

DSAM insights

quarterly newsletter to support persons with Down syndrome and their families



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DSAM

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Stepping Up and Moving Forward

The Down Syndrome Association of Memphis and the Mid-South (DSAM) is excited to share developments for our October Down Syndrome Awareness Event. The 2008 Buddy Walk for Down Syndrome Awareness raised \$130,000, and had 4,200 participants! This annual event allows us to continue our mission of supporting and empowering people with Down syndrome and their families.

DSAM has watched the Buddy Walk grow and impact the community for eleven years. In an effort to continue our positive outreach to the community, our Board of Directors has joined with other Down syndrome affiliate groups across the country to rename the annual awareness event.

Step Up for Down Syndrome is our redirected effort to include Down syndrome in the event name as well as initiate a positive call to action for the entire Mid-South community.

What happens to funds raised through this awareness event?

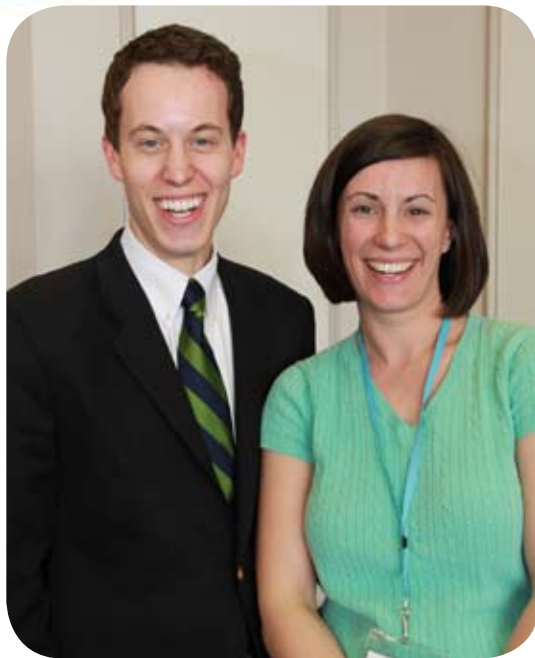
- DSAM donates a portion to the National Down Syndrome Society (NDSS) Policy Center
- Event expenses are covered through the \$10 registration fees
- Additional donations and funds raised go towards our local programming:
 - New parent packets
 - Parents and Schools in Partnership
 - Education and training for families
 - Advocacy efforts
 - Social events

Step Up for Down Syndrome will take place on Sunday afternoon, October 18, 2009 at the Memphis Botanic Garden. You can plan on many of the same exciting activities that we have had in the past plus a heightened focus on awareness and the ABILITIES of people with Down syndrome. We are excited about this new direction and look forward to seeing you there! Your continued support of this awareness event will help us to show the community that individuals with Down syndrome are *More Alike Than Different!* Your support is greatly appreciated!

Alyson Edwards
Executive Director

Mike Karst
DSAM Board President

inside DSAM



Dr. Brian Skotko and Alyson Edwards at the Focus, Aim, Achieve! Spring Conference

From the Desk of the Executive Director

The beginning of 2009 has been so full of activity it has just flown by. Looking back, I am inspired at the many things we have accomplished. DSAM has grown by leaps and bounds over the last twelve years. This growth can be attributed to positive change. We have seen much change already this year as DSAM continues to grow.

We have seen a change in staff and board members. DSAM added seven new board members this year, each with a unique skill set to offer. DSAM also hired a new Executive Director and Administrative Assistant, each with a passion for the organization and a drive to enhance the lives of people with Down syndrome. We will also be hiring a new Events Manager in the near future.

In February, DSAM launched our redeveloped website. The change in the information and capabilities on this site will provide educational and medical professionals, as well as parents and caregivers, new resources that are easily accessible. There will be continued change with the weekly email distribution as well...keep a look out for a new format with DSAM Happenings.

A change in our programming saw the addition of the first annual spring conference on Down syndrome. *Focus-Aim-Achieve!* was a huge success and benefitted many family members and professionals. We will make additional changes to programming this year by adding the Self-Advocate Scene and workshops for tweens.

The nation has seen many changes in the Down syndrome movement this year, as well. Several DSAM staff and board members visited with legislators in Washington D.C. in February. This was a very successful trip that resulted in three representatives co-signing the ABLE bill. Watch for DSAM Policy Updates and learn how you can help create change in policy by contacting your legislators to ensure a positive future for people with Down syndrome.

