

DSAA Today



The Newsletter of the Down Syndrome Association of Atlanta • January/February 2007

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SAVE THE DATE:

JANUARY

- 17 DSAA Strategic Planning Committee Meeting

FEBRUARY

- 10 FOCUS Conference (DSAA Sponsor)
- 10 Young Adult Valentine's Dance
- 21 DSAA Board Meeting Strategic Planning
- 22 Disability Day At The Capitol

MARCH

- 10 Bregman Dance (DSAA Sponsor)
- 11 Bregman Educational Conference
- 24 DSAA Spring Educational Conference

APRIL

- 23 DSAA Golf Tournament and Silent Auction
- 25 DSAA Board Meeting



Accomplished Marimbist, Daniel Skandera Entertained Music Lovers of all Ages With Fabulous Holiday Selections

A Wonderful Holiday Event . . . Recognition And Revelry!

by Michelle Norweck, LCSW

The 2006 DSAA year ended with an extra-special treat! On December 9, 2006 over 300 individuals representing 61 families attended the Annual Holiday Party hosted by Creekside United Methodist Church. The committee co-chairs, **Diane Bromelow** and **Lauren Biggs** along with the help of over 30 "elf" volunteers did an **OUTSTANDING JOB** of giving close attention to every detail. The party included a special performance by the **Tracy Davison Voice Studio Singers**, and a holiday marimba concert by **Daniel Skandera** who is an amazing 34 year old self-advocate with Down syndrome. The room was filled with children of all ages enjoying hot cocoa, arts and crafts and photos with Santa. Santa Claus also gave an engaging reading of the Polar Express. A special presentation was made by Etowah High School Teacher, **Bill McElderry** from the **RVI Club**, for their fundraising efforts in their annual "**Dimes for Downs**" campaign. A check in the amount of \$3,206.65 was donated to the DSAA. Another presentation was the 2006

Board of Directors acknowledgement awards. Each attending 2006 Board Member was handed a Certificate of Excellence for their dedication and service to the DSAA.



Dale Greig received a special Presidential Award for his outstanding dedication to the DSAA for his service as Co-President for the years 2004-2006 (*above with DSAA Executive Director Michelle Norweck*).

—see Recognition pg. 3

DSAA Executive Board

Executive Director:

Michelle Norweck
Executive_Director@AtlantaDSAA.org

Co-Presidents:

Steve Harrison
President@AtlantaDSAA.org

Stephanie Meredith
President@AtlantaDSAA.org

Co-Vice Presidents:

Morgan Allen
Vice-President@AtlantaDSAA.org

Diane Saliceti
Vice-President@AtlantaDSAA.org

Treasurer:

Jennifer Durden
Treasurer@AtlantaDSAA.org

Secretary:

Emily Gilcreast
Secretary@AtlantaDSAA.org

Newsletter:

Rick Raschke
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What is a Down Syndrome Parent Network Group?



by Michelle Norweck, LCSW

A **DSAA Parent Network group** is comprised of parents whose children have Down syndrome. Parent network groups are similar to support groups in that they provide information, resources and emotional support to new parents looking for answers and solutions to rearing a child with Down syndrome. The group may also include relatives, friends, siblings, foster parents, professionals and interested members of the community.

The Purpose of a DSAA Parent Network Group:

A Parent Network group can be organized to do whatever the members agree the purpose should be. Some groups are informally organized and hold occasional meetings over coffee while others are more structured and have regularly scheduled meetings. Meetings may occur in the living room of one of the member's homes. Parents talk while the children play. Some of the DSAA groups coordinate a speaker while the children are treated to a group session with a Music Therapist. Parents generally discuss and compare the developmental changes in their children, or help one another locate service providers such as pediatricians, therapists and dentists specific to their community. They also share information on medical or educational services, programs and other resources available.

The Benefits of a DSAA Parent Network Group:

A primary benefit of Parent Network groups is that they serve as a forum for discussing common fears and concerns. There is a therapeutic value in knowing that other families experience similar situations, and participation in group meetings helps to alleviate feelings of isolation and helplessness. By sharing concerns and problems with one another, parents are able to gain valuable insights and advice. Lessons learned, especially from more experienced parents, can help to build successful coping skills that will make life easier for parents and children alike.

