

The Down Syndrome Association of Charlotte
Serving Families Since 1986!

New Parent Handbook



PO Box 34787 • Charlotte, North Carolina 28234-4787
704.536.2163 • www.dsacnc.org



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The Down Syndrome Association of Charlotte
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Welcome!

Dear New Parent,

Congratulations! Having a baby is an exciting and anxious time for all parents, and even more so for us as parents of children with Down Syndrome. We want you to know you are not alone and that we understand many of the feelings you are experiencing right now. We are here for you and your family in any way that we can be.

We know you will be overwhelmed with information and questions so we have put together this notebook that will, hopefully, help you and your family as a resource base. You may also request, free of charge, the *Down Syndrome: The First 18 months* DVD.

The Down Syndrome Association of Charlotte is available to try and answer any questions that you or your family may have. Our group has annual social events including a holiday party, summer picnic, the annual Buddy Walk celebration and a fundraising golf tournament. We also publish a newsletter with information on current topics. Please fill out the enclosed card or e-mail newbaby@dsacnc.org to begin receiving the newsletter. The newsletter is also available online at www.dsacnc.org.

Also available are small parent/infant support groups that meet on a regular basis. Our goal is to be there for each other and share information. We invite you and your family to join us at our social events, meet other families and get to know a new group of wonderful, caring people.

If we can be of any assistance to you or your family (siblings, grandparents or other relatives), please feel free to contact us. Even if you just want to talk with a parent of a child with similar needs, the DSAC can put you in touch with families willing to help. You can also meet a family in person and talk if you wish. Just remember, you are not alone. Your baby will need all the love, support and understanding you can provide. With this, your baby and your family will thrive!

Please feel free to contact us:

Conni & David Branscom

Parents to Kyle, born February 2004

Home 704-759-3050

Email: Cali21@carolina.rr.com

Email: newbaby@dsacnc.org



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 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 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. And you must learn a whole new language. And 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. 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, ever go away... because the loss of that dream is a very 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.

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The Down Syndrome Association of Charlotte (DSAC)

Who We Are

The Down Syndrome Association of Charlotte (DSAC) was formed in 1986 by a group of parents who understood the importance of supporting families who experience the birth of a child with Down syndrome. We continue to be a parent-lead organization seeking to be the premier resource on Down syndrome in the greater Charlotte area.

The DSAC is pleased to be affiliated with both national Down syndrome organizations. We support their efforts to provide education and advocacy to break down stereotypes about Down syndrome and advance positive outcomes for individuals with Down syndrome and their families. We invite you to learn more about the national organizations by visiting their websites or calling them at:

National Down Syndrome Congress
www.ndscenter.org, 1.800.232.NDSC

National Down Syndrome Society
www.ndss.org, 1.888.221.4602



Our Mission

The Down Syndrome Association of Charlotte (DSAC) is a volunteer run non-profit 501c 3 organization. Our mission is to enhance the quality of life for all individuals with Down syndrome by providing information and support to families, professionals and the community. The DSAC does not promote particular therapies, institutions or professional systems.

Our Vision

The vision of the DSAC and its families is to enable individuals with Down syndrome to reach their full potential and become respected participants in their communities.

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How We Help

- Bi-Monthly newsletter
- Camp Horizon for children with Down syndrome; ages 10–17
- Camp Holiday for children with Down syndrome, ages 5–16
- Community groups
- Information on DSAC web site (www.dsacnc.org)
- Lending library
- Local educational seminars for families and professionals
- New parent brunch
- New parent information packets
- On-line chat group
- Scholarships to national conferences
- Social gatherings
- Support for Spanish speaking families

Community Partners

- The Down Syndrome Clinic at Carolina's Medical Center
- Exceptional Children's Assistance Center, Davidson, NC
- The Arc of Mecklenburg
- The Arc of Gaston County



Why You Should Be Involved Parent Testimonial

"As parents, we all want to do the best we can to raise happy and healthy children. As a parent of a child with special needs, we are often faced with more complex challenges. Being involved with the DSAC has provided a wonderful network of support, information and fellowship that has guided us in navigating better parenting decisions for all of our children."

