

DOWN SYNDROME

News

ON THE ALTAR WITH BENNETT

By Anthony Campise, Dallas, TX

Colored lights from the stained glass beam on his white cassock as Bennett sits next to me in the altar server's chair near the pulpit. He stares intently at his white loafer and out of curiosity occasionally feels his shoe's textured sole. "Bennett," I whisper and gesture at the same time, "Fold your hands." He instantly responds by folding his hands as I assure him, "You are doing a real good job." With that comment, he grins from ear to ear. Bennett and I sit waiting patiently for a few more minutes before we must get up for our next task on the altar. The deacon then signals us, so I tap Bennett and whisper, "Okay, Bennett, it's show time." With that cue, he knows that we have another task to do as altar servers in the Roman Catholic Church.

Learning new tasks can be difficult for Bennett because he has Down syndrome (DS). He and I work carefully together on the altar to make sure things are accomplished correctly and reverently. Bennett has been an influential person

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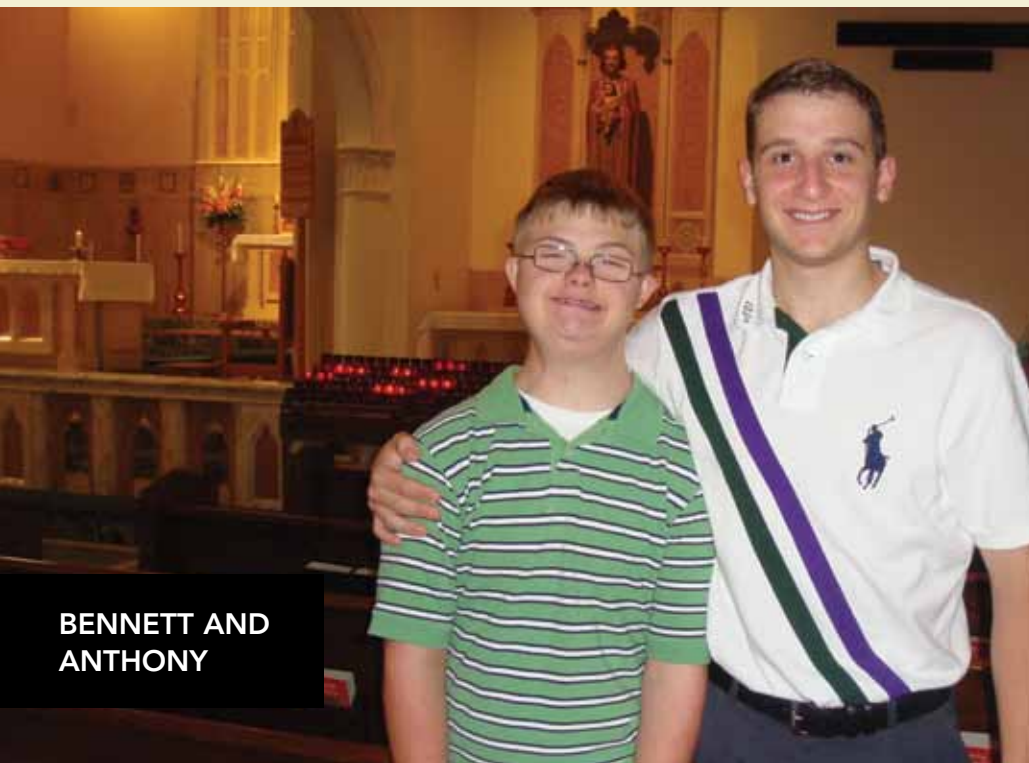
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**BENNETT AND
ANTHONY**

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Statement of Policy and Disclaimer:

This newsletter reports items of interest relating to Down syndrome and will provide a forum for others. The NDSC does not promote or recommend any therapy, treatment, etc. NDSC will not espouse any particular political or religious view. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. We wish to bring together those interested in Down syndrome and attempt to create an optimistic outlook and attitude.