If you would like to start a group in your community, please contact the DSAA at contactus@AtlantaDSAA.org. If you haven't already taken advantage of a group that exists in your area I encourage you to do so. The friendships and support that you will receive there will last a lifetime.

Cobb County Families, if you are interested in a playgroup and/or parent networking contact Cara Plugge at 678-560-4167, or caraplugge@comcast.net

Rockdale & Newton County Families, if you are interested in a new playgroup and parent networking contact Melissa Kendrick at 770-860-0485, or mhkendrick2@yahoo.com

Area Networking Groups

Hispanic / Latino

Susy Martorell 404.931.6619

Young Adults

Evan Nodvin 770.396.8056
Megan Sydney 770.491.0155

Alpharetta

Karen Wise 770.664.8141

Americus

Valerie Moates 229.924.4022

Atlanta / Decatur / Tucker

Valerie Harrison 770.939.8489

Augusta

Wanda Miller 706.855.7440

Carroll County

Jennifer Turner 256.568.9742

Cartersville

Betty Schaaf 770.383.9085

Cherokee County

Alyssa Allen 770.517.9970

Fayette / Coweta Counties

Virginia Cook 678.364.9131
Nancy Millsbaugh 678.364.0158

North Fulton / South Forsyth

Gay Hall 678.455.9483

Gwinnett County

Shere' Owens 770.967.4775

South Fulton

Cathy Webb 770.969.0238

Macon

Leslie Hales 478.471.9225

Marietta / Cobb County

Cara Henley Plugge 678.560.4167

Rockdale / Newton County

Melissa Kendrick 770.860.0485

Rome

Toni Puckett 770.748.5037

If you are interested in starting a Parent Network Group in your area, please let us know at: contactus@AtlantaDSAA.org

The 2006 DSAA Holiday Event Was Sponsored

By:  **Allstate**
You're in good hands.

Recognition...

Other 2006 Board members included: **Steve Harrison**, Co-President; **Stephanie Meredith** and **Kathy Everett**, Co-Vice Presidents; **Susan TenEyck**, Secretary; **Jennifer Durden**, Treasurer; Membership Co-Chairs, **Alyssa Allen** and **Jenny Cudabac**; Social Committee Chairs, **Shere' Owens**, **Lauren Biggs** and **Diane Bromelow**; Education Chair, **David Glass**; Newsletter Editor, **Sharon Baron**; Advocacy Director, **Heidi Moore**; Buddy Walk Co-Chairs, **Gabe and Rebekah Lyons**; Golf Tournament Fundraiser, **Russ Plugge**; Self Advocate, **Patrick Essen** and his mother, **Joan Essen**; Hispanic Family Support Director, **Zoila Martinez**; AHSDA Social Worker, **Susy Martorell**; and Family Support Co-Directors **Katherine Hunter** and **Karen Wise**. I want to again thank each and every one of you for your time, talent and commitment to the DSAA's 2006 success.

A brief business meeting occurred in which the attending membership voted unanimously to receive the Nominating Committee's recommendation for the 2007 Board of Executive Officers. These include: Co-Presidents **Steve Harrison** and **Stephanie Meredith**; Co-Vice Presidents **Morgan Allen** and **Diane Saliceti**; Treasurer, **Jennifer Durden**; and Secretary, **Emily Gilcrest**.

One of the first tasks of the new 2007 Board of Directors is to help create and develop a mission/vision and 3 year Strategic Planning Goals for the Association. The Strategic Planning Process (SPP) facilitated by **Eleanor Hooks, Ph.D** of The Smart Change Group, Inc. will assist the Board in developing a strategic direction for the DSAA that will give clarity about what we want to achieve as an organization and how to achieve it. The process considers the organization's capacity, strengths and challenges. The completed project will take approximately 4 months and will work to enhance current programs and projects provided by the DSAA, but will also seek to establish new programs, services, and an awareness campaign that will better meet the needs of its members and the Atlanta community today and well into the future. This new strategic direction will help the DSAA to create policy, decisions and programs that will help us to continue to Inspire Strength, Understanding and Success for families and individuals with Down syndrome.



