



Sarah Clarke (center) presents appreciation plaque to Mac and Bob's Restaurant owners Joe Dishaw (left) and Bob Rotanz for sponsoring our benefit golf tournament for the 14th year in a row. More details and photos on pages 3 and 7.

# DSAR

DOWN SYNDROME ASSOCIATION of ROANOKE

*Serving Southwest Virginia*

*Providing Support & Information to the Community Since 1990*

Newsletter

Fall 2006

P. O. Box 4683 • Roanoke, Virginia 24015 • (540) 772-6460 • www.dsar.org

## MISSION STATEMENT

*The Down Syndrome Association of Roanoke is a not-for-profit, nondenominational organization providing advocacy, educational and support services for families and friends of individuals with Down syndrome, as well as professionals who work with individuals with disabilities. The DSAR's goal is to improve the quality of life for all persons with mental and/or physical handicaps and to make Southwest Virginia a model community for individuals with disabilities.*

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*The Down Syndrome Association of Roanoke is an affiliate of the National Down Syndrome Society*



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Non Profit Org.

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## PRESIDENT'S ADDRESS

Perhaps the only big disappointment for me this year has been the cancellation of the Buddy Walk picnic. We have been so fortunate in past years to have great fall weather for it. Alas, I dreaded making the decision to cancel but the park was soaked. And to add insult to injury the sun came out later that afternoon. So now we focus on our end of the year event - the Holiday Party! The date is Sunday, December 10 from 1:30 to 3:30 at the Brambleton Center. In the past we've had this party on a Saturday but due to some scheduling conflicts we had to book a Sunday. The party will start a little later than usual so please eat a big breakfast that day so you'll be ready for a late lunch. The DSAR will provide lunch and we'll set up a craft table again this year. And of course, we anticipate another visit from jolly Old St. Nick! If you are interested in helping out with the crafts or being an elf (i.e. help shop for gifts from Santa) or picking up food, drinks, etc. please email me at sarah.clarke@cox.net or call 342-3304.

Due to my due date, Pat will take over the presidency of the DSAR once again and I will be Vice President in January 2007. I have so enjoyed being President. I have learned so much and met so many nice people. I hope that anyone reading this newsletter would consider an officer position with the DSAR. It may seem daunting at first but it's really not that overwhelming. If an officer position is not your cup of tea please help the DSAR in other ways. If in the course of your day you meet someone who would make a terrific speaker at a monthly meeting, ask them and then let us know. If you're a party planner, please take on organizing one of our social gatherings. If you could pick one or two (or even more!) tasks that you are willing to do regularly that would greatly relieve the burden on the officers to seek volunteers. Please email or call with what you would like to do. Every little bit helps! My heartfelt thanks goes out to all of you who do volunteer. We couldn't do it without you!

Fondly, Sarah

## Executive Board Members 2006



- Sarah Clarke, President
- Pat Macdonald, Vice President
- John Cloeter, Treasurer
- Kathy Cole, Secretary
- Leigh Ann Bowen
- Adam Sarbin, M.D.



## Upcoming Events . . .

Please Join Us!

### DSAR Sponsored events

**Thursday, November 9, 2006 7 PM** at Roanoke County Headquarters Library, 3131 Electric Road, Roanoke Speaker: **Maureen Weyer** from Virginia Tech will talk about the College Bound program, an orientation for students with disabilities who are considering college

**Sunday, December 10, 2006 1:30-3:30 PM**

#### HoHoHo Holiday Party

Brambleton Center • 3738 Brambleton Avenue • Roanoke  
Lunch and a visit from Santa!

**RSVP Required (540/772-6460 or by e-mail to [info@dsar.org](mailto:info@dsar.org))** so we will have enough food and Santa can be ready too!

**Saturday, February 17, 2007, 1:00-3:00 PM**

#### Bowling Party

Lee-Hi Lanes, 1830 Apperson Drive, Salem

#### April

Presentation on the new federal regulations for school-aged children

**May 11, 2007**

#### 15<sup>th</sup> Annual Mac and Bob's Benefit Golf Tournament

Hanging Rock Golf Club in Salem

### Volunteer opportunity

**Friday, November 24, 2-6 PM**

**Gift wrapping** at Barnes and Noble in Roanoke, donations to benefit the DSAR. Need 3 adult volunteers to work 2 hour shift each. Call (540) 772-6460 or e-mail to [info@dsar.org](mailto:info@dsar.org) to volunteer.