The editor reserves the right to make corrections as are appropriate and in accord with established editorial practice in material submitted for publication. Submitting an item to the editor to use in *DSN* gives permission to do so.

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Mission

The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

Vision

The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

On the Altar with Bennett

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in my life because he has taught me, through example, how to be patient and take pride in what I do. He has proven to me and everyone that he is capable of being an altar server and is a diligent person who understands and is aware of what occurs around him.

Being born and raised into an enormous Sicilian-American family, patience is not second nature to me. In my family, all the men are considered short-tempered. Every once in a while, when I blow off steam, I realize I often am creating more stress around me, not reducing it. When I was asked to mentor Bennett in the role of altar server, I knew I would have to change my impatient nature to become more supportive if he was struggling to learn something. As I continued working with Bennett, I realized that I was becoming a more patient person by not allowing small things to perturb me, not being so testy around my younger brother and becoming more collected during stressful times at school. Working with Bennett not only benefitted him. It also taught me that patiently working together was the best way to form a friendship.

**Bennett has been an influential person
in my life because he has taught me,
through example, how to be patient and
take pride in what I do.**

Society often views people with special needs as not capable of performing complex tasks and not being cognizant of their surroundings. Bennett certainly proves that theory wrong. Despite having DS, Bennett is fully aware of what he is doing both on and off the altar. Whenever I see him at church, he waves excitedly, calls my name, rushes over and gives me a handshake.

This also happens during mass when he sees friends and family. He nearly stands up to wave at them during mass and I have to whisper “Shhh, Bennett, they see you.” During these moments, I realize Bennett is not only demonstrating that he recognizes me and others, but showing his love and caring for us. This unwavering love for friends and family is something that Bennett teaches me. Mentoring Bennett was not always the easiest task. He is easily distracted and likes to wave to people he knows in the congregation; however, he is the most enthusiastic and dedicated server I know. Working with my friend Bennett has been a joyous experience in itself.

Structuring Recreation and Youth Programs to Facilitate Social Inclusion

By Lynn Anderson, SUNY Cortland, and Linda Heyne, Ithaca College

“See that man [sic] over there?” “Yes?”

“Well, I hate him.”

“But you don’t even know him!”

“That’s why I hate him.”

– Gordon Allport,
On the Nature of Prejudice

People do not automatically or even naturally get to know each other in a group situation unless it is structured to encourage the development of positive interactions. This is especially true if some of the group members are noticeably different than the majority, such as youth with disabilities in a social or recreational setting dominated by peers who do not have disabilities. Coupled with many people’s fears of disability, the chances of really getting to know other young people and develop friendships becomes remote in a recreation or youth program setting such as that.

In the 1950s, Gordon Allport developed the contact hypothesis, based on the theory of intergroup relations and social identity. The contact hypothesis provides guidance on how to facilitate positive interactions between group members that lead to improved relationships. The remainder of this article will discuss six principles for

structuring group recreation activities (from classrooms to teams to camp groups) for young people based on the contact hypothesis. These principles can help group leaders and other staff set up situations that will foster positive group interaction, social inclusion, and friendship development. These principles will benefit all participants in the activity, not just youth with disabilities.

Provide Frequent and Consistent Opportunities to Get Acquainted

It is essential that group leaders structure recreation activities so participants can get to know each other. By planning activities to have high acquaintance potential, leaders ensure social interactions will occur. When some or all group members are new to the activity, frequent and consistent opportunities to get to know each other become even more important. Suggestions for structuring high acquaintance potential in activities include the following:

- Provide ice breaker activities (e.g., introductions, share favorites).
- Break into small groups; do activities in small groups.

- Arrange seating to promote social interaction.
- Use pairs or partners; have one partner introduce other partner to group.
- Mix up groups often.
- Wear name tags.