Crafts



Friends



Family



Music



Fun



Food

The Emory Connection

Of Mice and Flies and Maybe Humans —New Answers and More Questions About the Effects of Trisomy 21

by Lora J. H. Bean, PhD, FACMG

Scientific discoveries rarely result in an all-questions-answered eureka moment, but instead occur in steps, some large and some small. Even the 1959 discovery that Down syndrome is caused by an extra copy of chromosome 21, which answered the question of the day - "What is the cause of Down syndrome?" - left unanswered the new question - "How does an extra copy of chromosome 21 cause Down syndrome?" A discovery reported by two groups of scientists, Arron *et al.*¹ and Gwack *et al.*², writing in the journal *Nature* provides new insight into the second question.

Our bodies are composed of billions of building blocks called cells. The physical changes that the human body undergoes throughout life and on a day to day basis (growth, brain development, learning, etc.) occur due to changes that take place at the cellular level. DNA, which is packaged into chromosomes, sits at the center of cells directing and coordinating their function. When the normal content of DNA is changed, as is the case when an extra copy of chromosome 21 is present, the directing and coordinating of cellular functions is disrupted.

Scientists believe that the health and developmental problems associated with Down syndrome occur when too much DNA from chromosome 21 is present, and cellular functions are misregulated. You can think of this as the instructions coming from three copies of chromosome 21 being louder than normal. A louder signal from chromosome 21 can increase some cellular processes and decrease others.

Working with laboratory mice (Arron *et al.*) and fruit flies (Gwack *et al.*), the authors discovered that having too much signal from two specific chromosome 21 genes, *DSCR1* and *DYRK1A*, causes too little signal to be made by a group of genes called *NFATs*. *NFATs* are known to be important for development of the brain, muscle, and heart.

So, does the fact that an individual with Down syndrome has three copies of *DSCR1* and *DYRK1A* instead of two explain the developmental delay, low muscle tone, and greater incidence of heart defects? Perhaps. However, more studies are needed to prove a direct link between these genes and the features associated with Down syndrome. If *DSCR1* and *DYRK1A* misregulation actually cause the hallmark features of Down syndrome, questions about why there is a range in severity of problems are still unanswered.

Are the studies by Arron *et al.* and Gwack *et al.* a small step, a large step, or even a misstep in understanding the effects of having three chromosome 21s? Will predictions about gene function made in mice and flies help us to understand a human condition? These questions can only be answered through future scientific endeavors.

¹Arron JR *et al.* (2006) NFAT dysregulation by increased dosage of *DSCR1* and *DYRK1A* on chromosome 21. *Nature* **441**: 595-600.

²Gwack Y *et al.* (2006) A genome-wide *Drosophila* RNAi screen identifies DYRK-family kinases as regulators of NFAT. *Nature* **441**: 646-650.

The Down Syndrome Clinic staff wish to thank the **Down Syndrome Association of Atlanta** for its support. We couldn't do it without you! As always, we welcome your comments and suggestions (contact Sallie Freeman, sfreeman@genetics.emory.edu). **To find our more about the Emory Down Syndrome Clinic contact Shelley Dills, Down Syndrome Clinic Coordinator at 404-778-8524.**



The 2007 Buddy Walk Committee Is Forming Now

All those interested in volunteering on the 2007 committee and event staff should send an email to:

contactus@AtlantaDSAA.org

DSAA Administrative Assistant Announced:



Please welcome Stefanie Baumblatt to the position of Administrative Assistant. Stefanie was selected from a diversely qualified field of 12 applicants for this first time position for the DSAA. Stefanie demonstrated exemplary oral and written communication skills as well as being very detail oriented, organized and proficient in many software programs required to do the job. Stefanie states, "I have seen the impact that the DSAA has on families first hand and I know that I want to be in a position to ensure that more families can experience what my family and I have over the last two years." Stefanie and her husband, Jeff reside in Alpharetta and are the parents to two daughters, Abigail and Sara.

Dentistry for Our Special Kids

part II

by Kris Jorgenson, D.D.S. and DSAA Member

This information is no news flash to us as parents of a child with Down syndrome: Trisomy 21 has some unique characteristics which set our kids apart. What may be news to some parents is the fact that DS affects our children's dental health as well. One special medical consideration that has an impact on the health and well-being of our kids in the dental chair is the presence of any cardiac issues (anything involving the heart or its function) that may require premedication with antibiotics prior to any dental treatment. Many of our kids have had (and all should have had) a screening with a cardiologist where a two-dimensional echocardiogram (ultrasound of the heart) has been done. From this test the cardiologist can determine if such premedication is required to protect the heart from an assault of bacteria. This bacterial assault can come in the form of a dental cleaning, which can elicit bleeding, or from a number of other dental procedures. The antibiotics prior to treatment are designed to bolster the body's defenses and help protect the heart muscle from infection. If your child has any cardiac history or you have been told that they have a heart murmur, it is important to inquire with the physician about their recommendation for premedicative antibiotics. Usually it is tablets or liquid taken one hour before the procedure. Amoxicillin is the most common antibiotic used if the child has no allergies or other risk factors.

