

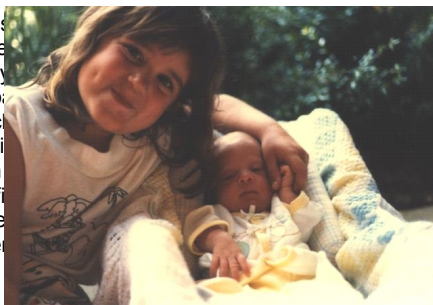
Sibling Strength

Laura Watts, M.Ed.
Program Director

When our son Jonathan was born, he was the picture of technological advancement. Wires going everywhere, monitors beeping steadily and a tiny glass enclosed bed keeping him safe and sound. A vision of joy to a new parent? Hardly! But to his 6 ½ year old sister, an image to be cherished. "Oh mom, he is the most beautiful baby in all of Jacksonville!" are the words Meaghan exclaimed as she viewed her brother for the first time through thick glass which kept her from the cradling she had been hoping for. These simple thoughts— pure in their sincerity and so much wiser than we could ever suspect—helped set the scene for our family's acceptance of this unexpected picture. Jonathan has long since outgrown his medical issues, matured through his "little brother is a pain" stage, and become his sister's favorite friend. She has helped him build self-esteem, confidence and a deep sense of belonging.

At the Center we meet siblings from around the world— all with different feelings about their brother or sister, and all with the potential of being that child's strongest teacher, encourager and friend. Some are filled with worry and some with hope, but all with the realization that having a sibling with Down syndrome has provoked a different view on life than they had expected. We hear comments ranging from "He embarrasses me so much— he asks every guy I date if he has any children!" to "I want to have a *bunch* of children with Down syndrome when I grow up!" Adult siblings often go into related professional fields – therapists, teachers, social workers – and the impact of the sibling on the child with Down syndrome begins to reverse as the sibling becomes more and more influenced by what he has learned from his brother or sister.

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Meaghan and Jonathan Watts

Hope Haven's annual Sounds of Hope fundraising event was held on November 29, 2005. Thanks to the following sponsors for making the evening a HUGE success!

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AUCTION COMMITTEE

Jennifer Ancelin Stacey Harper
Amanda Harrington Carol Lombardo
Laura McDonald Rebecca McNeil
Laurie Schellenberg Ingrid Wilson
Linda Van Landingham

Refreshments provided by **Carrabba's Italian Grill**



THANKS TO
COTTAGE BY THE SEA

FOR HOSTING AN EVENING OF HOLIDAY
SHOPPING TO BENEFIT
THE DOWN SYNDROME CENTER!



Be on the lookout for details on next year's repeat event



Friday, November 17, 2006
Featuring Andrew Clarke, Organist
With Carolyn Snyder-Menke, Vocalist



Reception, Silent Auction and Concert Benefiting
**Hope Haven Children's Clinic and Family Center's
Programs for Autism and Down Syndrome**

The Down Syndrome Center at Hope Haven Children's Clinic and Family Center is

dedicated to bringing positive, strength-based assessments and information to the families of children with Down

syndrome. An interdisciplinary team evaluation consists of an education consultation, behavioral / medical evaluations, physical, occupational and speech therapy evaluations.

Families receive a comprehensive report describing their child along with home and/or school suggestions for further growth. In-school visits are available upon request.

DSC team evaluations are funded by a matching grant from the Jessie Ball duPont Fund and other individuals and businesses.

Current funding allows families to pay only a minimal co-payment for evaluations.

For information or to schedule an appointment, contact Diane Simmering (904) 346-5100 ext. 266 DianeS@hope-haven.org www.Hope-Haven.org

These evaluations are not intended to replace primary care or services already in place.

SIBLINGS WITH DOWN SYNDROME

By Lori L. Frazier, LMHC

The birth of a child with special needs impacts a family in many ways. It results in changed plans, shifted dreams, and altered relationships. The good news is that research tells us about the benefits—families may emerge stronger, and self-concepts of siblings with Down syndrome may be enhanced.

Despite special challenges and stressors, there may be more similarities than differences in the sibling relationships of kids with DS and sibs of “normal” kids. Rivalry is a given, and at times the sib with DS may share of parental attention and medical care, education, and... Parents may expect some competition, and even some unusual bids for attention from an older sib. If possible, avoid overreacting to this. *Reflection* is a useful tool – telling your child what their behavior is telling you. “When you throw your toys, it looks to me like you are angry because I am holding your little sister.”