And finally, we see change with the Buddy Walk. The movement to **Step Up for Down Syndrome** is a positive one. It allows us to continue to positively impact our community. We are asking all Mid-Southerners to "Step Up" and help make change in our community to enhance the future of people with Down syndrome.

DSAM will continue to grow and change this year. We appreciate all of your support and efforts to empower people with Down syndrome. Should you have any questions or concerns, please do not hesitate to contact me.

Alyson Edwards

STEP UP for Down Syndrome Needs You!

Interested in being a part of the largest disability awareness event in the Mid-South? Work behind the scenes with the 2009 Step Up Committee. As this awareness event continues to grow and impact our community, it also needs more volunteers. Donate your skills to make Step Up for Down Syndrome the best ever. Areas of service include: PR/Marketing, Team Recruitment, Donations, Registration, Imagine the PossABILITIES, Advocacy, Stage, and more!

Do you know any companies that could become sponsors? The 2009 Corporate Sponsor package is ready to be distributed. If you know of a business or organization that might be interested in Step Up for Down Syndrome sponsorship opportunities, please contact Alyson Edwards, DSAM Executive Director, at (901) 547-7588 or alyson.edwards@dsamemphis.org

Aggie Coughlin Fratta - A Journey with Many Paths

Which path will you chose on this journey? The journey is raising a child with Down syndrome. Our journey began on July 4, 2002 at 8:00 in the morning. My husband, Michael, and I went through many emotions in those early months. Anger, disappointment, fear, joy and love were just some of the emotions we experienced. Maybe your own journey began with the birth of your precious child. Maybe it was days, weeks or even months after his/her birth. Possibly the journey began even before your child was born. It is a day that will not soon be forgotten.

It is a journey that I would not have chosen; however, I know there is a specific purpose for our journey. We will encounter many different paths along the way. Some of these paths include early intervention, preschool, kindergarten. Should one home school, attend public or private school? There is no right or wrong path on the journey. Every family must decide what is best for their child and their family. I feel the goal is to teach our children to be happy, healthy, successful and productive members of society.

It is important to support each parent's decision; for only they can choose what is best for their family. There are many community resources available to help make this decision. The Down Syndrome Association of the Mid-South is an excellent source in our area. It has been my honor and privilege to serve on the board for this wonderful organization. It has been very rewarding to see our long term goals become realities. Our successes today will be found in the future of our children tomorrow. Other invaluable sources are parents of older children with Down syndrome. Therapists, teachers and other professionals can assist in the decision making process as well. Ask questions, visit all types of schools and then determine the most appropriate path for your family.

Which pediatrician should be our doctor? Which therapy will we utilize? Inclusion or special needs classes? Public, private or home school? These are just some of the paths you will travel on this lifelong journey. I pray that your journey is long, filled with laughter, love and many blessings. There will be good days as well as bad. But I have found that the bad days are few and the good days are miraculous. Which path will you chose on this journey, this journey of raising a child with Down syndrome?

Aggie Coughlin Fratta

Aggie is married to Michael and they have one daughter, McKinnon. She attends Madonna Learning Center and will be seven years old July 4th. Aggie is a nurse practitioner for a gynecologist in Germantown. She also serves on the board for DSAM and volunteers for the October Awareness event, Step Up for Down Syndrome. Michael works at Federal Express and attends the DADS support group.

2009 DSAM Day at the Zoo...Rain or Shine!

What a day! The rain held off for a few hours and the sun was even shining. This year's Zoo Day was a huge success with more than 250 participants, including many friends from the Northeast Mississippi Down Syndrome Society. We want to say a special thanks to the volunteers that helped with the face painting and entertaining, photography, and registration.



Parents & Schools in Partnership Update

We are excited to announce that we will be adding five more specialists to each of the three school systems (Memphis City Schools, Shelby County School and Desoto County Schools). Is there a need for a specialist in your area? Do you know someone that is interested in becoming a specialist? If so, please contact the DSAM office or write a letter to your school administrators to let them know about the success of this program.

Christmas in July

Join DSAM for the 2nd Annual Christmas in July Marketplace and fundraiser on Tuesday, July 14 from 5pm-9pm at Devonshire Gardens Clubhouse, 3257 Devonshire Way, Germantown, 38139. Christmas might still be five months away but it's time for Santa to start thinking about stuffing that sack and looking around at what goodies will slip down the chimney most easily. Get a jump-start on your Christmas shopping. Join DSAM for shopping, food, beverages, door prizes & more.

