



HEART STRINGS

A bi-monthly publication for families and friends enriched with the Down syndrome connection.

Our children and adults with Down syndrome are the heart of our organization - and our most precious gifts.

May/June 2008

Message from Executive Director

The school year is almost over and it's time to start making plans for summer activities. For parents who need full-time care for their school-aged children or who could benefit from well-deserved respite time, the summer months can be difficult. I am pleased to report that the YMCA has increased its focus on including youth with disabilities in their summer day camp program. A committee was formed last fall, comprised of staff from the YMCA, specialists from both school systems, and parents of children with disabilities, to explore ways to improve their services to this population of children. OMHS has joined this collaborative effort by providing some limited funding that will increase the number of trained counselors available.

My son, Matthew, attended the YMCA Summer Day Camp last year and loved every minute of it. It kept him active and engaged in different activities with his peers. Space is limited and campers are enrolled on a first-come, first-served basis, so if you are interested, please contact Amanda DeLacey at 926-9622.

This issue of *Heart Strings* contains information on educational opportunities, ideas for summer recreation, and a story on Sam Fenwick's successful year in the regular kindergarten classroom, as well as tips on how schools can support inclusion for students with disabilities. While there is a whole spectrum of inclusion, parents should be aware that there are many options available so they can make an informed decision based on what they feel is best for their child.

Many of you may not be aware that the Sherrard family is moving to Louisville the end of May. We will miss them and hope they will keep in touch with their GRADSA family. I would like to thank Catherine and Eric for their support of GRADSA, through the use of conference & lodging facilities, sponsorships, and help with the Buddy Walk. We wish them all the best!



Please keep the following individuals in your prayers:

Ben Pace had his tonsils and adenoids removed in March at Vanderbilt. His surgery went well but he developed bronchitis and had to be readmitted to the hospital. They are still hoping to get his trach out soon.

Krystyn Randolph had spinal cord surgery (due to atlanto-axial instability) on April 2 in Louisville. Her surgery and recovery have gone amazingly well and she was able to come home on April 25.

Jonah Edge had oral surgery on April 22 in Cincinnati. He had 10 teeth extracted but was home the same day and is currently doing well.

Be sure and check the Calendar of Events for upcoming activities. Hope to see you soon!

Cindy Huston

Calendar of Events

Assistive Technology - Thursday, May 8, 6:00 p.m., at the Wendell Foster Center, 815 Triplett Street, Owensboro. Kris Hayes, Coordinator of the Western Kentucky Assistive Technology Center (WKATC), will take us on a tour of the center, which houses developmental toys, positioning tools, and computer gadgets that can enhance sensory adaptation, speech skills, and cognitive ability. Families are allowed to borrow items to use for a short time or test-drive new products before deciding whether to purchase it. Snacks and refreshments will be available. **Please RSVP to Cindy Huston.**

Dad's Golf Outing - Saturday, June 7, 8:00 a.m. at Ben Hawes State Park Dust off those clubs and get ready for a day on the greens. **Please RSVP to David Huston at 771-4945 or dhustonuk@yahoo.com**

Education Fair - Thursday, June 26, 6:00 - 8:00 p.m., at the Family YMCA (After School Room on 2nd floor). Submit your order for an educational item (see page 2) by May 30 and pick up on June 26. Pizza and refreshments will be provided. If you are not able to pick up your item on this date, please contact Cindy Huston.

Pool Party - July (Date TBA - more details in next issue)

SibShop - Saturday, August 23 (more details in next issue)

Holiday World Outing - Saturday, September 13 (more details in next issue)

Annual Meeting

GRADSA's Annual Meeting will be held in conjunction with our Education Fair on June 26. We will be holding elections for the position of President-Elect, a 2-year commitment. **If you are interested in serving GRADSA in this capacity or to find out more information, please contact Matthew Williams at (270) 929-6348.**

2008 Buddy Walk

It's time to gear up for the 2008 Buddy Walk, scheduled for Saturday, October 4. **As our walk continues to grow and impact the community, we are in need of a Buddy Walk Coordinator, a part-time paid position, to coordinate all aspects of the walk and provide leadership to a committee of volunteers.** The coordinator position would require a 6-month commitment, from May - October, at approximately 15-20 hours per week. The coordinator would chair sub-committees of fundraising, registration, facilities, and public relations, while overseeing auction, food, and activities committees. Candidate must be highly motivated, a self-starter, detail-oriented, with excellent computer skills, and the ability to communicate with a wide range of constituents, including children and adults with Down syndrome and their families, as well as the media.