Bill Thomas, *Will's Dad*

"Since "normal" at our house looks different than "normal" at our neighbor's house, it is helpful to have the DSAC on hand to help promote connections to local resources and to other families. The DSAC is a powerful reminder that I am never alone on my journey."

Toni Robinson, *Ted's Mom*

DSAC Volunteer Opportunities

The Down Syndrome Association of Charlotte (DSAC) is a volunteer based organization that is primarily managed and funded by local families. Established in 1986 by a small group of caring parents, our organization has grown to include over 500 families and professionals. We offer family-to-family support, educational meetings, newsletters, social events, fundraising activities and networking opportunities for families with children of all ages. We hope you will join us as we discover the unique potential in all individuals with DS.

Camp Horizon

Camp Horizon is a three-day overnight camp for children with Down syndrome, ages 10 to 17. It provides these children a special and safe place where they discover a renewed sense of self-confidence, develop friendships, enjoy the beauty of nature and have a fun and memorable experience. The camp requires a one-to-one counselor/child ratio so lots of volunteers are needed. If you are interested in the camp, becoming a counselor, or would like to donate your time, please contact Jennifer Jones at 704.562.0839 or email camphorizon@dsacnc.org.

Camp Holiday

Camp Holiday for 5–16 years old campers is staffed by degree professionals in the fields of Special Education, Early Childhood Education, Music Therapy and Occupational Therapy. Some teen campers will be considered for a Counselor-in-Training program unique to this camp. If you are interested in the camp, becoming

a counselor, or would like to donate your time, please contact the camp director, Marcia Stern by email at CampHoliday@dsacnc.org or by phone, 704.536.2163.

Buddy Walk

The Buddy Walk was established in 1995 to promote acceptance and inclusion of people with Down syndrome. The Buddy Walk is a largest event of the year for the DSAC and volunteers are needed to participate as planning committee members, putting together goody bags, recruiting participants, fundraising and seeking sponsorship from local businesses, and or helping on the day of the event. If you are interested in donating or volunteering for the Buddy Walk, please contact Buddy Walk Committee Chair at BuddyWalk@dsacnc.org.

Golf Tournament

The DSAC Annual Golf Tournament is our fundraiser for Camp Horizon. If you would like information, wish to play, would like to volunteer, or donate to this event, please contact Tom Mulroy at 704.893.2857 or tmulroy@carolina.rr.com

DSAC's New Horizons Symposium

Each year the DSAC brings a national speaker to Charlotte who has insight on issues that parents and professionals deal with when caring for children with Down syndrome. If you would like information or wish to volunteer for this event, please the DSAC Program Director, Terri Leyton at tleyton@dsacnc.org or 704.916.9871.

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Small Groups

The following are small sub-groups of the DSAC. They provide support to families according to specific needs such as location and age of the child. If you would like more information or to volunteer for any of these sub-groups, please contact the person listed for each group. If you are interested in starting a new group in your area, please contact Richard Morrow at 704.383.5981 or richard.morrow@wachovia.com.

Roots and Shoots (ages birth to 3 years)

rootsandshoots@dsacnc.org

South End: Laurie Maddex

704.288.4620, lmaddex@gmail.com

North End: Christi Wood

704.577.4990, cwilliamswood@bellsouth.net

Rising Stars (age 4 to 8 years)

risingstars@dsacnc.org

South End: Conni Branscom

704.759.3050, cali21@carolina.rr.com

North End: Terry Leyton

704.916.9871, tleyton@dsacnc.org

Duck Soup (age 9 to 13 years)

Leadership Needed

Teen/Self-Advocates (ages 14 and up)

Leadership Needed

Latino Families (*Josette habla español!*)

Josette Duncan

704.491.6503, Duncans926@gmail.com

Gaston County Group

(Serving west of Mecklenburg County)

Kathryn and Mark Lariviere

704.823.1282, Klariviere@carolina.rr.com

North Mecklenburg Group

(Serving in and north of Mecklenburg County)

Paula Swift

704.892.2346, paula_swift2003@yahoo.com

D.A.D.S.