Maintain Equal Status

Leaders need to work carefully to structure the recreation activity and situation so each participant has equal status in the group, including the participant with a disability. Equal status reduces negative stereotypes, communicates respect, and is fair. Some ideas for how to structure activities to promote equal status are:

- Include everyone in the decision-making process.
- Mix up groups and responsibilities.
- Change the format in which information is given; provide alternative formats.
- Ask different group members to demonstrate.
- Assign roles in activities — everyone gets to try a role.

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Structuring Recreation and Youth Programs to Facilitate Social Inclusion

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- Break down activities and skills to enable everyone to try.
- Accentuate the equal status of group members: no “special” volunteers, “special buddies,” or “charity cases.”

Set Mutual Goals

Goals are an important part of many youth programs, even if the goal is to just have fun. Group leaders have the power to shape how goals are formed, and can improve social interaction by structuring the recreation activity so participants perceive they all share a common goal. Some ideas for structuring mutual goals are:

- Accentuate teamwork to reinforce equal status.
- Clearly set mutual goals; set the tone for cooperation.
- Ask the group to set mutual goals.
- Verbalize and reinforce mutual goals.
- Allow everyone a chance to play; rotate positions.
- Instill a spirit of camaraderie.
- Give feedback to the whole group on progress toward goals.

Support Cooperation and Interdependence

Cooperation is a powerful force in creating relationships between people. Group leaders can structure the recreation activity to promote

active cooperation and a feeling that each individual’s successes depend on the successes of the other group members. There are many different types of interdependence (Johnson, Johnson, & Holubec, 2008):

- **Positive goal interdependence:** Participants perceive they can achieve their goals if, and only if, all members of their group also obtain their goals.
- **Positive reward interdependence:** Each participant receives the same reward for completing the task. A joint reward is given for successful group work. Everyone is rewarded or no one is rewarded.
- **Positive resource interdependence:** Each participant has only a portion of the information, resources, or materials necessary to complete the task. The participants’ resources must be combined in order for the group to reach its goal.
- **Positive task interdependence:** The actions of one participant must be completed if the next participant is to complete her or his part.
- **Positive role interdependence:** Each participant is assigned complementary and

interconnected roles that specify responsibilities that are required to complete a joint task.

- **Positive identity interdependence:** The group establishes a mutual identity through a name, flag, motto, or other unifying symbol.

Among the ways to structure activities to support cooperation and interdependence are these:

- Assign duties or tasks, all of which are needed to successfully complete the activity.
- Have participants sit in a circle or around a table.
- Cultivate team spirit and group identity.
- Use team nicknames, t-shirts, or other group identifiers.
- Keep verbal communication clear.
- Use a cooperative structure, where each person completes a part of the whole task.

Provide Accurate Information About the Person with a Disability

Leaders in youth and recreation programs have a unique opportunity to help change attitudes and misperceptions about disability and ability by virtue of having diverse participants jointly succeeding in activities. Group leaders can structure the recreation activity so that all participants receive information about the participant with a disability that is accurate and that doesn’t perpetuate

stereotyped beliefs about the disability. Some tips for doing so are:

- At the initial session, explain the disability, or supports and accommodations the individual needs.

leaders, participants, and spectators. Suggestions leaders can use to structure egalitarian norms include:

- Model positive, accepting behavior.
- Don't patronize or "over help."

These principles can help group leaders and other staff set up situations that will foster positive group interaction, social inclusion, and friendship development.

- Let the individual determine what should be shared with the group.
 - Have the individual demonstrate how to use a communication device or piece of adaptive equipment.
 - Create an environment of open communication.
 - Do ice breakers that focus on similarities and differences.
 - Assume a "can do" attitude.
 - Draw attention to the participant with a disability when she or he is doing something very well.
- Rotate positions, roles, and tasks.
 - Accent positive attributes and skills.
 - Emphasize teamwork.
 - Get diverse input from all group members.
 - Reinforce rules and fairness.
 - Equal out or balance skill levels among participants.