We also need energetic and dedicated volunteers to serve in a variety of positions on the committee. If you are looking for a way to get involved in GRADSA activities and make a difference in the lives of individuals with Down syndrome, this is your chance to help support a wonderful event!

For more info, please contact Matthew Williams at (270) 929-6348.

Education Fair

GRADSA has expanded its Education Fair to provide a variety of options for continuing educational opportunities. Below are just a few items that you may be interested in. GRADSA will purchase the items and they will be available for pick up on June 26 from 6:00 - 8:00 p.m at the Family YMCA. **Please submit your order to Cindy Huston by May 30. If you have any books that you no longer need, please send them to us so we can pass them on to other parents.**

Wrights Law Books

From Emotions to Advocacy
No Child Left Behind
Special Education Law

Woodbine House Books

Mental Wellness in Adults with Down Syndrome
Fine Motor Skills in Children with Down Syndrome
Gross Motor Skills in Children with Down Syndrome
Early Communication Skills for Children with Down Syndrome
Classroom Language Skills for Children with Down Syndrome
Negotiating the Special Education Maze - 4th Edition **(New!)**
Teaching Math to People with Down Syndrome Book 1: Basic Survival Skills
Teaching Math to People with Down Syndrome Book 2: Advanced Survival Skills **(New!)**
Teaching Reading to Children with Down Syndrome
Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality **(New!)**

The Education Fair is open to parents and educators! Please take advantage of this opportunity to choose an educational item that will benefit your child/adult with Down syndrome or students with Down syndrome in your classroom. There are many things to choose from on this list, however, if there is a specific item that your child's teacher or therapist has recommended, please let us know.

Signing Time DVD's

Choose from the following volumes: My First Signs, Playtime Signs, Everyday Signs, Family, Feelings and Fun, ABC Signs, My Favorite Things, Leah's Farm, The Great Outdoors, The Zoo Train, My Day, My Neighborhood, Time to Eat, and Welcome to School

Talking Calculators - Great for teens and adults!

Simplify math computations with this easy-to-use calculator that "talks." States all entries and computations in two ways: complete number speech ('seventy-eight') or digit by digit ('seven, eight'). Allows students to see, hear, and learn math.

Super Duper Publications - Fun and Creative Educational Materials

Check out their online catalog - www.superduperinc.com - and choose an item up to \$25. If you do not have access to a computer, we can send you the catalog. Please submit the product number and complete description of the item.

Educational Opportunities

The National Down Syndrome Congress is hosting its 36th Annual Convention on July 11-13 in Boston. Through this convention, you can connect - meet, hear and learn from the best minds in our community on virtually every aspect of Down syndrome. From keynote speeches to workshops to casual gatherings of parents and professionals, you will discover exactly what you need to meet challenges, present and future. Early response to this convention has been extremely high, and since space may be limited, you should register ASAP. More info about the conference can be found at www.ndscenter.org.

The ARC of Kentucky will be hosting its 53rd Annual Conference "Unbridled Possibilities: Best Practices for People with Intellectual and/or Developmental Disabilities and their Families" on June 6 & 7 at the Executive West Hotel in Louisville. Below are a few of the breakout sessions:

- * Supporting Positive Behavior
- * Future Planning
- * It Takes a Village: Outside Resources/Linkages
- * Transition Means College, Too!
- * Transition Rich IEP's
- * Inclusion for Students with Intellectual Disabilities in an Age of Accountability
- * Knowing Your Rights...Including Voting
- * Transition to Adult Life
- * Employment with Social Security & Medicaid Supports

In addition to GRADSA's Education Conference Fund, there are also stipends available for parents through the Kentucky Council on Developmental Disabilities. Through both organizations, you should be able to cover your expenses to attend either of these conferences. For more information, contact Cindy Huston at (270) 771-4945 or e-mail info@gradsa.org.