Focus-Aim-Achieve! First Annual Spring Conference Success

April 4, 2009 was another historical day as the Down Syndrome Association of Memphis & the Mid-South hosted the First Annual Focus-Aim-Achieve! Spring Conference at Memphis University School. Twenty three informative speakers presented keynotes and workshops to more than 100 parents, family members, educators, medical professionals, service providers and direct care staff that were in attendance. There were 14 self-advocates with Down syndrome that attended sessions including Nutrition and Health, Telling your Story and Yoga.

DSAM was excited to be able to bring in national speakers Brian Skotko, M.D., M.P.P. (www.brianskotko.com) and Nancy and Bridget Brown (www.butterfliesforchange.org). These individuals present at conferences and events across the nation and we were excited for them to bring their experiences and knowledge to share with the Mid-South area.

Additional speakers from the Mid-South and Nashville areas presented workshops that helped DSAM achieve the conference goal of providing attendees with practical information and tools to help all individuals with Down syndrome become successful in inclusive settings in the community and to enhance all attendees' knowledge of available local resources.

The DSAM strategic plan put an emphasis on education for 2008. Products of that plan have been the development of the Parents and Schools in Partnership Program in 2008 and the First Annual Spring Conference in 2009. Thank you for your support for existing programs and for the development of new programs and events to Support and Empower People with Down Syndrome and their Families!

The positive overall conference and workshop feedback has been incredible! Did you attend the conference, but did not complete the overall conference evaluation? If so, please take a moment to provide your feedback and return to us. This will help us as we plan for future events. Go to www.dsamemphis.org/springconference to locate the form.



FAA Conference Planning Committee:

Alyson Edwards
Mary Claire Giffin
Carol Greenwald
Martine Hobson
Sonya Oliver
Julie Olsen
Kelli Polatty
Lauren Powers
Pam Selby
Nina Staples

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In-Kind Sponsors:

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Starbucks Coffee

Another special thanks to:

DSAM Board Members, DSAM Office Staff and the many volunteers that assisted with conference preparations and the day of event to help make the conference a huge success!



Teachers & Parents Share their Conference Experiences

Memphis,

Let's dwell in the possibilities of...celebrating life with Down syndrome. Now that I've taken the liberty of borrowing a few headlines from this year's Spring Conference for "Focus, Aim, Achieve!" I would like to describe my Saturday, April 4, 2009. After 16 years of teaching special education I would have thought I had heard it all after so many conferences, etc. each year, but the keynote speakers and the three breakout sessions I attended were wonderful, held my attention for the duration, and I anticipate daily use of these activities in my classroom. If I had to use a single word to describe the conference I would use "refreshing!"

Dr. Brian Skotko, M.D., M.P.P. was delightful. His perspective inspired me to think more outside the "Special Ed" box by looking for more mainstream hopes, dreams and expectations out of each child. He quoted Aristotle, "It is the mark of an educated mind to be able to entertain a thought without accepting it," but the stories he shared about his sister, who happens to have Down syndrome, brought a point of view that everyone should hear. As he described his journey through the different phases a sibling has to go through, he always seemed to think of his sister first. This is not the typical boy...most likely much more mature than other boys his age. The stories he tells are hilarious. What could have been horrifying was instead a great childhood that where great care and empathy was shown to the wants and needs of his sister.

Later in the day, the mother-daughter team, Bridget and Nancy Brown, made it all look so easy. Coming from Chicago, Nancy fought for her daughter, and Bridget was able to be part of the first inclusion program in their public school system. As Bridget grew older, one of her teachers asked her to be on the debate team, which provided her many early experiences that now exposes her abilities to be a powerful speaker. In the end, Bridget displayed the possibilities of what could happen for the children in Tennessee if they are just allowed to follow their dreams instead of being limited by the fears of their parents and teachers.

This conference has inspired me to set the bar so much higher. As the teacher of so many children, I realize my professional goals should always include setting the goals for each child higher...never waiting for the parent to initiate.

*Michele R. Wilson
Special Education Teacher
Harwood Center, East Classroom*

As parents of daughter Madison and son Tyler, our four-year-old with Down syndrome, it was a pleasure to be able to attend the first local Down syndrome conference, Focus-Aim-Achieve! We thoroughly enjoyed being able to fellowship with other parents as well as having access to the knowledgeable professionals who dedicate themselves towards helping children, and their families, facing the challenges brought on by Down syndrome.

