

*Flying Lessons*

**Laura Watts, M. Ed.**  
Program Director

When our son, Jonathan, was born with Down syndrome 18 years ago, he spent 16 days in intensive care before being released to come home. A special time of bonding began the very next day – the first day since his birth that I had him free from wires, tubes and machinery. The rest of the family was gone, the house was quiet, and I sat with him, glasses-in, and our house filled with delight. I was a mother sparrow who had hatched their wings.

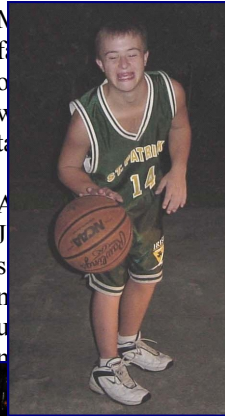


After modeling times around the ten-foot by ten-foot square, Bird flew to the top of the atrium and perched comfortably on a rafter ready to enjoy the called to Baby One and waited. Up he flew, soaring around her and finally she called for her next offspring. He spread his wings and flew – stunned, he carefully picked his way back up to the nest. Mama called with the same enthusiasm, same result. For two days, the thud of bird wings was heard all over the house. The place of peace and refuge for me.

It was frustrating to watch - and I wanted to reach into the nest and catch him. I played music. I turned on the air conditioner, closed all the windows. But still I could hear the shrieks of the mother and the thud of the baby. Occasionally Mama would fly away with Baby One, always returning with louder shrieks and more animation. Eventually she returned alone, yet her patience was undaunted, her attitude unchanged. She would settle back up on the rafters and wait. Oh, how she must have longed to scoop her baby up under her wings and carry him to his freedom!

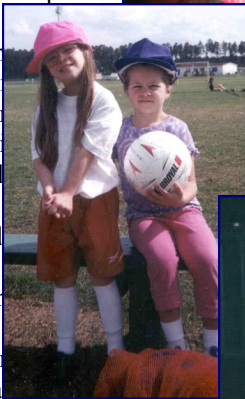
I became an avid part of that family as I hurried to the

window every time I heard silence in anticipation of Baby Two's upward flight. Finally, the consistent calling became excited and changed to a faster twitter as the thuds ceased. I watched as Baby Two joined me and my heart soared with them. I ran to the house, and the oppressive air was lifted. I knew I had been allowed to learn a lesson in child rearing that would I comprehend.

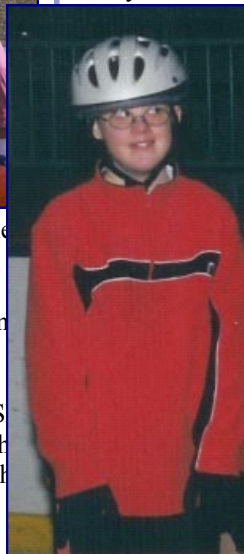


As I have watched with pride as Jonathan finally developing skills his mother mastered with ease. The true sparrow's lesson has steadily become to be awed by what I saw in the of the lesson was not the but simply that *both* of them had to fly.

At times we are sometimes afraid of this flight to freedom. We have valid concerns – safety, fear of assessment (for the child and parent) or health. Over the years, the Down Syndrome Center has worked with parents who have helped their children spread their wings. From their experiences, we have learned that safe flight is possible.



Get ready to be airborne! Begin the flight to independence as early as the toddler years. Provide practice sessions in the home where a situation is acted out and the appropriate way to respond is modeled. Give your adolescent responsibilities with a check list similar to the pay check he may someday receive. Well done. Define safe boundaries and be responsible for his actions. Talk about ways to make them a reality. And be patient. Watch. Try again. And expect her to



*...it seems impossible, but I figure if I let my child aim for the stars, she might get to hit the tree tops. It's better than aiming for the tree tops and merely leaving the ground!"*

Tracy Adams, mother of Amanda, now age 24, is celebrating Amanda's younger years.