Summer Vacation: Time for Fun and Time to Plan

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

Ahhhh, summertime—vacations, swimming, camping, family time, lazy days, and more. Make this your family's best summer ever, and at the same time, lay the groundwork for a successful school year when September rolls around.

If your child is included in typical, inclusive community activities this summer, not only will she have a wonderful time and make new friends, she'll also demonstrate that she can be included in "regular" activities. This can be a very important piece of "evidence" at her next IEP meeting! And while your child is having fun, you'll be creating new friends who can be valuable allies in your efforts to ensure your child is in an inclusive classroom at school!

You may be thinking, "My child can't participate in 'normal' activities—there's no way all this will work for us." But your child can be successful in inclusive community activities! Read on—

Begin by checking out all the organized activities in your community that your child might enjoy, such as YMCA or Park and Recreation classes/sports; library/museum classes; and Scouts, Campfire, 4-H, etc. Look for activities that will enable your child to be with similar-aged children without disabilities who may be classmates during the next school year.

In addition, put your thinking cap on and consider what activities you could orchestrate: a neighborhood play date every Friday, a field trip to community activities (zoo, park, etc.) once a week, or anything else that will enable you and your child to make new connections in inclusive settings.

As you check out organized activities, learn as much as you can about them ahead of time: ask other parents; observe the activity, if that's possible; and/or call the sponsor and ask lots of questions (but don't mention your child's disability at this point).

While you're doing this "reconnaissance," think about what your child will need to be successful: physical or environmental modifications, assistive technology devices, support from other children or an adult leader, and so forth. Your child doesn't need a one-to-one aide; that person will get in the way of your child making real connections. Instead, teach your child how to ask for help from whoever is closest—another child or the adult leader or volunteer. (My articles, "Ask and You Shall Receive" and "When Less is More" might be helpful.)

Next, talk to your child and enthusiastically share what you've learned! Describe the activities, share your ideas about supports and modifications he might need, get his input, listen to his concerns, and let him make the final decision about which activities he might want to try. It might even be possible for your child and another family member to participate together. When my then 9-year-old son, Benjamin, took karate classes, his dad took the class with him! This class was for all ages, and my husband knew to "back off" and allow Benjamin to make friends, instead of sticking to him like glue!

Next, enroll your child and don't say one word about his disability at that time. At enrollment time, try to learn more about the activity, the other participants, and so forth, and then modify, as necessary, your ideas about supports, accommodations, etc. A few days before the activity starts, call the leader and, in a positive, helpful manner, describe what your child will need and

describe how it can be done. You do not need to disclose your child's diagnosis (that can be scary for some people to hear)—you only need to share what your child needs!

Say something like, "Since my son uses a wheelchair, he'll need some assistance with..." or "My daughter will do best if she has a couple of peer helpers." Don't ask permission for these things and don't whine or get angry! Simply state what your child will need and describe how to provide it. If you tell people what your child needs, without describing how to provide the help, they may not know what to do and failure is likely. And, of course, do all this with excitement, good manners, kindness, and patience, developing allies in the process! If the leader of the activity demonstrates any concerns or resistance, stay positive and ask, "What will it take for you to feel more comfortable," and assure the person that this will be a successful adventure if the lines of communication remain open!

You may not think you know what supports and accommodations your child needs, but you really do—you're an expert on your child! Sit and ponder, talk with others, brainstorm with family members, and ask your child. Your first ideas may not be perfect, and that's OK. After the activity begins, you and your child, along with the activity leader, might need to fine-tune things. And this is great—everyone can learn together!

Now, onto the next phase: developing allies! Contrary to popular opinion, the best people to assist parents in achieving school inclusion are not other parents of kids with disabilities or professional advocates. Bringing "big guns" to the IEP meeting can inflame an already heated situation. The best helpers are those who do not bring "special ed expertise" to the meeting—like the new friends you'll be making over the summer—who can bring common sense and cool heads to IEP meetings.

Once your child is involved in inclusive summer activities, your job is to become friends with the other kids' parents, the activity leaders, and/or volunteers. Reach out to them: invite their children over to play, offer to carpool, organize a pot luck supper after a big game, volunteer to help with the activity (but not as your child's aide—help all the kids), or do whatever it takes to create and maintain new friendships.