(Dads Appreciating Down Syndrome – all dads welcome!)

Tony Cirone, tonymcirone99@yahoo.com



Meet Our Families

Amy Silver, Single Parent to Alex
Email: ammeesilver@aol.com

I found out that Alex had Down syndrome when I was eighteen weeks pregnant. I was given the new parent handbook and did a lot of research on the internet. I made sure that when he came I was as prepared as I could be. At thirty-three weeks, I found out that Alex has a duodenal atresia and would need surgery as soon as he was born. Alex was born five weeks early. Right after he was born, they took him to perform an echocardiogram to check his heart. He came through his ok, but had issues with sleep apnea. He spent four weeks in the NICU. Then he was on an apnea monitor for six months. He had issues with eating in the beginning but is now thriving. I have had tremendous help with family and friends who adore Alex. My family does not live here but they drive from Asheville just to give me some time to myself. He is a joy to everyone. He is in physical therapy three days a week. I am constantly on-line researching things about Down syndrome and what I can do to help him. He is now thirteen months old and is rolling over. He is a really happy baby and is doing something new everyday.

Stacey Cunningham, Adoptive Parent to Gigi
Email: staceyjc@carolina.rr.com

In July of 2003, we adopted our beautiful Gigi. We had three children and wanted a fourth child. So we set out on our adoption journey to adopt a child with Down syndrome. Both of our families were very supportive of our decision and throughout our adoption journey. Gigi's birth mom did not know until she delivered Gigi that she had Down syndrome. Within the first two days at the hospital, the local Down Syndrome Association visited her as well as a local adoption agency. We met with Gigi's birthparents and they chose us to be her adoptive family.

Our three children accepted Gigi from the moment we brought her home. The love they have for her is overwhelming. Our friends, family, and neighbors were so happy and excited for us when we brought Gigi home. We can't imagine our family without Gigi in it—she has truly completed our family. Gigi reminds us every day of what is important in life. Her smile lights up a room, her personality is contagious, and she is beautiful on the inside and the outside. She is an absolute blessing to our family.

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Other Family Contacts

James & Jeannette Little

Parents to MeKyah

Born: November 2003

E-mail: jeannttelittle@bellsouth.net

Cell Phone: 704.617.3957

Josette Duncan (Habla Español)

Parent to Nathan

Born: June 1995

E-mail: Duncans926@gmail.com

Cell Phone: 704.491.6503

Jan & Walter Kellogg

Grandparents to Sidney Fuerstman

Born: June 2002

Phone: 704.364.1343

Toni Robinson

Seasoned parent to Ted

Born: August 1983

E-mail: winntoni@aol.com

Home Phone: 704.365.2840

Cell Phone: 704.517.9550



The First Year

Timeframe Guidelines

Birth – Three Months

Enjoy, love, and nurture your new precious baby! They are a true gift and already have amazing potential!

- Locate a pediatrician (if not already done so) and find out all you can about the medical needs of your child.
- Contact the Child Development Services Agency (Charlotte, Shelby/Gaston or resident county); they will schedule your child for an assessment or evaluation of their development. This will identify specific needs to address with a variety of available services in the near future - such as physical therapy.
- Request a full cardiac evaluation (if not already done in the hospital) to address any heart concerns or issues common with children with DS.
- Locate a focus group for family and child connections in your new journey (DSAC, The Arc, and other local service providers).
- Complete the developmental evaluation through your local CDSA. This evaluation will help you determine if/when you child should start physical therapy, occupational therapy and speech therapy.
- The case manager will assist in creating a developmental plan of goals for your child to work on (IFSP - Individualized Family Service Plan). Realistic goals will be established for your child, for example, building upper body strength for stability in sitting up, head control, etc. that can be worked on at home, in daycare, etc.
- Therapy doesn't have to be serious... have fun with your baby! You can address many of your therapy goals in ordinary activities – Mommy & Me, Gymboree, YMCA infant swim classes, etc. Be creative!
- Follow the DS Healthcare Guidelines (www.ds-health.com) and have a BAER hearing test by three months of age. Referral to ENT doctor if hard to see inside baby's ears. Request baby's first eye exam and repeat thyroid screening at six months.