**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 Tracy Carter**  
(904) 346-5100 ext. 266  
TracyC@hope-haven.org  
www.Hope-Haven.org

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

# INDEPENDENCE: A CONDITION DEVOUTLY TO BE WISHED

By Timothy Stavropulos, M.A., CCC-SLP  
Director, Speech and Language Department

from tyranny. Innovative sports associations struggle for independence from established leagues. Independent candidates strive to give voice to ideals apart from the political mainstream. Teenagers endeavor to gain independence from their parents. Special-needs individuals battle for independence from the constricting bonds of their handicapping conditions - whatever they may be.

*FIGHT..... STRUGGLE.....  
STRIVE..... ENDEAVOR.....  
BATTLE*

Wherever the call to independence exists, it takes effort to make it a reality. That, plus an accepting environment where opportunities to apply effort abound and reinforcement for positive and proactive behavior is commonplace.

One common factor in all quests for independence is an ability to communicate. This is no small challenge for many individuals with Down syndrome; and to be certain, much time is spent on bolstering fundamental communication skills such as articulation, voice control, fluency, sentence-making ability and vocabulary development.

However, even during these more basic tasks of speech/language acquisition, the opportunity to foster independence exists.

Choosing high interest materials can facilitate ownership of a task and an enthusiasm for it. The more familiar an individual is with the subject matter to be discussed, the more animated and voluntary the participation will be. Since high repetition is part of building speech and language capabilities (Think of

I"; instead of, "Me and my friend"), the advantage of utilizing high interest materials becomes even more apparent.

Predictable language routines which are a natural part of all play and/or learning activities should be shaped and emphasized. Typically, these are statements used to request play objects, phrases used repeatedly throughout the course of play, and those statements which can be used to signal the end of an activity or the desire to move on to something else.

Greeting and parting phrases, family story sharing times, show-and-tell exercises, repetitive use of social/polite language, directed question-and-answer exchanges, encouragement to ask for help when needed -- all serve as key elements in reinforcing the power of initiation -- which is the essence of communicative independence.

When it comes to communication, independence is a goal for all to achieve. For it means an ability to sort through incoming messages, process meaning, and formulate responses on one's own. It means recognizing occasions where initiation of the message is called for and acted upon. It means possessing enough speaker confidence to start to and maintain conversations.

Independent thinking is almost always followed by independent communication. In order for both to thrive, individuals and families must be willing to put forth the effort and to seize upon the endless number of day-to-day communication "moments" during which each participant is expected to share a statement, an opinion, a feeling, or a

ion.

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 Tracy Carter at 346-5100 ext. 266.

# MARK YOUR CALENDARS

## **Admiral Homes and Radio Disney Team Up to Help Hope Haven Kids**

Mark your calendar for two great Radio Disney live events at Oak Leaf Plantation model homes in Southwest Jacksonville on September 17 and November 5. Join the Disney fun squad between 1 p.m. and 3 p.m. for two hours of fast-paced entertainment, music, the Radio Disney Street Machine and great Disney prizes.

Sponsored by Admiral Homes, the events will include the chance to meet Radio Disney AM 600 personalities and an opportunity to buy tickets for a Pro Trainer Swing Set, valued at \$3,500, which will be raffled off at

**Hope Haven's Concert and Silent Auction on  
November 29.**

Call Anne Wall at 904-346-5100 ext. 250  
for information and directions,  
or visit our website at: [www.hope-haven.org](http://www.hope-haven.org)



**Raffle tickets \$10 each or three for \$25.**

## **WE NEED YOUR HELP!**

**WE ARE SEEKING ITEMS  
FOR THE  
NOVEMBER 29, 2005  
SILENT AUCTION AND  
CONCERT.**

**SUGGESTED DONATIONS  
INCLUDE:  
GIFT CERTIFICATES  
GET AWAY PACKAGES  
DONATED SERVICES OR ITEMS  
PROFESSIONAL ARTWORK  
CHILDREN'S ITEMS**