As the relationships develop, brag about your child's gifts (has a great memory, is happy, is trying really hard to talk, collects baseball cards, etc.). After you've detailed positive characteristics—and only then—share more about your child's needs related to his disability, and do this in a way that generates a positive, respectful, and accurate portrayal of your child. Say, "My son needs behavior supports," instead of, "He has behavior problems." Say, "My daughter uses a communication device," instead of, "My daughter is non-verbal."

As you get to know these new friends, tell them you'd like your child to be included in a regular ed class in the neighborhood school with supports and accommodations. At the same time, do not tell all your war stories about educators you don't like! You want to build bridges and create allies, and slamming others (even if they deserve it) doesn't help! You can, however, share general information about how schools have traditionally undereducated students with disabilities in segregated classrooms, and how harmful this practice has been (like contributing

(continued on page 5)

A Successful Inclusion Experience



I can't believe this year is coming to an end! It seems like yesterday that I was walking Sam to class on his first day of Kindergarten. I had so many questions in my head as I left him that day.

Keith and I had decided it would be best for Sam if he were in a regular education setting at our home school, Deer Park Elementary. While I believe this is best for him, I did have concerns about several issues (i.e. the length of the day, going to specials, fitting in with the other kids, bathroom issues, and eating lunch). I was worried the teachers and assistants wouldn't be able to figure it all out.

I felt like I was holding my breath for the first month or so. Each day when I would pick him up I would ask "How was his day?" and the answer was almost always "very good." By October, I felt myself start to relax a little and realized that this is working and he loves school! I knew it was going to be a successful year when I heard positive comments from the principal, music teacher, his therapist and many others that worked with him.

I am still amazed at how much he has learned this year. He is writing his name, knows many

of his letters and numbers and surprises me daily with knowledge that he has gained!! We cannot say "Thank You" enough to all of his teachers, assistants, therapists, the principal, and everyone else that comes in contact with Sam throughout the day. Without their support and belief that he could be successful, none of this could have happened!! I saw many situations where adults at Deer Park would take the time to show Sam the right way to do something or redirect him. It is a team effort from everyone involved.

When I visit school, I love to watch how other students, from kindergarden through 5th grade, interact with Sam and talk to him when they pass in the hallway. It is a wonderful opportunity for all the students to develop friendships with each other and learn more about the differences in our world! It is amazing the impact that our children can have on others. I am sure we could all write a book about the experiences we have had.

To sum it up, Sam had a great year and I can exhale—at least until next year!

Susan Fenwick

Sam enjoys going to the reading center each day. He has impressed me with the sight words he can read. He has many friends who love to help him any way they can. Sam is often found in the hallway with his signal up following his class. I'm so proud of the growth that Sam has made this school year.

Julia Boling, Teacher

Supporting Inclusion

Although children with Down syndrome have additional educational needs, they also have many of the same needs as the other non-disabled pupils of their age. They will make the most rapid progress if they are fully socially included and accepted, benefiting from age appropriate role models and from the benefits of feeling that they are part of the ordinary community. This social acceptance will have a profound effect on self-confidence, self-identity and self-esteem – if the whole school community is one that is caring and supportive to all its members.

For achieving successful inclusion in school, the most important predictor of success is staff attitude. The staff must feel positive about inclusion and believe that the child should be in their school.

Whole school responsibilities include:

- valuing diversity
- the importance of positive attitudes and setting the framework for inclusion – understanding why the pupil is in your school, your class, and how the pupil will progress through school
- organizing management responsibilities for planning and support systems, including making resources
- proactive involvement of parents, carers, and services
- positive approach to problem-solving.

Planning for the individual child:

- learn about the specific profile and effective interventions for pupils with Down syndrome
- learn about the pupil's understanding, skills and strengths

Supporting Inclusion (continued from page 4)

- learn about the times and situations in the school day that are more difficult to manage successfully – for the pupil, peers and staff
- use the pupil's strengths to support successful learning and development e.g. social strengths, learning with peers
- adapt and plan, as necessary, for the individual – using the curriculum for age peers as your starting point
- be flexible, but also cautious about interventions that do not have a clear rationale/evidence
- share adaptations with partnership services and parents.