Dr. Brian Skotko's opening presentation, which focused us on the positive qualities a child with Down syndrome blesses us with, set the course to finish out the day with a series of informative and value-laden seminars. Either as a couple or separately we attended the presentations on the medical conditions which might be faced by a child with Down syndrome, the behavioral issues one might encounter with a child with special needs, the thoughts and concerns a sibling of a child with Down syndrome may have, and finally a presentation on incorporating music and fun into everyday learning and development of motor skills. Each presenter was very knowledgeable and personable and made themselves available for plenty of questions and answers, all of which we found to be very beneficial.

While the challenges faced by each family affected by Down syndrome may be slightly different from one another there is certainly the common thread between us of wanting the best for our children. To succeed at achieving that sometimes Herculean task, it takes having the best resources of knowledge from which to act upon. This conference was an ideal mechanism with which to bring together the combined resources of professionals and peers in a local setting. The complete day of activities not only left us with a positive gain of knowledge which we could begin to apply immediately in our daily activities, it also led us to desire to attend additional conferences such as the NDSC National Convention coming up at the end of July.

We sincerely thank the DSAM staff and other volunteers who made this event possible, and we highly recommend attending future conferences.

*Sincerely,
Ray and Cari Jancso*



Health Care Concerns for Adults with Down Syndrome

More alike than different? Absolutely! Adults with Down syndrome have the same basic health care needs as any other adult. Consistent and thorough health screenings and preventative measures are just as important.

Even so, there are certain medical conditions that occur more frequently in adults with Down syndrome versus the general population. It is very important for families and caregivers to be aware of these common problems because it can be easy to overlook symptoms and attribute them to Down syndrome instead of disease. This can be due to an individual's limited expressive speech and decreased tendency to complain of pain. Also, patients with Down syndrome often exhibit behavior problems when they actually have underlying medical problems.

Common medical conditions to be aware of include:

- Endocrine
 - Thyroid disease--hypothyroidism and hyperthyroidism
 - Diabetes mellitus
- Mental health
 - Depression
 - Obsessive-compulsive disorder
 - Abuse (physical or sexual)
 - Conduct disorder
- Otolaryngology
 - Obstructive sleep apnea
 - Hearing loss
- Musculoskeletal
 - Spinal cord compression
 - Atlantoaxial subluxation
- Periodontal disease
- Alzheimer's disease
- Cataracts, refractive errors and keratoconus
- Seizures
- Testicular cancer
- Xerodermatitis
- Acquired valvular heart disease, including mitral valve prolapsed



While every adult with Down syndrome will not be faced with all of these common issues, it is important to refer to these possibilities when behavior and mood changes occur. Good health and mental well-being go hand-in-hand. Physicians are partners that not only diagnose disease and sickness, but they also play a vital role in helping to manage an individual's mental health as it relates to external influences.

Family physicians can help patients with Down syndrome develop communication and social skills that will enhance their ability to live independently, have a job and interact with others. Stresses that may overwhelm the adult with Down syndrome should be anticipated by the family or caregiver and discussed with the individual's physician. Appropriate planning can help to ensure a successful transition, such as those from home to apartment or from one job to another. Any signs of loss of independence, loss of living skills or function, depression or behavior changes should be brought to the attention of the physician.

Given the probability of multiple physicians and extra office visits throughout the year, it is helpful to follow a few guidelines. During office visits, it is important for a physician to address an individual with Down syndrome directly. This can help the physician to assess the individual's expressive language, hear their story and also gain the confidence of the patient and their family or caregiver. The physician, as well as the family or caregiver, can also help by preparing the patient prior to visits or treatment. All of these steps can help develop a successful doctor-patient relationship.

Resources:

- <http://www.ds-health.com/adults.htm>
- <http://www.ds-health.com/health99.htm>
- <http://healthlink.mcw.edu/article/1001820316.html>
- <http://www.aafp.org/afp/20010915/1031.html>
- <http://www.aafp.org/afp/20060615/2175.html>

Program Resource for Families:

TENNderCare is a full program of check-ups and healthcare services for children who have TennCare. These services make sure babies, children, teens and young adults receive the healthcare they need. Families should be aware of this program and are encouraged to utilize this benefit. The flyer is in English and the Spanish version is on the back of the flyer.