Our kids with Down syndrome also typically develop their teeth later than other children and the teeth do not generally follow typical eruption patterns; this means that any tooth could come in any order at any time. This fact hit home with me when my son, Jack, who is 2, did not erupt any teeth before the age of 18 months. Unfortunately for him, he has a neurotic mom . . . with an x-ray machine! I took two small x-rays on him (with much assistance from my staff) and low and behold, the teeth were where they belonged and began erupting shortly after that . . . out of order, I might add!

Early introduction of a toothbrush, even before tooth eruption, can also help to avoid some of the oral defensiveness we sometimes see in our children, as well as help establish good oral habits at an early age. Getting our kids used to the feel of the bristles of the brush or the vibration of a mechanical toothbrush early on may make toothbrushing less of a chore/struggle when the teeth do come in.

Good oral hygiene as well as a good, balanced diet cannot be stressed enough when it comes to our kids. While children with Down syndrome seem to be at slightly lower risk statistically for tooth decay, poor diet and poor home care tip the balance the other way and lead to nothing but problems. Keeping our kids away from sweet drinks (sodas and sweet tea, for example) and candy especially the sticky kind (raisins and dried fruits can be a problem, too), can be a help in keeping the cavities away. When the children are able to rinse and spit well into the sink, then it is time to introduce daily fluoride rinses. Fluoride rinses are readily available over the counter (ACT or Fluorigard are two common brands) and should be used after brushing well, before bedtime. Do not allow the children to eat, drink, or rinse out after using the fluoride or it will diminish its effectiveness.

Remember, too, that the primary (baby teeth) are important!!! Although they will be shed and replaced by permanent teeth, our kids will keep their primary teeth longer than their typical peers will and it is not uncommon for some permanent to be missing altogether in children with Down syndrome. Sometimes our kids are blessed with extra teeth, which need to be dealt with on an individual basis. This means that each and every tooth should be cared for as if it was the only one that our child is going to get. In this way, we instill good habits and keep all the teeth healthy. It is unacceptable to ignore the primary teeth because "the permanent teeth will be coming in soon anyway". Many primary teeth are not replaced until the teenage years and for our kids, even later. Toothaches and infections can happen in the primary teeth as well if they are neglected. Periodontal disease (gum problems) seem to be more prevalent as our children mature and therefore a good solid home care program that becomes a daily habit will go a long way toward keeping both the teeth and gums healthy. We are on top of so many other aspects of our kids' lives, their dental health should be no different.

So, does Down syndrome throw us all yet another challenge when it comes to the dental health of our kids? The simple answer is "yes", but truly, establishing good dental habits is a challenge with all children. Typically developing children are no more interested in it than our children with Down syndrome are. The important thing to remember is that prevention is key. With the right knowledge and a little bit of creativity and perseverance, we can arm our children with the tools they need for healthy teeth and gums for the rest of their lives. There are few things more precious than the smiles of our children!

Dr. Kris Jorgenson is a practicing general dentist in Sugar Hill, GA. She and her husband, Dan are the proud parents of Joey, who is seven and Jack, who is two and has Down syndrome. If you have any questions for her, please feel free to call her at her office: 770-932-0992 or email her at kristinjorgenson@charter.net

Times Square Buddy Walkers . . .



The Medranos from Americus; Courtney-12, Dayton-8, and Joshua-4 years old.

"I wanted to let you all know that my three kids who all have Down syndrome had been picked for NY Buddy Walk Time Square Video. It was such an exciting time we just wanted to share the news with you all too."