Applying the typical profile:

- strengths as visual learners
- learning from listening is difficult
- reducing speech and language demands
- reducing literacy demands – support for reading and recording
- reducing motor demands – mounting work into scrapbooks, increasing text size
- reducing sustained attention demands and building on memory skills
- good awareness of social and emotional cues; use of reward and praise
- good social learners; learning from peers through observation and imitation.

Promoting effective learning skills:

- meaningful activities based on pupil's experience
- visual resources and approaches to aid comprehension of abstract concepts and task demands
- new activities based on existing skills
- small steps with opportunities for practice
- applying skills in different contexts, situations.

Differentiation and individualized learning:

- IEP targets – specific outcomes for the child across different curriculum areas over a short period of time
- Some learning may take place in a 1:1 setting – all children could benefit from some 1:1 time.

(Note that too much individualized learning can reduce exposure to age-appropriate models of behavior/language and opportunities for student-student interaction. It can lead to social exclusion and the pupil feeling 'different' from the class. It is also very demanding for the pupil and the assistant to work 1:1 for long periods.)

Inclusion will work differently for each school and for each individual child. What works for one may not work for another. A flexible approach needs to be adopted so that successes can be celebrated and changes can be made for those areas where the outcomes were less favorable. As with most things, we can all learn from each others' experiences. If we wish to make a difference in the life experiences of children and adults with disabilities, all children need to grow and learn together. Neighbors, friends and workmates of adults with disabilities will then have the opportunity to value the person first, to realize that everyone has strengths and weaknesses and that everyone has a contribution to make to a caring society. Developing caring, inclusive communities improves the quality of life of all members of the community.

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Summer Vacation: Time for Fun and Time to Plan (continued from page 3)

to the 75 percent unemployment rate of people with disabilities). Your new friends will see that since your child is experiencing success in typical summer activities with supports and/or accommodations, he could also be successful in a regular ed classroom with curriculum modifications, supports, and so forth.

As the lazy days of summer pass and your friendships deepen, ask your new allies for help with school inclusion. They may be able to recommend general ed teachers, get you connected to educators who can become allies, and/or use their influence on behalf of your child! They can attend the IEP meeting and provide "testimony" about your child's inclusion in summer activities.

Resolve to enjoy every precious moment of summer vacation! Have fun as you get your child involved in inclusive community activities, make new friends, and begin a journey that can lead to inclusive education! With the appropriate supports, accommodations, assistive technology, and/or modifications, every child can be successful in inclusive settings—in the community and at school! Success in these settings will put your child on a path to success as an adult—in a job, at college, and for the rest of his life!

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A Reason to Celebrate

GRADSA invites its readers to share their reasons for celebrating! Please send your submission to P.O. Box 2031, Owensboro, KY 42302, or email: info@gradsa.org



Trevor Brown attended the Hancock County High School Prom on April 12 and had a GREAT time!



Matthew Huston was selected by his teacher, Mrs. Duke, to receive the Character Kid award for "Courage" during the month of March. Mrs. Duke chose Matthew because he did a wonderful job in the P.T.O. performance. He showed courage performing in front of a large crowd, something he would not have done last year. Matthew is in kindergarten at Sorgho Elementary School. Good Job Matthew!



Forget about the bunny, **Landon Ashby** is excited about his new baby brother, who will arrive this summer. Congratulations!

News

Brescia University will be offering tutoring services this summer during the weeks of June 9 - 26. Details are still tentative, but 1-hour sessions may be held in the mornings on Monday/Wednesday or Tuesday/Thursday. Cost is \$10 per hour. Space may be limited based on tutors available and finances. For more information, please contact Mary Alice Wethington at (270) 686 - 4230 or maryw@brescia.edu.

The YMCA will be offering summer day camp for children with disabilities ages 5-16 who are toilet trained. The summer camp program is a great opportunity for your child to be in an inclusive recreational environment. Space is limited so please contact Amanda DeLacey at 926-9622 for more information.