Create Fair and Tolerant Norms

It is essential that group leaders structure the recreation activity so that the situation favors group equality and fairness. They can do this by creating and reinforcing egalitarian norms that promote fair and caring behavior and tolerance of diversity on the part of the

Conclusion

Relationships and friendships are critical for social and emotional well-being, and group leaders must not leave social interaction to chance (Anderson & Heyne, in press; Heyne, Schleien, & McAvoy, 1993). Since many people, whether they have a disability or not, develop and sustain relationships through their leisure, it is important to nurture that development during recreational activity. While the suggestions in this article do not necessarily guarantee close social

ties will occur, they will help create environments where youth have opportunities to get to know each other, learn each other's strengths, and build lifelong friendships.

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D.S. Headline News

is a special publication of the Youth/Adult Committee of the NDSC to promote stories about people with ~~Down~~ Up! syndrome written by people with ~~Down~~ Up! syndrome.

All About Me

By Daniel Walker Jordan, Age 25, Tallahassee, FL

My name is Daniel Walker Jordan and I live in Tallahassee, FL. I am 25 years old. For two and a half years, I have worked at Westminster Oaks, a Presbyterian retirement community. I first volunteered there in their Physical Therapy and Physical Fitness Departments. After six months of volunteering, they noticed that I did a good job and then they hired me! I now work in Dining Services and I use my organizational skills in the dining room for preparation and set up of the tables. I help with special events by bussing

and breaking down tables. I also work in the dish room where I'm responsible for all the silverware on the carts.

I enjoy being around the other employees in Dining Services. If I need support, they are there to help me do my job better and faster so I get the job done right. I even received a gift card from the Health Center for helping with the safety of the residents.

After I work for two hours each morning five days a week, I still volunteer with the Physical and Occupational Therapists. I volunteer an extra hour every day by bringing the



**DANIEL JORDAN WITH
CO-WORKER KRIS QUILLIN**

residents to their therapy, encouraging them to complete their therapy, and then I return them to the nurse's station. The best part of this job at Westminster Oaks is putting a smile on the residents' faces.

The Book Project

By Meredith Martin, NDSC Self-Advocate Council

My fellow Self-Advocate Council (SAC) members and I recently returned from San Antonio, and another great NDSC Family Reunion. The SAC continues to have many projects that promote positive awareness of Down syndrome (DS). Our most famous and ongoing project is the one started by Tracy Hile (AR) back in 2003. Although this project began small, it continues to grow and grow. This year was the best ever! Because of the efforts of many, 64 books were presented to schools in the San Antonio area and 12 book bundles were taken back to schools in the communities of several of the self-advocates or to local affiliate support groups.

In order for us to continue the growth and success of this project, your help and support are needed. Here are a few ways that self-advocates raised money this

year to purchase the book bundles:

- Jennifer, Stephanie and Allison (OH) had a successful bake sale.
- Carrie (NY) was able to raise money by emailing friends and family. She described the project and then asked for donations.
- Melissa (MD) had the idea to contact an author, Brian Skotko, asking him to donate some of his latest books.
- Christi and Austin (TX) donated a book bundle to a school in California where Christi's sister teaches.
- Tracy (AR) likes to donate books as birthday presents.
- Jeremy (SC) saved some money out of each of his paychecks to purchase his book bundle.

These are just a few of the ways of fundraising that I



MEREDITH MARTIN

know. The SAC would like to encourage you to help us continue to expand the positive awareness of Down syndrome and how *We're More Alike Than Different*. Please accept the challenge to follow in these self-advocate's footsteps, or dream of a new way to help us make this project continue to grow.

For more information and photos visit the NDSC website — www.ndsccenter.org, then click on the Book Project link. You can also join us through our SAC Group on Facebook.

My Very Interesting Life

By Beth Hatch, Age 28, Dresher, PA

Hello! I am Beth Hatch. I am 28 years old and I live in Dresher, PA, with my Mom and my Dad. There are so many great things to tell you about my life, because my life is very interesting.

I grew up with my younger sister, Jackie. We're really close. Right now, Jackie lives in Cleveland, OH, with my future brother-in-law, where they are both doctors at Rainbow Babies Hospital. When Jackie gets married next year, I will be her maid of honor.