By Six Months

- Use the Child Development Services Agency (CDSA) to assist in selecting a service provider/case manager; this person will be your family's direct contact for all of the needed services your child requires for their development. They will ensure that all needs are met with available resources.



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At One Year

- Request an updated evaluation from CDSA. This evaluation will help you determine if your child's therapy needs have changed.
- Maintain relationship with your case manager. (However, if a family is not satisfied with the person assigned to their child, they have the choice of changing within that service provider or changing provider companies all together.)
- Continue updating the IFSP, setting new goals, revisit and reinforce goals to continue progress.
- At your one year pediatric check-up, make a plan with your pediatrician to follow the DS Healthcare Guidelines which include repeat hearing testing every six months and thyroid screening and eye exams yearly on baby's birthday.
- Schedule yearly medical evaluation at the Genetics Clinic or the Down Syndrome Clinic at Carolinas Medical Center, 704.381.6810.
- Now is a good time to be sure your wills are up to date. Consider meeting with a financial professional for assistance with estate planning.

Family Resources

Down Syndrome Association of Charlotte (DSAC)

704.536.2163

www.dsacnc.org

Exceptional Children's Assistance Center (ECAC)

800.962.6817

www.ecac-parentcenter.org

The Arc

www.arccnc.org- to locate agency in your county

Mecklenburg CDSA/Watkins Center

704.336.7100

Shelby CDSA

(Cleveland, Gaston, Lincoln, Polk, Rutherford) 704.480.5440

Concord CDSA

(Cabarrus, Iredell, Rowan, Stanly, Union) 704.786.9181



Health Care Guidelines

(Based on 1999 Down Syndrome Healthcare Guidelines)

Neonatal (Birth–One Month)

- Review parental concerns. Chromosomal karyotype; genetic counseling, if necessary.
- If vomiting or absence of stools, check for gastrointestinal tract blockage (duodenal web or atresia or Hirschsprung disease).
- Evaluation by a pediatric cardiologist including echocardiogram. Subacute bacterial endocarditis prophylaxis –(SBE), in susceptible children with cardiac disease.
- Exam for plethora, thrombocytopenia.
- Review feeding history to ensure adequate caloric intake.
- Thyroid function test - check on results of state-mandated screening at birth.
- Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (at birth or three months).
- Pediatric ophthalmological evaluation (by six months) for screening purposes.
- Discuss value of Early Intervention (infant stimulation) and refer for enrollment in local program.
- Referral to local Down syndrome parent group or family support and resources, as indicated.
- Referral to NDSS. 800.221.4602, www.ndss.org.

Infant (One–Twelve Months)

- General neurological, neuromotor and musculoskeletal examination.
- TSH and T4-Thyroid Function Test (six and twelve months).
- Evaluation by pediatric cardiologist including echocardiogram (if not done at birth). Consider progressive pulmonary hypertension if VSD or atrioventricular septal defect and little or no symptoms of heart failure.
- Subacute bacterial endocarditis prophylaxis (SBE) (as indicated).
- Well child care - immunizations.
- Feeding consult, especially if constipated. Consider Hirschsprung disease.
- Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (by 3 months if not already, or if suspicious).
- Ear, nose and throat exam (as needed), especially if suspicious of otitis media.
- Well-balanced, high-fiber diet.
- Vision exam (by 6 months and annually; earlier if nystagmus, strabismus or indications of poor vision).
- Discuss Early Intervention and refer for enrollment in local program.
- Application for Supplemental Security Income (SSI), depending on family income.
- Consider estate planning and custody arrangements; continue family support.

For more information contact NDSS:
800.221.4602 • www.ndss.org.