Would you like to receive the newsletter electronically instead of by mail? If so, email us at info@gradsa.org. The newsletter is also posted on our website - www.gradsa.org

The Buddy Baseball League is for individuals with physical or mental disabilities ages 5 - 20. The Brescia University baseball players and the Owensboro Oilers have committed to being buddies/coaches for every player. Tentatively, the season will run during June-July and games will be played at the Cliff Hagan Boys & Girls Club. There are no registration fees to participate. **For more information, contact Billy Shain at (270) 315-9925 or bshain@omuonline.net.**

A "Lose the Training Wheels" Bike Camp will be held in Evansville on June 2-6. Each rider will participate in a 1 hour and 15 minute session per day. Cost is \$150 and includes a helmet and T-shirt. For more information, please contact Patty Balbach at (812) 479-1411, ext. 268.

The Golden Access Passport is a lifetime entrance pass to national parks, monuments, historic sites, recreation areas, and national wildlife refuges for citizens or permanent residents of the United States who are blind or have a permanent disability such as Down syndrome. The Golden Access Passport admits the pass signee and any accompanying passengers in a private vehicle if a park has a per vehicle entrance fee. For locations where a per person entrance fee is charged, the Golden Access Passport admits the pass signee, spouse, and children. The pass also provides a 50% discount on federal use fees charged for facilities and services such as camping, swimming, parking, boat launching, and tours. The passport must be obtained in person at a federal area where an entrance fee is charged. You must show proof of medically determined disability.

Check out
www.gradsa.org
for links to
media stories on
Down syndrome.

Easter EGGstravaganza



Colin Powers enjoyed visiting with the Easter Bunny.



Ashley Hagan showed off her Easter tattoo.



Leland Isbill checks out the goodies he found in his eggs.



Despite the cold weather, we took a quick trip outside to hunt the eggs.



Ethan Smith played ball with his brother.



Robbie Sherrard flashes his trademark smile.



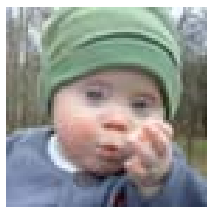
Krystyn Randolph gets a hug from the Easter Bunny.



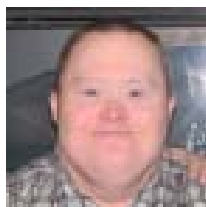
Zeb Wells was ready to play ball.

May/June Birthdays

Larry Basham, 29 years old on May 25
Mason Clark, 1 year old on May 1
Joseph Clements, 6 years old on June 27
Amanda Eaton, 30 years old on May 25
Chris Hagan, 45 years old on June 18
Dustin Lee, 25 years old on May 31
Tina Miller, 44 years old on June 17
Colin Powers, 9 years old on May 13
Jason Snell, 39 years old on June 15
Blake Spainhoward, 9 years old on June 26
Neal Sweeney, 50 years old on June 1



Mason Clark will be 1 year old on May 1 .



Neal Sweeney will be 50 years old on June 1.

Fazoli's Birthday Club - Fazoli's, 5060 Frederica Street, is treating individuals with Down syndrome to a free meal to celebrate their birthday. Children ages 12 & under can choose a kids meal while teens & adults have their choice of a small spaghetti with marinara or meat sauce. To receive your free meal, show this column to the cashier during the month of your birthday.

Mission Statement

GRADSA's mission is to enable families enriched with the Down syndrome connection to share resources, build friendships and advocate together for the future of individuals with Down syndrome.

Services

GRADSA, an affiliate of the National Down Syndrome Society and the National Down Syndrome Congress, is a non-profit, 501(c)3 organization that provides its members with a bi-monthly newsletter, educational workshops, social activities, a website (www.gradsa.org), a new parent outreach program, and a hospital outreach program. There are no membership fees to join.

Policy Statement

GRADSA does not endorse any specific therapy, treatment, or educational setting. We provide a variety of information and viewpoints, however, each family must make an individual choice.

Printing of Articles

GRADSA welcomes articles from parents, professionals, and other interested parties. Material for consideration should be sent to Cindy Huston. Articles written for *Heart Strings* may be reproduced if credit is given to the author and GRADSA. Permission to reprint articles not original to *Heart Strings* should be acquired from the original source.

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The next board meeting will be held on Monday, May 12, 5:30 p.m., at the Family YMCA. All board meetings are open to the general membership.

If you have an address change or would like to discontinue your subscription to *Heart Strings*, please contact us!

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GRADSA
GREEN RIVER AREA
DOWN SYNDROME ASSOCIATION