—*Cynthia & Rusty*

Congratulations to the Medranos for being selected as one of the families to be included in a special video presentation on the 40-foot NBC Astrovision screen in the heart of Times Square. The broadcast took place on Sept 17, 2006, the morning of the New York City Buddy Walk. To view the entire 20 minute video, visit the link below.

www.buddywalk.org



PLANNING ON BEHALF OF PEOPLE WITH DISABILITIES

Helping Improve a Loved One's Quality of Life

One of the most important challenges confronting the families of individuals with disabilities is formulating a financial plan for the future. Such planning can be a complex, difficult and emotionally draining experience for everyone involved. In cases where a person may qualify for financial support from the government, securing and maintaining those benefits generally requires careful attention.

The goal of an overall plan is to improve the quality of life for the family member with special needs while simultaneously preserving government assistance to which that person is entitled. Quality of life considerations might include medical care and additional services beyond those covered by public assistance as well as other expenses for personal needs. Families can secure an effective plan for their loved ones with disabilities using a variety of methods, but some questions must be answered first.

- If the individual cannot live independently, who will care for him or her when the parent or caretaker is no longer able?
- What types of care, education or support will the individual need?
- What types of assistive technology will the individual require?
- Where will the individual live? What are the preferred living arrangements?
- How can financial assistance be provided to maintain or improve the individual's quality of life without jeopardizing any government benefit?
- How can someone provide for the individual without penalizing other beneficiaries?

Answers to these questions require knowledge of government entitlements, awareness of strategies that can provide additional resources for the disabled individual, and an intimate familiarity with the individual's unique situation and needs. This report focuses on ways to develop an efficient, well-organized plan that improves quality of life, preserves government assistance and provides financial stability for a person with a disability.

Sources of Government Assistance

Government programs such as Supplemental Security Income (SSI) and Medicaid were established to help people who are elderly, blind or disabled and living at the poverty level. These programs are supported by tax dollars, and eligible individuals are entitled to receive benefits.

SSI is a federal needs-based program administered by the Social Security Administration and provides cash benefits on a monthly basis from the federal government to certain individuals with disabilities according to Social Security rules and regulations. SSI qualifications are different for children and adults. In short, SSI is intended to supplement any income an individual already receives to ensure that he or she is afforded a minimum level of income. This minimum level is known as the "Federal Benefits Rate." A recipient must pass an income and resource test to receive an SSI benefit.

SSI benefits may be reduced or forfeited, depending on how much monthly income an individual earns. Each state has established varying income level thresholds. Accumulation of assets over a certain amount could also lead to termination of SSI benefits. The SSI thresholds for asset accumulation levels are virtually the same nationwide. Currently, the asset accumulation limit for a single person is \$2,000; the limit for a married couple is \$3,000.

Medicaid is a federal program, administered at the state level, that pays for necessary medical care for eligible persons. Eligibility for Medicaid is based on need and disability. An applicant's age, medical diagnosis and finances may factor into his or her eligibility for Medicaid. There are multiple programs within the Medicaid system, and individuals may be declared ineligible for some programs while eligible for others. To apply for Medicaid benefits or to find out more about your state's program, contact a local Medicaid office or your state health department.

Guardianships and Conservatorships

A guardianship proceeding is a legal means of protecting and supporting children and adults who cannot take care of themselves. A guardian should make decisions in the best interests of these individuals and/or handle their assets. When the court determines that a person is incapable of handling his or her personal and/or financial affairs and appoints a guardian, the person who is disabled is often referred to as the “ward.”

Guardianships arise when an individual is disabled or incapacitated and there is no other legal document in place to ensure sufficient care. Every state has guardianship statutes. Through a guardianship proceeding, a court will appoint a guardian to protect the person who is unable to make or communicate responsible decisions concerning his or her person or property.

There are two types of guardians: a guardian of the person and a guardian of the estate, sometimes called a conservator. The same person may be appointed to serve in both capacities. The appointment process can be expensive. A “guardian of the person” will be appointed for someone when his or her disability prevents communication and evaluation of information to the extent that basic needs (food, shelter) cannot be met without assistance. For example, an adult will usually need a guardian of the person if the adult is unable to live independently, even with appropriate supports in place.

A “guardian of the estate” or conservator will be appointed for a person when his or her disability prevents the individual from managing financial affairs. A conservator of the estate is responsible for the care, management and investment of the ward’s property. Court supervision may also be required for management of investments.

This judicial process is ongoing, cumbersome and often expensive. It usually requires the assistance of an attorney and at least annual accountings of assets, income and expenses. Court permission may also be required. The conservator is entitled to compensation and usually a fidelity bond is required to insure against negligence or malfeasance of the conservator, adding to the expense.