### Other Local Events of Interest

**November 9, 2006**

Sixth Annual **Bridging the Gap Special Needs Symposium**. FREE and lunch is included. This event is tailored specifically for the parent who has a child with special needs. An all day event (8:30 am to 4 pm) at the Wyndham Hotel in Roanoke. You must register by phone to be eligible for the free lunch. Call (540) 400-0548 or (540) 366-3730. Conference flyer with more details is posted on our web site at [www.dsar.org](http://www.dsar.org).

**Sunday, November 26, 1-5 PM** at Virginia Heights Masonic Lodge #324, 2742 Grandin Road, Roanoke. Mr. Andy Lucas has extended an invitation to DSAR families to visit with Mr. and Mrs. Santa Claus. The Lodge will provide refreshments and digital pictures of the children with Santa. Mr. Lucas has known Santa for many years and takes a great deal of pride in entertaining children. Several years ago Mr. Lucas donated stuffed Santa toys for the DSAR holiday party as he wanted to attend our event but was unable to due to illness. This November 26 event is his only event for this year so he wanted to invite the families of the DSAR.

#### Editor's Note

Please direct all inquiries about this newsletter, including new subscriptions, address changes, and requests to be dropped from the mailing list to Patricia Macdonald, Editor, at the Down Syndrome Association of Roanoke (DSAR). Every intent is made to keep our information accurate, but we do make mistakes so please let us know if you notice an error that we have overlooked.

The DSAR is a non-profit organization and is staffed entirely by volunteers. Contributions to our organization are always welcome and may be mailed to the DSAR at the address below. The DSAR does not charge membership fees and provides this newsletter free of charge.

Down Syndrome Association of Roanoke, P.O. Box 4683, Roanoke, VA 24015  
Telephone (540) 772-6460, web address [www.dsar.org](http://www.dsar.org), e-mail [info@dsar.org](mailto:info@dsar.org)

## Disability Mentoring Day Program

Program Held during National Disability Employment Awareness Month  
From a press release from the AAPD

On October 18, the American Association of People with Disabilities (AAPD) hosted their eighth-annual Disability Mentoring Day. This national AAPD program is officially commemorated during the month of October, which is National Disability Employment Awareness Month; activities continue year-round.

AAPD is honored to partner with Darden Restaurants, Inc., the lead sponsor, and the Social Security Administration (SSA), lead public sponsor.

Disability Mentoring Day is designed to provide students and job-seekers with disabilities a firsthand experience in learning about career opportunities in a variety of their chosen fields. Disability Mentoring Day helps to promote the importance of encouraging these students and job-seekers to develop the necessary skills and experiences to compete in today's competitive workforce. For many people with disabilities, their past participation in Disability Mentoring Day has resulted in ongoing relationships, internships, and firm job offers.

Disability Mentoring Day has expanded from a small DC-based event for three dozen students, when it was a program conducted by The White House in 1999, to a national event now hosted by AAPD. This year, more than 14,000 mentees are expected to participate in Disability Mentoring Day in communities in every state, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and many international locations, including Brazil, Germany, and Kosovo.

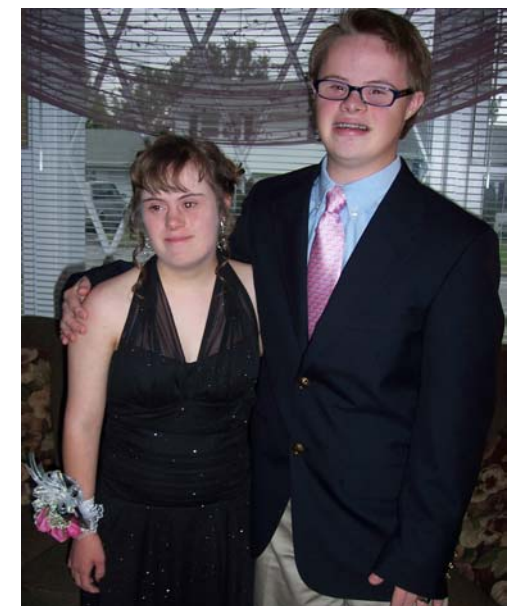
"Employers say that their own lack of exposure to people with disabilities is one of the biggest barriers to hiring qualified disabled employees," said AAPD President and CEO Andrew J. Imparato. "AAPD's Disability Mentoring Day program connects disabled students and job seekers with employers who are working in a field of interest. This informal exposure is leading to a stronger connection between employers and potential employees with disabilities, and ultimately, this leads to a more diverse workforce, and more directed and motivated students and job seekers with disabilities."