**CALL ANNE WALL AT  
(904) 346-5100 EXT. 250  
FOR INFORMATION**



**TUESDAY, NOVEMBER 29, 2005  
6 P.M.**

***Back By Popular Demand!*  
AN EVENING WITH CHARLOTTE AND FRIENDS**

**featuring Charlotte Mabrey, Percussionist**

**REFRESHMENTS PROVIDED BY CARRABBA'S ITALIAN GRILL**



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

## **Down Syndrome Association of Jacksonville**

offering parent support, public awareness, social activities, and program funding

- **Social Skills Groups**
  - Age-based groups focusing on emotions and socially acceptable behaviors
  - Age and gender-based groups focusing on sexuality
- **Individualized Assisted Tutoring**
  - DSA individualized computer instruction program:  
This program can be tailored to provide help with classroom studies and homework, introduce basic computer skills or supplement a child's academic instruction, depending on parent request.
  - Small group weekly computer sessions focusing on fun academic programs
- **Keyboarding Classes**
  - A tutor-based keyboarding class with OT consultation introducing basic keyboarding skills and introducing email and keyboarding skills for employment
- **Speech Therapy**
- **Summer Programs**

For more information, contact **Debbie Revels** at (904) 346-5100 ext. 286 or via email at [dsa@hope-haven.org](mailto:dsa@hope-haven.org)

**New Website for The Down Syndrome Association of Jacksonville:**  
Please take a moment to visit the new and improved website of The DSAJ. You will find recent articles on Down syndrome, links to other resources, current events of the association and much more. Save it in your favorites as the information will be updated on an on-going basis.

The address is: [WWW.DSAJ.ORG](http://WWW.DSAJ.ORG).

**Mark your calendars: Buddy Walk — October 15, 2005**  
The Down Syndrome Association is in the process of forming a Buddy Walk Committee. There are many opportunities for you to explore. If you would like to be a part of this committee, please contact Debbie Revels at 904-346-5100 ext. 286 or Jennie Ponder at [dsa@hope-haven.org](mailto:dsa@hope-haven.org).

# The first Day

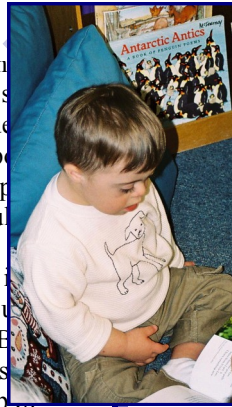
By Jennifer Ancelin

As I stood in the hallway, waving on my face, I watched the profile smaller through the crack of the door. He was seated on the floor with an apple and as the door clicked shut, I instantly turned on the ears. Was that a cry? Then why was I trembling so with my throat? Wasn't I standing in, after countless visits to schools around the entire city, what I considered to be the best, state-based, learning environment to develop my son's unique potential? Did I not check teacher credentials, acquire professional referrals from other parents, and yet most importantly spend hours getting to personally know the school's wonderful and exceptional staff?

My husband, who was pleased to be changing the film on the camera for the third time in the last 15 minutes, looked up and raised his brow, then asked if I was going to throw up. Before I could choke out an answer, I felt the arm of the school's principal slip into mine. Not exactly the brown paper bag and cup of strong black coffee I was yearning for, but stability for sure. I asked my husband and me if we would like to come into the office next to my son's classroom where we could observe him through a one way window.

There he was, still sitting on the floor. He had a little gooby hanging out of his nose but was no worse for the wear. His look had changed to more like cautious curiosity than apprehension. He became a little miffed when the teacher came over and wiped his nose, but that was par for the course. What was my problem?

It was the first day. Not just the first, first day of school, but the first day of an intense uncertain educational journey. This was



Arik Ancelin

(IEPs, ESE, IDEA, LRE, and were tough enough.) But here I am, a single parent, getting on with the director showing my son how to enhance fine motor skills. When I was dropping pig toys, I began to cry. I wasn't riding alone. There were many other gifted, professionals on board, too. My breathing began to slow, and finally my husband was able to drag me out of the office. So I could run directly to the one hour photo session to get one of those pictures, of course.) Thank you for choosing to journey with my son, and my greatest hope is that even when the ride gets bumpy like there is a dead end, you will stay on board and find alternative routes. Together, we can get through the first few more days, and arrive at potential.

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