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Childhood (One–Twelve Years)

- TSH and T4-Thyroid Function Test (annual).
- Echocardiogram by a pediatric cardiologist if not done previously.
- Behavioral Auditory Testing (every six months to age three, then annually).
- Lateral cervical spine x-rays (neutral view, flexion, extension) to rule out atlanto-axial instability.
- Radiologist to measure atlanto-dens distance and neural canal width (at three and five years, then as needed).
- Pediatric and neurological exam with evaluation for spinal cord compression: deep tendon reflexes, gait, Babinski sign.
- Use Down syndrome growth charts and head circumference charts with others.
- Eye examination (annually, or as indicated).
- Screen for celiac disease IgA antiendomysium antibodies and total IgA (between two and three years)
- Question about obstructive sleep apnea; ENT exam (as needed).
- Dental Exam (two years; follow up exams every six months after). Twice daily brushing.
- Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) for cardiac problems (as indicated).
- Brief vulvar exam for girls.
- Well child care: immunizations; pneumococcal vaccine (two years).
- Evaluation by speech/language pathologist.

*[HEALTH CARE GUIDELINES FOR INDIVIDUALS WITH DOWN SYNDROME: 1999 REVISION (Down Syndrome Preventive Medical Check List) is published in Down Syndrome Quarterly (Volume 4, Number 3, September, 1999, pp. 1-16) and is reprinted, duplicated, and/or transmitted with permission of the Editor. Information concerning publication policy or subscriptions may be obtained by contacting Dr. Samuel J. Thios, Editor, Denison University, Granville, OH 43023 (email: thios@denison.edu).]

Adolescence (Twelve–Eighteen Years)

- TSH and T4-Thyroid Function Test (annual).
- Auditory Testing (annually).
- Monitor for obstructive airway; sleep apnea.
- General physical and neurological exam; check for atlanto-axial dislocation. Cervical spine x-ray (as needed for sports).
- Eye examination (annually).
- Monitor for obesity by plotting height for weight on growth charts for typical children
- Clinical evaluation of the heart to rule out mitral/aortic valve problems. ECHO - Echocardiogram (as indicated by findings).
- Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adolescents.
- Adolescent medicine consult for puberty/sexuality issues; health, abuse prevention and sexuality education. Pelvic exam (only if sexually active).
- Low calorie, high fiber diet; regular exercise
- Smoking, drug and alcohol education.
- Begin functional transition planning (sixteen years). Monitor independent functioning.



Resources

Down Syndrome Recommended Reading and Viewing Lists

DVDs

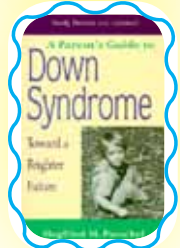
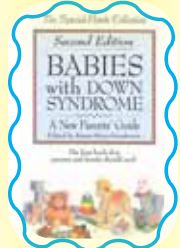
- **Down Syndrome: The First 18 Months **** (see page 21)
Includes interviews with families and experts on health and developmental issues for the new baby with DS.
** This DVD is available to all new families **FREE OF CHARGE** from the DSAC.
Send an email to newbaby@dsacnc.org or contact Conni Branscom, 704.759.3050, Cali21@carolina.rr.com to receive your copy.
- **Emma's Gifts**
Documentary filmed by a local Charlotte family, this film challenges viewer's perceptions of difference.
- **DISCOVERY: Pathways to Better Speech for Children with Down Syndrome**
Interviews with experts on speech and language development.



Books

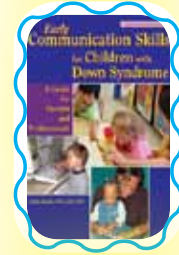
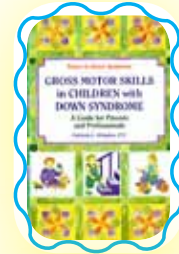
All of these titles are available for loan through the Down Syndrome Association of Charlotte Lending Library. This is just a small listing of the books and DVDs that are available. To see the entire list, go to www.dsacnc.org. Contact Cam Brasington at 704.381.6810 to borrow these materials.