When I was younger, before I went to school, I went to KenCrest where I had my first teachers. KenCrest still helps me today. I work with a great person named Katie White.

Ever since I was little, I have really loved show business. I like to watch plays and shows, and I also like to be in them too. I started in dance class when I was very young and was in many recitals. When I was 18, I joined Harmony

Theater at Gwynedd Mercy College. We do one concert and one show a year. Last year our concert was all Beatles songs, and I sang *All You Need Is Love*. Our show was called *Beyond the Sea*. Our director, Barry, wrote the show by combining *Finding Nemo* and *Little Mermaid*. I played Nemo.

My favorite sport is baseball and my favorite team is the Phillies. My all time favorite Phillie was David Bell, who played third base. I was there the night he hit for the cycle. It was very exciting. I also go to see the Phillies in spring training in Clearwater, FL, every year. I always get to talk to Dallas Green and Ruben Amaro, Jr., who is the general manager. In the picture, I am standing next to a new statue of Harry Kalas, who was my favorite Phillies announcer before he died in 2009.

For the last five years, I have worked at Arcadia University for a company called Parkhurst, which runs



BETH HATCH

the dining hall. My main job is serving the students their lunch. I have many great co-workers, including Emory Jackson, who works at the grill. Emory makes a great cheeseburger.

I am very proud to be in Special Olympics. My two best sports are swimming and bowling. I have gone to Penn State to swim in the State Special Olympics many times. My best stroke is freestyle and I have won many medals. In bowling, I get to hang out with my friend, Kelly, and my boyfriend, Matt. My best bowling score ever was around 137.

I belong to a group called ADD, which stands for Adults with Developmental Disabilities. One of the great things about ADD is the trips the members take together. Some trips are day trips to shows and dances. Once a year we take a long overnight trip to some fun place. This year we went to Niagara Falls and New York State. I saw the falls from the *Maid of the Mist* and I went to the Baseball Hall of Fame in Cooperstown, NY, where I saw an exhibit for the original Ladies Baseball League. They made a movie about it called *A League of Their Own*.

When I'm home relaxing, I like watching TV. Some of my favorite shows are *Glee*, *American Idol*, *Secret Life of the American Teenager*, *Dancing with the Stars*, and *Pretty Little Liars*. My favorite TV star right now is Selena Gomez. I love her show *Wizards of Waverly Place*. I watch it every day. I also have her first and second CDs.

I have so many things to do. Life is never boring.

Magic Bullet Blender

By Lori Turbenson, Age 31, Blaine, MN

I have a new kind of blender that is advertised by three people. This new appliance that I'm sharing with you is called a Magic Bullet Blender and it comes with the power base, short and tall cups, party mugs with comfort lip rings, a recipe guide, cross and flat blades, stay fresh re-sealable lids and shaker/steamer tops.



LORI TURBENSON

Before using the Magic Bullet, make sure to read all the instructions and directions of how to use it properly and safely. What's amazing about the Magic Bullet is that it can make meals in less than 10 seconds without dirtying up a single pot or pan. You can even cook with it. This kind of blender makes everything that you love and any meal. If you want to get rid of your old blender, then I would recommend the Magic Bullet to replace any old blender. It is a new way of cooking food that you love. You can do any meal any time of the day. Do not put the power base in water, but hand wash it with a damp cloth (or paper towel) and dry with a paper towel. The cups, party mugs, including blades are dishwasher safe. This Magic Bullet does make a good gift to any occasion. To let you know that the salsa is a 3-second salsa and nanosecond nacho dip takes regular cheese and milk. If you're doing jalapeño peppers, wash hands and pulse that first. So enjoy the Magic Blender. Don't forget to be safe.