In addition to the support provided by Darden and SSA, AAPD is also proud to partner with the U.S. Department of Education, the Verizon Foundation, and the following national corporate sponsors: Hewlett Packard, IBM, Microsoft, Pitney Bowes, and SunTrust Banks, Inc. Additionally, SAP is the founder and sponsor of the AAPD/SAP High Technology Disability Mentoring Program and of AAPD's first-ever Disability MentorNet program, a premiere online mentoring program for people with disabilities. All of these partners are playing significant roles in making Disability Mentoring Day an effective public-private partnership and helping to tackle the longstanding problem of unemployment and underemployment among people with disabilities.

For further information regarding Disability Mentoring, contact AAPD at 800-840-8844 (V/TTY), by email to [dmdaapd@aol.com](mailto:dmdaapd@aol.com) or visit the AAPD website at [www.aapd.com](http://www.aapd.com).



Photos from Mac & Bob's



Lindsey & Chase at Homecoming

# The Second Diagnosis

By Sharon Randall, North Andover, Massachusetts

Reprinted from *Down Syndrome News*, newsletter of the National Down Syndrome Congress, 1370 Center Drive, Suite 102, Atlanta, Georgia 30338, [www.ndsccenter.org](http://www.ndsccenter.org)

We all remember where we were when we got the First Diagnosis- in the hospital right after delivery, in the doctor's office, on the phone with the geneticist. We heard the words, "Your child has Down syndrome." However we processed the information, those are words we will never forget. They instantly seem to divide us from all of the families who have only "typical" children, and they instantly lump us together with that group of families who have children with "special needs."

Hopefully we go on to find that being in the second group- of families with children with special needs and more specifically of families with children with DS- can be a good thing. We can form wonderful friendships, exchange information and share burdens. We are united as we stand together.

But then comes the Second Diagnosis, the one that we impose as it divides this wonderful community that has developed. Hints of it bubble up in conversation. She's already holding her neck up which the therapist says is a good sign, he's very alert which the doctor said is a good indicator, she's babbling quite a bit which is very promising, and then out it comes- he surely is going to be "high functioning." And those around the table who also think that their child is "high functioning" nod in approval, and those with concerns about their children become silent. Tragically, the community has divided itself and increased the pain of some.

This discussion often begins as an outlet for a new parent's anxiety. Perhaps someone has an infant- not yet two months old- and is grasping for some indication that the news isn't so bad. Perhaps this news of DS will be manageable if the child is high functioning.

If the hope of having the perfect baby has been dashed, there is a new hope that the child will be off the charts for children with DS. Perhaps this baby will be one with just physical indicators, keeping all mental capacities functioning as normal. Perhaps amidst this feeling of failure that may come from already comparing our new baby to others there will be some feeling of accomplishment.

Certainly there is a clinical discussion to be had with medical professionals around one's ability to function. Therapies need to be decided upon. But since there are so many accounts of children who have exceeded the abilities predicted by medical professionals, I wonder if the discussion of high functioning vs. low functioning makes sense at all.

So, at the end of the day, what good is this discussion of high functioning vs. low functioning? Are these children loved? Yes. No more and no less for where they function on the spectrum. Do these children love back? Yes. No more, and no less for where they function on the spectrum. Is where one's child falls on the spectrum an indication of better parenting? Absolutely not.

As we know, we are in a society that loves to divide...by race, religion, gender or accomplishment, no matter how large or small. There are many wonderful things about the community we find ourselves in when we have children with DS. Let's hope that differentiating ourselves by refusing to buy into meaningless divisions is one of them.

## Welcome

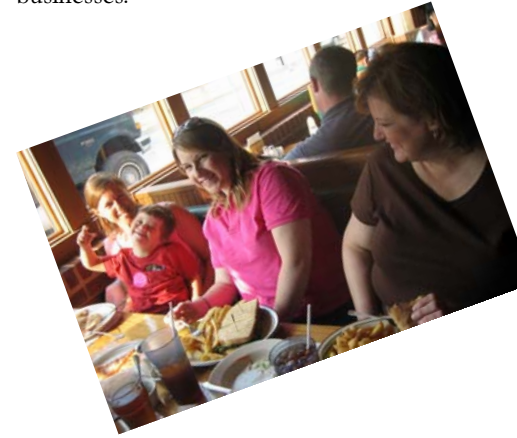
Please join us in giving a warm welcoming to the following families:

Sally Esolen  
Keshia Gravely  
Erin Moore  
Herbert Moore  
Ralph and Diane Owen  
Rebecca Smith  
Dan and Amy Stilwell

We hope to see you very soon. Let us know if there is anything we can do for you.