- **Babies with Down Syndrome: A New Parent's Guide**
by Karen Stray-Gundersen
Covers everything parents need to know about raising their child in an environment of love, pride and achievement.
- **A Parent's Guide to Down Syndrome: Toward a Brighter Future**
by Siegfried Pueschel
Guides parents through all stages from infancy to adolescence and beyond. Reassuring guidance, straightforward explanations, and clear information.



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- **Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals** by Patricia Winders
Provides parents with essential information about early motor development.
- **Early Communication Skills for Children with Down Syndrome** by Libby Kumin
Insights into early speech and language development with information parents can use at home.
- **We'll Paint the Octopus Red** by Stephanie Stuve-Bodeen
Children's book on welcoming a new sibling with Down syndrome.



Web Sites

This is by no means an exhaustive list of the excellent websites that you may visit online. However, we have found that these are a good place to start.

- **National Down Syndrome Congress**
www.ndscenter.org
- **National Down Syndrome Society**
Comprehensive sites containing general information about Down syndrome, education, research and advocacy. www.ndss.org
- **Down Syndrome Association of Charlotte (DSAC)**
Local parent organization offering a variety of educational and social activities. www.dsacnc.org
- **Down Syndrome: Health Issues, News and Information for Parents and Professionals**
Operated by Dr. Len Leshin, a pediatrician and father of a child with Down syndrome, contains many articles addressing health and medical issues for children with Down syndrome as well as links to the DS HealthCare Guidelines and growth charts. You will want to take these with you to your pediatrician visits. www.ds-health.com

Other

- **Down Syndrome Clinic at Carolinas Medical Center**
The DS Clinic meets every other month and includes physicians, therapists, parents, social worker, and nutritionist. Call 704.381.6810 for more information.
- **DSAC Yahoo Discussion Group**
Discussion forum for local DSAC families. It is a place to chat with other members, ask questions, offer advice, as well as post pictures of your family. For more information, contact Sandra Donahue, SDonahue@rbh.com or Angie Tate, atate526@charter.net. To join, please visit: <http://health.groups.yahoo.com/group/DSACSupportPage>.

Free DVD for New Parents

Down Syndrome: The First 18 Months

Down Syndrome: The First 18 Months (Published in 2003. 108 Minutes.) is the best, easiest, most up-to-date source of information for new parents. International and US experts, plus knowledgeable parents, give a view of the early years of Down syndrome that is honest, positive and practical.

Section 1: The Newborn

- *A New Baby*
Focus on the changes a baby with Down syndrome can bring to families—and why not to focus on it.
- *Health Care for Newborns*
Advice and steps to take in the first few days of life.
- *Focus On: Breastfeeding*
Practical information on overcoming breastfeeding challenges from birth.

Section 2: Health Concerns

- *Working with Professionals*
Strategies for talking to health care professionals about Down syndrome.
- *Ear, Nose and Throat*
Dr. Sally Shott leads the discussion of ENT and related concerns.
- *Nutrition and Mealtimes*
An introduction to the nutritional needs of children with Down syndrome.
- *Little Teeth*
Common problems with the teeth of young children with Down syndrome.

Section 3: Therapies

- *Therapies Overview*
What therapists do, why they do it, and a bit about how they do it.
- *A Story: The Bridge*
A father remembers the change he saw in his son and himself when he gave his son a chance to prove himself.
- *Language and Speech Therapy*
An introduction to the process of communication and fostering language in young children.
- *Physical Therapy*
Patricia Winders discusses therapeutic concerns and strategies.
- *A Story: Stepping Back*
Why too much therapy is not a good thing.



Grief

No one ever told me that grief felt so like fear. ~ C. S. Lewis

When a grievous event occurs, when something happens that catapults us into grief, it cuts us off suddenly and dramatically from other people. We have been struck by something unexpected, unwanted, undesirable. Most of us experienced the discovery of our baby's disability as a grievous thing, an event that marked us out and separated us from the group. To be alone in the sense of not belonging is terrifying.