Be on the alert for *survivor guilt*, that is, a sibling’s heightened sense of responsibility because he or she does not have DS. Siblings may fear that they are loved less, or that they need to overcompensate for the challenges their sib with DS may face. Clues to this may be a sense that your child is driven academically, is a perfectionist, or has become overanxious – all typical findings in an older child that may be exacerbated in an older child with a younger sib with DS.

Parents need to be aware of their own needs and feelings, and see to it that they have an opportunity to sort them out through counseling, support groups, or caring friends. Parents who divert their own grieving, self-blame, or other feelings into denial may miss or even deal punitively with similar feelings in their child. It is helpful to recognize that negative feelings need to be acknowledged. They are perfectly normal and acceptable, so long as the behaviors associated with them do not become self-destructive or punitive toward other family members. A child may be angry, embarrassed, or sad that his or her sib has DS and may need to express those feelings before being able to move to acceptance and times thereafter.

By the same token children pick up on their parents’ worries and will benefit from clear communication. If there are health or medical issues, it is important to explain to the sibling of a child with DS the extent of the problem. However, be sure to provide information at a developmentally appropriate level and to filter out parental anxiety whenever possible. Kids look to parents for reassurance and security, and parents are role models for handling stress.

Guidelines for parents may be summarized as **education, expectation, and communication**. Educate siblings on the needs of the family member with DS, and allow your children to feel a variety of conflicting emotions as new abilities and challenges unfold. Expect that the children will adjust in a healthy and positive way, and have confidence that the outcome will be a valuable and unique sibling relationship. Do not expect the “normal” sib to assume the role of caretaker, but allow her to participate in the family member with DS and interest will help parents assume responsibility that is... be alert for a tendency to mimic parental behaviors in an attempt to gain positive attention. Finally, communicate openly – feelings are facts to your children, and there will be a range of those feelings to communicate. Help her to articulate them and do not blame her for expressing negative emotion or tell her that she should not feel what she feels. Rather, help her to deal with the feelings she expresses, while emphasizing the realities and your confidence in her ability to make good and loving choices.

“Guidelines for parents may be summarized as education, expectation, and communication.”

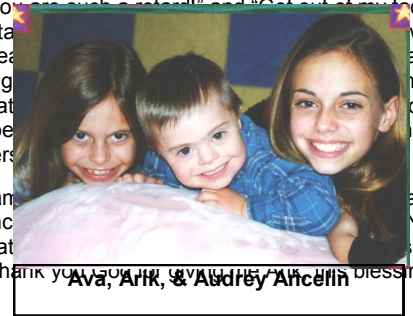
“My brother is sweet. Yes he is the best”
Ava Ancelin, Age 7

My Little Brother Arik

Unedited Version
by Audrey Ancelin, Age 11

There are some days that I just sit in my room and try to imagine what my life, and my family’s life, would be like without Arik. I try and try and try, but the only thing that I can imagine is that our lives would all be revolved around us, and we would not think about other people, and we would not have this happy for who he is, brings a smile to my face little toddler that Arik is. I just feel like Arik came to our family as a blessing, and that God gave him the Ancelin family for a reason.

Here is an example. When Arik was born, I was at the age when my classmates were starting to say, “You are such a nerd!” and “Get out of my face you nerd!” I remember what it meant now. It does not mean that I am a nerd, I am encouraged that I am a blessing. Thank you, God, for giving me Arik, his blessing.”



Ava, Arik, & Audrey Ancelin

ANNOUNCING FUN THURSDAYS

June 5 through July 28
Ages 10-16

- Fun-based small groups
- Designed to improve and/or maintain strength and coordination, motor planning, handwriting and communication
- Taught by licensed therapists and assistants
- Coordinated by a Florida certified teacher
- Scholarships may be available through the Down Syndrome Association of Jacksonville

Space is limited!
For Further Information Contact:
Tara Fox (904) 346-5100

COMING UP SOON.....

WEE P.T.

- Small group physical therapy sessions for parents and young children
- Learn interactive play skills for daily home use
- Enhance weekly therapies
- Meet other parents

For information contact:
Kris Owen (904) 346-5100 Ext. 288

Thank you to
THE BROGAN FAMILY
For their help with Winn Dixie’s Jeans for

“Brothers of mine are cute. Ready always to play. Ofcourse Arik is awesome. The things Arik does are cute. He has the cutest laugh. Every thing he does is just right. Really loves his family.”