This flyer is available on the TENNderCare website for downloading at <http://state.tn.us/tenncare/tenndercare/index.html>. If you have any questions, please contact Teresa McCathern at 615-507-6447 or Teresa.McCathern@state.tn.us.

Tips for Teaching Math to Learners with Down Syndrome

In all learning it is important to avoid rote memorization of facts. It is better to learn to understand the concept through actual experience. Teaching people with Down syndrome to recite numbers is a rather simple task. Helping people with Down syndrome understand the "language of mathematics" is a slow, time-consuming task. Mathematics is a language of symbols which describes relationships between figures, forms and quantities. Mathematics is not merely teaching to recite numbers. The steps to teaching include:

- **The ability to see similarities**

These similarities may be of any type or nature. They may be color, shape, size, taste, brightness, or even such personally abstract things like favorite foods or music. A learner with Down syndrome needs to have repeated experience seeing how things are alike, before there is any reason for wanting to group and later count these things.

- **The ability to group similar things**

In the beginning, actually placing the similar things side by side is necessary. Most things can belong to several different groups. A coat may belong to a blue group, a clothing group, a cotton group, and a buttonhole group. Organizing and reorganizing these groups is necessary in order to develop understanding.

- **The desire to count things in groups**

Even after things are grouped, there is frequently not a need to give a symbol name to the number of things in the group. Some languages do not have all the numbers that we are familiar with in the English language. They simply have a label for one and a label for many. Needing to make things even as with teams, is one of the more basic reasons to count.

- **The understanding of 1:1 correspondence**

It is difficult for some people to learn that for each number there must be something that is counted. It is important in early learning for individuals with Down syndrome that they are actually counting objects. Some teachers have used small stones, blocks or other tangible objects. It is important that learners can handle these things themselves.

People with Down syndrome are concrete learners; this means it is important that the objects are actually present and that they can handle the objects and group the objects according to their own interests.

- **A purpose for comparison of the amounts in groups**

Abstract or arbitrary comparisons do little to enhance learning. Comparison between numbers of boys and girls, black shoes and white shoes or school lunches and sack lunches may be necessary in order for the learner to be interested in comparisons.

- **Some numbers may have no ordinal meaning.**

Telephone numbers, street addresses and social security numbers have only arbitrary meaning; they are not "counting" things. It is necessary to memorize these numbers rather than to use them in computation.

With all these steps to learning coupled with inconsistency of number meanings, it is no wonder that individuals with Down syndrome usually have little interest in abstract mathematical concepts.

A better understanding of the grouping process and one-to-one correspondence is probably the most vital concept for day-to-day use. Without the understanding, reciting numbers or number facts is a meaningless rote process.

Donations – 4/1/09 through 4/30/09

Donations

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Memorials

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In memory of Ashlee Nicole Taylor

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In memory of Lori Michelle Siegal in
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The Brandon & Shelley Wann Family

In honor of Gracie Crook
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In honor of Jena Leland
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In honor of Lauren Rittenhour
Mr. & Mrs. Cletus Welch

DSAM makes every effort to recognize all donations and gifts. We apologize if we inadvertently missed a donation. Please notify us at 901.547.7588 or email admin@dsamemphis.org.

calendar

Calendar Events List –

May

Tennessee Disability MegaConference

May 28 to 30, 2009

For more information visit

<http://www.tndisabilitymegaconference.org/>

June

DSAM Night at the Redbirds

June 6, 2009 at 6:05pm

Tickets are \$5 per person and can be reserved through the DSAM office. There are a limited number of tickets so call and reserve your today!

Get Bowled Over with the D.A.D.S.!

The D.A.D.S. (Dads Appreciating Down Syndrome) have a special bowling event coming up on Saturday, June 27th from 1 to 3 pm! Strike Zone Lanes in Southaven, MS is offering two free games, including shoes, for the Dads and their children, including sibilings. We need your RSVP no later than Thursday, June 19th, by calling the DSAM office at 901-547-7488 or emailing admin@dsamemphis.org. Strike Zone Lanes is located at 3330 Pine Tar Alley, near Snowden Grove Park.

July

Christmas in July

July 14, 2009

Save the date for this great event. It is never too early to get started on your holiday shopping. Watch for more information soon.

National Down Syndrome Congress

37th Annual Convention

July 31 to August 2, 2009

Sacramento, California

For more information visit www.ndscenter.org

or call 1-800-232-6372. Watch the DSAM newsletter and website for up-to-date information.

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Simone Wilson, Laurel Ryan, Cari Jancso

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