Our trauma may make us feel disconnected not only from society, but also from time, from the flow of our life. Our past experiences with disabilities may be limited, offering only negative images about what lies ahead. With no useful history to feed a vision of the future, we are filled with fear. Questions flood our minds: "How serious is this disability?" "Will she have friends?" "What will happen to my life?" "What will happen to her?"

It is normal to be afraid and to feel alone. Just for today remember that you are not alone; others have walked the road you are on now. Even though they don't know you, their love is with you.

Reprinted with permission from
Changed by a Child: Companion Notes for Parents of a Child with Disabilities,
Barbara Gill, Doubleday, 1997



Frequently Asked Questions

About Down Syndrome

My baby has just been diagnosed with Down syndrome. What is that?

Down syndrome is a genetic condition caused by an extra copy of chromosome 21. The extra chromosome causes some differences in how babies with Down syndrome grow and develop. Down syndrome is fairly common, about 1 out of every 800 babies is born with DS. There is nothing parents do or do not do during their pregnancy to cause this to happen. It is just one of those things!

Babies with Down syndrome usually have some subtle physical characteristics that cause doctors to suspect the diagnosis and order chromosome testing for confirmation. There is a wide variety of physical and cognitive characteristics that can be seen in individuals with Down syndrome. Your baby will most likely have some of these characteristics but no baby has all of them.

What should I be concerned about now?

Almost half of babies with Down syndrome will be born with some type of heart condition so it will be important for your baby to have an echocardiogram (a heart ultrasound) soon after birth. Babies will also typically have some degree of low muscle tone which can affect feeding. Don't hesitate to ask for a lactation specialist if

your baby is having trouble nursing. You will also meet with a geneticist or genetic counselor to review the chromosome results and answer any questions about Down syndrome you might have.

How will this affect my baby in the next few weeks and months?

Your baby has the same needs as any other baby. Your pediatrician can take care of her usual medical needs. Depending on other associated medical conditions, your baby may need to see other specialists. Your doctor may also refer your baby for early intervention services which will monitor your baby's developmental progress and offer any assistance if needed. Otherwise, just treat your child like any other child!

What should we expect long term?

Your baby with Down syndrome is more LIKE other children than different! He will have his own unique personality, likes, dislikes, and capabilities. Children with Down syndrome go to daycare, attend school, participate in sports activities, dance, and hobbies just like any other child. Keep your expectations high! Many adults with Down syndrome are now pursuing secondary education, are living independently, and working in their communities.

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What do I tell my other children, family and friends?

With children, it is not necessary to go into long explanations about Down syndrome. Answer questions simply and honestly as your child asks them. For family and friends, you might explain that while you have received some unexpected news about your new baby, you are asking for their love and support in welcoming this baby into the family. The way you interact with your baby will set the tone for everyone else.

What if I have more questions?

The genetics staff at Carolinas Medical Center and Presbyterian Hospital are always available to answer any questions you might have. If you would like to speak with another parent, call any of the parents listed in this packet or email newbaby@dsacnc.org. Someone will be right back in touch with you!





The Down Syndrome Association of Charlotte
Serving Families Since 1986!

New Family Information

Please complete and return so that you can begin receiving bi-monthly issues of the DSAC newsletter and be added to the Roots and Shoots email list.

Parent's Name(s): _____

Address: _____

City/State/ZIP Code: _____

Phone Number(s): _____

E-mail: _____

Baby's Name: _____

Date of Birth: _____

Name(s) and Age(s) of Sibling(s): _____

Where did you receive a copy of your new parent handbook?

Name of Hospital: _____

Name of Friend: _____

Other: _____

I prefer the DSAC's initial contact to be via:

Home visit

Phone call

E-mail

No contact at this time.

I would like to receive a DSAC newsletter via:

U.S. mail

E-mail

Not interested in receiving a newsletter.

Mail to:

DSAC • PO Box 34787 • Charlotte, North Carolina 28234-4787