Meet Travis Raefield

By Travis Raefield, Age 26, Danville, CA

Hi my name is Travis Raefield. I am a 26 year old from Danville, CA. I was diagnosed with Down syndrome (DS). I was born 1984 in Concord, CA, with DS. I and my family lived in Concord. In six months we moved to Seattle, WA, lived there for 12 years and also I had a baby sister whose name is Adrianna when living in Seattle. Then in 1997, we moved to Los Angeles, back to California to live in San Ramon. I grew up in Seattle and finished growing up in San Ramon.

After I turned 18 years old, my mom and Dad taught me to be on my own with washing dishes, lawn mowing, working, cleaning my room and cleaning up after my dinner. When I turned 21 on my B-day that year, I and my family went to Hawaii. At dinner one night, I stated that I would like to drink fruity alcohol beverages. Also, my family went to Italy to see my grandmas in Rome and to

learn about the history of Italy. When I turned 22½ years old, I went to Taft College to be independent. In 2010, I got a job working with a program in a cafeteria at a café. I work with Thrive Support Services to continue to learn to be independent.

In the past, I have lost a job due to my big appetite. Recently, I am working at a CSS program in Concord, CA, which is where I was born.

Having DS involves having support from my family and love. It's often challenging financially and I need the support. I have good self-advocating skills to "stand up" for myself. I enjoy having fun, such as being with family, parties, and Danville Valley Young Life. My hobbies include bowling and basketball for the Special Olympics. I like being in a job program because it helps me to learn skills to get a higher level job. I liked attending a Taft College program because it



TRAVIS RAEFIELD

helped prepare me to be on my own, learn skills, and have a roommate. I like having a personal life that includes my girlfriend, Amy. We have a lot in common and have fun together such as playing games.

I am so happy that I am being supported by my family which includes my Mother Sheila, Dad Jeff, Sister Adrianna and her boyfriend, Matt. Being independent is very important to me. I have support from Thrive Support Services and learn how to set goals, how to achieve them, and learn new things. I like having an income from a job to pay the bills and the rent. It's fun to have my own

apartment and sharing it with a roommate.

My hopes and dreams for the future include getting a real job, working as a WWW Wrestling general manager, meeting a WWW superstar, getting a gold medal in Special Olympics in the state games for basketball and bowling, getting married to my girlfriend, Amy, and to meet the president of the U.S.A. Barack Obama and his wife, Michelle.

I think having DS, a developmental disability, is very special. Learning and living in America helps me to cope with challenges in my life. I'm used to having DS and have accepted it. I have been supported by my family with money and love. I have a good family to help me with my health and well-being. I am thankful for my sister and love to show love to her. I am so happy to see my family love me for who I am.

Life at Down Home Ranch

By Julia Burns, Age 36, Elgin, TX

This is the story about the ranchers at Down Home Ranch. My story is for the people that have Down syndrome (DS). The story is about living at the Down Home Ranch. I've learned to be more responsible and be more independent while living here. Every day in my life. Because I believe the people with DS need to know what life is like at Down Home Ranch

and how to be a part of the ranch life. It changed everything in my life and know it will do the same for you all. If you would like to volunteer or just to live at Down Home Ranch in Elgin, TX, please contact my case worker Casey Dickerson at 20250 FM619, Elgin, TX 78621. My hopes and dreams for this ranch is to be responsible and to be independent for my life.

My hobbies are watch TV and coloring and I collect girls and guys names as my hobbies. My school is in Austin, TX. I went to Anderson High School. My job here at Down Home Ranch is The Foodies Team. I help make lunches for ranchers and clean up afterwards. My family lives in Austin, TX. They support me. Thank you.



JULIA BURNS

Movie Magic

By Meghan Zellmer, Age 21,
Inver Grove Heights, MN

My name is Meghan Zellmer. I live in Minnesota. I am 21 years old. I graduated in June from my transition program at Dakota County Technical College. Now I work at Proact.

This summer I took a class called *Movie Magic* from Highland Friendship Club.