The advantage of a guardianship or a conservatorship is that the court closely monitors the person and property that is subject to the proceeding. This helps ensure that the guardian or conservator acts in the best interest of the ward.

Investment Planning Options

Some choices available for providing for an individual with a disability, each with advantages and disadvantages, include:

1 Disinheritance – leaving the individual to rely solely upon government entitlements and his or her ability to provide independently.

While this may solve the problem of qualifying the individual for government aid, it may not sit well with the responsible family members. It would be a difficult choice for a parent to leave a loved one who is a dependent child solely under the auspices of the government.

2 Outright gifts or inheritance to the individual with either the person or a court appointed guardian and/or conservator managing the assets.

Simply gifting assets to a person with disabilities may or may not make sense. If the person does not or is not expected to require government aid, then the outright gift will not endanger any monetary benefits. However, if the person is eligible and in fact entitled to government aid, an outright gift will almost certainly disqualify the individual from further aid until the gift is spent down to levels of eligibility.

3 Providing funds to a sibling or other caregiver who would then provide for the individual with special needs.

Funds provided to an individual with an expressed hope that the assets will be used for the benefit of a person with disabilities may preserve government aid. (Funds that the person with disabilities could demand and/or sue for could potentially be considered in qualifying or disqualifying him or her for assistance.) Nonetheless, the moral obligation imposed upon the caregiver can create havoc of its own.

- *First*, the sibling or other caregiver may eventually lose the sense of obligation and commitment to the individual as time passes or simply become too busy with his or her immediate family or other responsibilities.

- *Second*, a sibling who takes that obligation seriously may actually overextend himself or herself emotionally and financially even after the intended funds are spent. The caregiver may offer his or her own funds – a decision that may be detrimental to the caregiver’s own family. The parent or original contributor in most cases, does not contemplate such consequences.

- *Last*, these funds become the property of the caregiver and are subject to any and all liens placed on them, including litigation, creditors, judgments and divorce.

4 Providing for the individual by leaving funds in trust.

Transferring assets to a trust can provide for management of asset without court intervention. The trust dictates how the assets are to be managed and used.

Note: If the beneficiary has an unrestricted right to distribution of the assets from the trust, government entitlements can be jeopardized.

5 Providing for a trust that integrates government entitlements with discretionary powers of the trustee to provide for the special needs of the individual.

Parents or relatives can establish a special needs trust to provide financial resources for their loved one with disabilities without causing forfeiture of government benefits currently in place or projected to be available in the future. Government agencies have recognized the importance of special needs trusts. As a result, these agencies have imposed a variety of stringent rules and regulations on them. A special needs trust uses carefully drafted language to direct a trustee to use the funds for purposes that do not overlap with the intent of any government benefits received by the person with disabilities. Providing additional resources that maintain or improve the quality of life for the beneficiary – without forfeiting any government benefits – is the most important aspect of using a special needs trust.

—end part one

Happy
Birthday
Wishes!



Hunter Roach, January 4th

Editor's Note:

After two plus years of doing a truly fantastic job DSAA Newsletter Editor, Sharon Jones Baron is passing the torch. Sharon has put forth an unparalleled effort in making *DSAA Today* current, accurate, informative and graphically/visually appealing. When you see Sharon do give her a great big Thank You! for such commitment in producing the newsletter over the past few years.

As of December, 2006 DSAA Member, Rick Raschke will be hustling in an attempt to fill those shoes—as the new DSAA Newsletter Editor. Some of you know me, some of you know me as Ricky's dad, in any case . . . my wife Linda, Ricky and I are happy to have been DSAA members for about six years now.

Please put a note on your "Old DSAA Newsletter File" file tab so you will have my email address at hand and remember—readership participation is a good thing! My goal is to continue to keep *DSAA Today* as current, informative and responsible as it has been known to be.

This is your Newsletter and content from you is always welcome . . . stories, essays, photos, announcements, events and dates etc.—thoughts, themes and dreams—all the news that's "fit" to print.

Email Rick Raschke at:

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DSAA Today

... Family Frolic,
Merriment and
Memory Making!



Statement of disclaimer: The editor of this newsletter writes as a non-professional. This newsletter reports items of interest relating to Down syndrome. The Association does not promote or recommend any therapy, treatment, etc. We wish to bring together those interested in Down syndrome.