By Ava Ancelin, Age 7
(Unedited)

Congratulations!!

Jeff and Stacy Leach, parents of two pre-schoolers, held the winning ticket for the ProTrainer Swing Set, donated by **ADMIRAL HOMES**.

Due to the generous donation in honor of **Jackson Becker Lee** by Eric Rankin Lee and Family, therapy equipment is available for check-out.

Contact Kris Owen at 346-5100 ext. 288.

THANK YOU

To **THE PILOT CLUB** for donating the proceeds of this year’s annual Cemetery Tour to the Down Syndrome Center.

My Best Friend, My Brother

By Jennifer Rimer

As a friend and sibling of a brother with Down Syndrome. However, with Doug as a major part of my life

I was recently married. Guess who helped me plan invitations, and even when I had my make-up done

We've gone on fabulous vacations together: cruises that meals are made a frequent and top priority,

Doug goes shopping with me, and I go to wrestling

Once a week, Doug meets me at work on his day

Doug works three days a week at Publix, where he and his customers came up to say hello to him and ask if he absolutely love him!

Were there times when Doug tested every last ounce of my patience not see as funny when they were happening.

There was the time I introduced a new boyfriend to the family, and Doug promptly shared with all of us that he would stop there - the moment my mom was out of the room, Doug told the new one that the old one was coming back.

And there is the time when I was in high school and I left my rings in the bathroom that my sister, Jill, took them to school to give to his girlfriend. His teacher called me to see if I was missing any of my rings.

The most "famous" Doug moment occurred when he decided to drive my dad's car while our parents were out of town. When I later asked him why in the world he had to do this while Mom and Dad were out of town here to drive when they are in town!"

Life with Doug has never been dull.

I am not just Doug's sister and best friend. There are days when I am also his mother, swim coach, job coach, and social calendar I've ever seen, and it takes our whole family of five to keep up with him and get him where he needs to go.

Being one of his swim coaches gives me a chance to spend additional time with Doug. He joined the swim team to Tampa with our parents and sister a few years later. When he moved back to Jacksonville in 1997, he needed extra coaches, so I volunteered. I had never swam competitively, but I love Doug and his friends, so I coached. Now, nine years later, I am still a coach and have taken on the additional roles of team treasurer and party and trip planner.

Most importantly to me, the swim team gives Doug an opportunity to have a broad social circle that he can go to for movie nights, parties, team trips, and competitions. Doug's only request is that when we do a team trip, he can go.

I want to stress that in no way is our friendship a one-way street. Two summers ago, I was diagnosed with multiple sclerosis and needed round-the-clock help for a couple of months. Not only did Doug stay with me at the hospital for a couple of months, but he also stayed at my apartment for six weeks and helped me do the daily things that I had difficulty doing: walking, cooking and cleaning.

Doug has taught me a great deal about how to enjoy life. I have learned that you do not have to be a "perfect" person, it is fun to get up in the middle of the night and sneak the last Twinkie, and a trip to Baskin Robbins is fun when someone's having a bad day.

I would offer this advice to others who have siblings with Down syndrome: become an integral and important part of their lives. Back everything you give and then some. I know I did. My brother is truly my best friend.



Jennifer and Doug

CALLING ALL SIBLINGS

loyal, fun, caring...and he is my brother, who is Here's YOUR chance to be heard!!

We are looking for siblings to share their thoughts, feelings or quotes about having a brother or sister with Down syndrome for the next issue of our newsletter.

Submit your one-line contribution to:

Diane Summering at DianeS@Hope-Haven.org

The Down Syndrome Association of Jacksonville Announces A New Location!

The Down Syndrome Association of Jacksonville, formerly housed at Hope Haven Children's Clinic and Family Center, has relocated to a new location in downtown Jacksonville that will allow them to expand their offices. The DSAJ is comprised of families, friends and community members who have been inspired by the life of someone with Down Syndrome. The DSAJ offers opportunities for parent support, public awareness and social/recreational activities as well as program funding.