# Since our last newsletter....

July brought our annual DSAR night at Mac and Bob's Restaurant in Salem. Folks came and purchased dinner to show their support to owners Joe Dishaw and Bob Rotanz for sponsoring our annual benefit golf tournament. This year was their 14<sup>th</sup> year sponsoring it! We also acknowledged the support and contributions of Duncan Acura Audi for sponsoring the hole-in-one car for the second year in a row as well as donating a prize package for the par 3 holes. Please mention your appreciation to both of these sponsors when you patronize their businesses.



In August the DSAR hosted a skate party with pizza and soft drinks for the Journey of Hope Push America Cycling Team on their stop through Roanoke. This was the third time they visited with us, and it may just become an annual event! The Journey of Hope is a cross-country cycling event that raises funds and awareness for people with disabilities. The mission of Push America is "building leaders of tomorrow by serving people with disabilities today." The 21-person team started out in Florence, Oregon on June 2 and visited with us on day 65, ending up in Washington, DC on day 71.



Also in August Mark and Lois Bisese invited members of the DSAR to their home to enjoy many of their baby animals that everyone could pet. This was planned on a short notice so we invited the members that were at the skate party and also posted the information on our web site ([www.dsar.org](http://www.dsar.org)). Everyone enjoyed themselves and we would like to thank Mark and Lois for being so gracious in opening up their home to us for this event.

Nancy Morehouse, Director for the Southwest Section of Virginia Special Olympics, was our guest speaker for our September meeting. It was a well-attended meeting with parents of children of all ages attending. In addition to the individual participation of those with disabilities, Ms. Morehouse spoke about their unified sports program, which pairs an athlete who has a disability with a non-disabled peer, friend, or family member. She also brought one of the coaches with her, Linda Maness, and two athletes, including our very own Erica Farley. For more information call Ms. Morehouse toll-free at (800) 526-6132 or by e-mail to [nmorehouse@specialolympicsva.org](mailto:nmorehouse@specialolympicsva.org).



Nancy Morehouse (left) & Linda Maness

Sadly we had to cancel our Buddy Walk that was scheduled for Sunday, October 8 because of the heavy rain. We hold this event in celebration of October being Down Syndrome Awareness Month. We missed our many friends who were disappointed about it being cancelled and hope that everyone will join us at a get-together very soon so that it is not too long before we see you!

## Announcements

If you would like to be added to an **electronic mailing list** for announcements between newsletters, please send an e-mail to [info@dsar.org](mailto:info@dsar.org) with your name and e-mail address and we will add you to our list.

The **DSAR** donated a copy of the DVD [Down Syndrome, The First Eighteen Months](#) and the book [Life Beyond the Classroom, Transition Strategies for Young People with Disabilities](#) to each of the public libraries in Bedford County, Covington, Franklin County, Galax, and Roanoke City this past August.

The DSAR sponsored **scholarship at Virginia Western Community College** (VWCC) has been awarded for this year. This scholarship is awarded to a student who has a disability and is continuing their post-secondary education. This year's recipient has chosen to remain anonymous, which is an option that we have provided with this scholarship. Officials at VWCC use strict academic criteria in selecting the recipient.

A **Friday Night Friends** (FNF) group is being organized in the Roanoke Valley. The program's mission is to provide medically supervised care to medically fragile persons and those with special needs for four hours Friday nights so parents can have respite from the continuous job of taking care of their child. Cave Spring Baptist Church has agreed to provide the meeting space. The goal of FNF is to open in early 2007. The next planning date is November 13, 2006. Caregivers are invited to come, see the facility, and give your input. For more information or to get involved with the planning, contact Loreda Cunningham at 776-8677.

**Mona Sams, OT**, is an animal therapist and an old friend to the DSAR. She would like everyone to know that she is now doing individual and small group therapy at the Didlake office on Thirlane Road in Roanoke. She can be reached at her home number at (540) 966-4941.

The **Individuals with Disabilities Education Improvement Act** (IDEA 2004) went into effect on October 14, 2006. These are the newest revisions of the federal regulations that dictate how state department of educations must conduct their special education programs to receive federal funds. For more information log onto the Wrightslaw web site at <http://www.wrightslaw.com/idea/law.htm>.

**Roanoke Parks and Recreation Therapeutic Recreation Services** is holding their winter 2006 sessions, which includes their 21<sup>st</sup> Valentine Dinner Dance and weekly social and recreational programs for ages 13 years and up. For more information, log onto their web site at [www.RoanokeCountyVA.gov/trs](http://www.RoanokeCountyVA.gov/trs) or call (540) 772-7529, ext. 2.

We have a **correction to our Summer 2006 newsletter**. The following line from the summary of Diane Rodil's talk should have read, "She also said that babies and children who are being fed through a tube should transition from continuous feeds to 30 minute feeds at scheduled intervals throughout the day as soon as medically appropriate to mimic meal time hunger cycles."