Katie and Dusty are the directors. Class was on Tuesday from three to five. We decided our movie name was *Pyrates of the Mississippi: Quest for the Ring*. I was pirate one in the movie. I had to say lines I memorized. I danced to songs. My other friends in the movie were Captain Pigsty, Grendolf, Elvis, Harry Potter, Ginny, Voldemort, Darth Vader and Biebers. The funnest part was dancing on a big paddleboat. All the actors took bows at the end. We had a movie premiere for family and friends. It was at a real theater. At the end there was an awards ceremony. I got an award for best female dancer.



MEGHAN ZELLMER

Woodbine House Contest for Artists with Down Syndrome

Woodbine House publishes books and they are holding a contest for creative teens and adults with Down syndrome. The winners will have their stories, photos, pictures, poetry and song lyrics published in a book. To enter the contest you must have Down syndrome, live in the U.S., Canada or Mexico and be at least 12 years old when you created your artistic entry.

There are more rules that you should know before you enter the contest. There are rules about what to enter, how to enter and what you will get if you are a winner at www.woodbinehouse.com/DScreativecontest.asp. If you want, you can send an email to Dscontest@woodbinehouse.com and they will send you everything you need to know.

Hurry! The deadline to enter is Saturday, December 31, 2011. Winners will be notified by Tuesday, March 1, 2012.

Development News

By John Kupris, NDSC Development Director

Dear Friends of the NDSC,

As this issue goes to press, the U.S. economy is either in an extended stagnation or one of the slowest recoveries since such activities have been tracked. An important consideration for all of us in public service is, "What happens to serving children and adults with Down syndrome (DS) in a challenging economy?" The answer may not be simple. However, at the NDSC we are dedicated to making sure that through our public policy staff in Washington, D.C., and the dedicated work of our staff in other parts of the country, we make a positive impact on the lives of all people with DS.

With your ongoing help, NDSC has been serving people with DS and their families for nearly 40 years. We hope you will continue supporting our efforts. By giving to NDSC's annual appeal, you help us provide support to families in their time of need. Your giving also enables us to offer high-quality materials to new families and to advocate for people with DS in our nation's capital. We're also changing attitudes through the *We're More Alike Than Different* awareness campaign and changing lives by providing our annual convention, thanks to your generosity, at an affordable price.

For more information on how to donate to the NDSC annual fund, please contact me at John@ndscenter.org. Thank you for considering a gift to this year's Annual Fund. Your gifts make a difference every day.



Reminder for suggested convention speakers and award nominations

In the last issue of *DSN*, there were detailed calls for general convention and self-advocate speakers for the 2012 NDSC Annual Convention in Washington, D.C. Speakers who are interested in presenting a workshop can find a workshop proposal form on the NDSC website, ndscenter.org, to complete and submit for consideration. Workshop proposals are due Friday, Jan. 4, 2012.

Down Syndrome News is a benefit of your annual membership in the National Down Syndrome Congress. To renew or join today, visit ndsccenter.org or call 1-800-232-NDSC (6372).



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DOWN SYNDROME
News

A newsletter published throughout the year
by the National Down Syndrome Congress.

Mark your calendars now!

Join self-advocates, families and professionals at the
2012 National Down Syndrome Congress Convention.

**Washington Marriott
Wardman Park
Washington, D.C.
July 19-22, 2012**

Make your hotel reservation today!
Before you do, check out the NDSC website,
ndsccenter.org, for important details on
getting the best value for your family's
convention lodging. When making your
plans, don't forget the July 19th Day on
the Hill event, too!

Convention registration begins March 5, 2012.

The logo for the National Down Syndrome Congress is positioned at the top right of the graphic. Below it is a blue illustration of the United States Capitol dome. To the right of the dome, the text "a Monumental Meeting" is written in a large, bold, red serif font. Below this, "Celebrating 40 Years" is written in a smaller, elegant, gold cursive font. At the bottom of the graphic, "Washington, DC ★ July 19-22, 2012" is written in a bold, red sans-serif font.

a Monumental Meeting
Celebrating 40 Years
Washington, DC ★ July 19-22, 2012