Social/Recreational/Educational Newborn Support Group

Parents expecting a baby with Down Syndrome or have children that are newborn to age five. Group meets once a month to share ideas, information and make friendships. The meetings are informal and often include a guest speaker on topics of interest. Contact Debbie Revels (904) 353-6300

Professional Resource Library

Library is housed at the DSAJ office. Library materials may be checked out for personal use. The DSAJ has the busiest Special Olympics swim team in 1992. He moved to Tampa with our parents and sister a few years later. When he moved back to Jacksonville in 1997, he needed extra coaches, so I volunteered. I had never swam competitively, but I love Doug and his friends, so I coached. Now, nine years later, I am still a coach and have taken on the additional roles of team treasurer and party and trip planner.

Programs funded by DSAJ and Hope Haven Children's Clinic

- **Computer Tutoring:** Individualized computer instruction tailored to provide help with classroom subjects and improve computer skills for students who really can make a difference depending on parent request. Small group weekly computer sessions focusing on fun academic programs for students ages 6 months to 21 years. Call Nancy Oldham (904) 346-5100 ext. 259.
- **Speech Therapy:** Ages 6 months (oral motor stimulation) to young adult. Call Tim Stavropoulos (904) 345-5100 ext. 226.
- **Social Skills:** Social skills group for ages 8 through young adult, to help develop lasting friendships, prepare for vocational opportunities and learn how to establish interpersonal relationships outside of the family. Call Debbie Revels (904) 353-6300.

Mark your calendars!
Buddy Walk—October 21, 2006

DSAJ contact information:
Debbie Revels at (904) 353-6300
1050 North Davis Street
Jacksonville, FL 32209

WWW.DSAJ.ORG

ARTSEACARDS
The Down Syndrome Center receives a percentage of sales from beautiful watercolor note cards depicting beach and Florida scenes designed and produced by Susan Dawood. For ordering information contact Susan Dawood 904-737-1926

We appreciate the many Down Syndrome Associations that have sponsored families to come to the Center for team evaluations!! Thank you for your support and encouragement!!

Some of us really are born to act

By Hector Rivera, Sibling of a mother of a child with DS

When I'd first discovered my new niece was confused and scared for both my no prior experience with DS. Even though I am very close and protective of my family. It was very frustrating to feel so helpless because of my lack of knowledge and understanding about Down Syndrome. I set out to educate myself and more importantly to get involved in whatever way I could with the DS community.

My goal was to either build a play ground or a theater group for special needs kids. I wanted to help but I did not know whom to contact or how to get started. I called information and got the number for DSA Los Angeles Chapter. It was there that I met Gail Williamson, the Chairperson. Gail is a general encyclopedia of information on the Los Angeles special needs community and a general whiz at organizing and fund raising.

When I approached her with my ideas, she mentioned that a theater group already existed. It was called the Born To Act Players. They meet every Saturday at the Los Angeles Valley College.

I did not know what to expect on my first visit. I met the most talented friendly people on that day not least of whom was Mary Rings, the founder and creative director of the Born To Act Players. I was amazed as Mary ran her young performers through improvisational actor's exercises and witty original skits. The Troupe is comprised of Down Syndrome kids and adults as well as actors with Aspergers and other forms of autism. Mary's music, acting, and, dance teachers were so professional and encouraging of the performers ability to explore new material, it was hard not to be impressed.

By the time Kristine Johnson began reciting a beautiful monologue from Shakespeare, I was fully aware that my beautiful new niece was going to be okay. As a matter of fact, after seeing how talented the Born To Act Players were and their love of theater and each other, I was proud to play any small part in supporting this group.

Born To Act has done an all—Broadway musical show that included

King," and "Oklahoma!" They've had two original shows of works we performed for the North Universal City Chamber of

Commerce, the LA Buddy Walk and the National Down Syndrome Congress. Many of the performers have appeared on TV shows like "ER," "The Guardian," "Nip Tuck," and "The Princess Diaries."

I dream that one day Mary and The Born To Act Players will perform and teach others how to create a BTA in their own town. My hope is that one day there will be a BTA in every major city in America. It really is that good, and if you saw them perform I am sure you would agree. We're presently pursuing nonprofit status, and the next big show will be in February. It is a production of all—Disney musical numbers. I am sure it will not disappoint. The Born To Act Players are always at the top of their game.

Please visit us at Borntoactplayers.com



Born To Act Players

Hope Haven Children's Clinic
Down Syndrome Center
4600 Beach Boulevard
Jacksonville, FL 32207-7700

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