The U. S. Department of Education has released a new **tool kit** to assist school leaders in fully implementing the accountability provisions of the *No Child Left Behind Act* for students with disabilities as well as those of the *Individuals with Disabilities Education Act*. Free copies may be downloaded at [www.osepideasthatwork.org](http://www.osepideasthatwork.org) and ordered on CD-ROM by calling 1-877-4ED-PUBS with identification number EHE0110C, while supplies last.

**Moms' Night Out, Dads Get-Together, Grandparents Group**\*\*\* Would you like to socialize on a more regular basis? We are looking for people to organize informal social groups, such as a dads' group and other groups just for moms or one just for grandparents. The person in charge of each group would let people know about getting together for coffee or dinner by phone calls or e-mail. If you are interested in organizing or being part of such a group, please let us know by calling 540.772.6460 or by e-mail to [info@dsar.org](mailto:info@dsar.org).

Teresa Julian of **Cub and Boy Scout Troop 2250** in the Bedford/Lynchburg area would like to invite boys with special needs to join her scout troop. They currently have 20 boys in the troop. You may contact Ms. Julian at (434) 384-0320 or by e-mail at [jtjulian2003@yahoo.com](mailto:jtjulian2003@yahoo.com).

Doctoral candidate Ms. Virginia Mackintosh would like to invite parents and caregivers of children with Down syndrome, autism, or cerebral palsy to participate in an online **study being conducted by Virginia Commonwealth University**. The study looks at parents' experiences in choosing and providing therapy for their children. You may preview the survey before deciding to participate. The link for the survey is <http://survey.vcu.edu/surveys/E4JY8Y>.

## Announcements (Continued)

### Other area Down syndrome support groups:

- **Down Syndrome Association of Central Virginia**, contact Sydney Gunn (434) 401-0788
- **Down Syndrome Association of the New River Valley**, contact Kristi Williams at (540) 651-6505 or by e-mail to [twilliams@swva.net](mailto:twilliams@swva.net)
- **Southwest Virginia GIRAFFE** (Giving Individuals Resources and Advocacy For a Fulfilling Education) serving Lee, Wise, and Scott Counties. Send Martha Davis an e-mail at [marthatdavis@yahoo.com](mailto:marthatdavis@yahoo.com).

## Next Chapter Book Club Headed for the Roanoke Valley

One of the goals of the Down Syndrome Association of Roanoke for the next calendar year is to organize and begin a local group of the Next Chapter Book Club (NCBC). Most of the following information is taken from the NCBC web site, located at [www.nextchapterbookclub.org](http://www.nextchapterbookclub.org).

The NCBC is a program of The Ohio State University Nisonger Center, a research and training center on developmental disabilities. The program was founded in 2002 and has grown from two groups in Columbus, Ohio, to over 25 groups throughout Ohio and the United States. There is currently one group located in Virginia in Fairfax County.

A group of parents, professionals, students, and individuals with disabilities founded the NCBC after a discussion about the prevailing assumption that people with intellectual disabilities are not readers, nor are they interested in lifelong learning. The group also discussed the isolation and segregation experienced by so many adults with disabilities who are living in, but not a part of, their communities.

The NCBC is designed to promote literacy, social connectedness, and community inclusion. The premise is simple. A group of 5 to 9 people with intellectual disabilities, regardless of their reading skills, gather with two volunteer facilitators in a local bookstore or café to read and discuss a book for one hour a week. Much like members of any other book club, NCBC members choose the book they want to read, as well as how they would like to structure their book club. Members are learning and making friends and having a lot of fun doing it.

The board members of the Down Syndrome Association of Roanoke are seeking several interested adults who would like to be facilitators or volunteers to lead a group. Once we are able to secure enough interested volunteers, we will arrange for a trainer from the Nisonger Center in Ohio to come out for a day long session to train our facilitators and volunteers. For more information or to sign up as a volunteer, contact Ms. Pat Macdonald, Vice President, Down Syndrome Association of Roanoke at (540) 772-6460 or by e-mail to [info@dsar.org](mailto:info@dsar.org).



Check out these books which are new additions to the lending library. If you would like to borrow any of them, just call (540.772.6460) or send us an e-mail ([info@dsar.org](mailto:info@dsar.org)) and we will get them to you.

**Adults with Down Syndrome** by Siegfried M. Pueschel

**Adventures in the Mainstream, Coming of Age with Down Syndrome** by Greg Palmer

**Mental Wellness in Adults with Down Syndrome, A Guide to Emotional and Behavioral Strengths and Challenges** by Dennis McGuire, Ph.D. and Brian Chicoine, M.D.