tested at birth and again at 1 year or sooner if there are concerns. Within the first 6 months of life, referral to a pediatric ophthalmologist or ophthalmologist will be done.
- Thyroid:** Thyroid hormone levels can be too low in infants and need to be checked (a TSH test). Low thyroid levels can cause a variety of problems that might not be easy to detect without a blood test. Repeat thyroid tests will need to be done at 6 and 12 months of age and then on annually.
- Stomach or bowel problems:** (reflux, constipation, blockages) Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue. Duodenal atresia or anorectal atresia/stenosis - this is a condition in which the first part of the small bowel has not developed properly or where a normal anal opening is absent at birth.
- Neck instability:** Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done and the results are abnormal, your child may be referred to a spine or neck specialist. It is recommended that the neck be positioned properly for any medical procedures.
- Obstructive Sleep Apnea:** At least once during the first 6 months of life, talk to your pediatrician if you have concerns of obstructive sleep apnea, including heavy breathing, snoring, uncommon sleep positions, frequent night awakening, daytime sleepiness, apneic pauses, and behavior problems that could be associated with poor sleep.
- Developmental services:** (for example, early intervention programs) can be of great benefit to the family with a child with Down syndrome. Developmental services can also help arrange for other related services. These services should provide information to your child's doctor to maintain a close working relationship with the doctor and the family.
- Social support services:** Many families need additional help with the issues that can arise with the care of children with Down syndrome. All families should discuss with their doctor or local Down Syndrome Association the social services that may be available and their benefits.
- Other:** Your doctor should also evaluate and discuss hypotonia (low muscle tone), cutis marmorata, stridor, etc.

Our Organization

Down Syndrome Association of Greater Cincinnati

The mission of the Down Syndrome Association of Greater Cincinnati is to empower individuals, educate families, enhance communities and together, celebrate the extraordinary lives of people with Down syndrome.

The Down Syndrome Association of Greater Cincinnati (DSAGC) partners with families and others to create an environment in which individuals with Down syndrome are welcomed with fairness, enthusiasm, and encouragement in the community. We envision a community that embraces, supports and inspires individuals with Down syndrome to live healthy, self-determined and fulfilling lives. We believe that diversity should be embraced, not merely tolerated, because the entire community benefits when individuals with differences are valued.

Support at Every Age

We provide support and resources to families of all ages and stages in a variety of ways.

- Meet with individuals with Down syndrome and their families whenever needed to offer continuous support.
- Make introductions to local agencies, intervention programs, county services, and more.
- Connect families to each other through in-person opportunities, on-line chat groups, and more.
- Attend important meetings (hospital, school, work, etc.) to advocate for the individual with Down syndrome's best interest.
- Research referrals, community opportunities, best practices, etc.
- Assist families in the preparation of transitions (IEPs, behavior plans, aging, etc).
- Organize presentations to enhance the community's understanding of Down syndrome.



Family Resources

Hospital Care Packages

We deliver care packages to individuals with Down syndrome who are admitted to the hospital. Our care packages include meal tickets, snacks, cards, activities, books, and more.

Lending Library

The Lending Library contains over 600 books and DVDs on various topics relating to Down syndrome, such as teaching strategies, medical concerns, social development, parenting and more.

Transportation Assistance Fund

The Transportation Assistance Fund provides financial assistance to caregivers facing transportation challenges limiting their availability to either attend DSAGC programs and/or need help getting to and from medical/therapy appointments for their loved one with Down syndrome.



Community Participation Fund

We offer scholarships to people with Down syndrome so that they can participate in community activities, such as camps, soccer or swim lessons. There are also scholarships available for parents to attend educational meetings or conferences.

Programs & Services

Empowerment Center

Our Empowerment Center is furnished with therapeutic equipment, a rock wall, swings, climbing mats, toys, and electronics. It is a space designed to help build upon skills for intellectual, social, emotional, and physical development as well as connect with others. The center also has a sensory room to provide a safe, calming space for all visitors.



We are located at
4623 Wesley
Avenue, Suite B
Cincinnati, Ohio
45212.

Programs

Our programs focus on therapeutic, recreational, educational and social opportunities for all ages. We tailor our offerings to reflect the needs of local families as we strive to provide valuable support and quality programs for those in our community. Programs rotate on a quarterly basis and include opportunities such as cooking, music therapy, circle time, swim lessons, fitness, independent living retreats, and much more!

Tutoring

In an effort to enhance student learning, we provide tutoring for students with Down syndrome. Our tutors are experienced, local special education teachers who customize each learning opportunity to fit the student's individual needs.

Community Groups

Community Groups create opportunities for families that have children with Down syndrome to network and share common interests, concerns, challenges and information. The groups do this through community events, informational meetings, playgroups, and on-line chat groups.

Outreach and Advocacy

We provide extensive outreach to local healthcare professionals, educators, employers, and legislators. In addition, we are involved in a variety of advocacy work that impacts the Down syndrome community.

This is just a snapshot of the programs & services we offer. To learn more, please visit www.dsagc.com.



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