



Pope Francis with  
Annie Beazley

# NADSNews

Newsletter for the National Association for Down Syndrome

July, 2015

## Dearest Pope Francis *Colleen Beazley*

**T**wo years ago while we were living in Rome, Italy, my daughter Annie and I had the incredible opportunity to meet Pope Francis in St. Peter's Square. We were taking friends who were visiting from Chicago to a Papal Audience, just months after the new Pope was elected. The crowds were immense, as I am sure anyone could imagine. It was a gloriously sunny but hot day in May.

As we were fighting our way through the crowd to find a place to sit, Annie caught the attention of a Swiss Guard. She was smiling and waving at him, and he stopped us to tickle her toes and squeeze her cheeks. Although I was anxious to find a place for us in the crowd, I stopped as I always do for Annie's little flirting sessions. When I thought they were done with their sweet meeting, I pulled the stroller away to push forward. But the guard stopped me and said, "Signora, vieni con me!" ("Come with me!"). He then led me through the crowd past a roped off section to the very front row of the audience. Apparently he had recognized that Annie has

Down syndrome, and escorted us to a special section that the Pope keeps for the sick and individuals with disabilities.

As I was pushing her stroller to our amazing seat in front of the crowd of over 100,000 that day, tears streamed down my face. I don't think of my daughter as sick or disabled, nor anything other than the greatest blessing in my life. Little did I know at the time that getting to sit front and center wasn't the only big surprise that day. After the audience, Pope Francis took the time to meet every single individual in our section. As he was coming down the line, Annie kept reaching for him like crazy and tears kept welling in my eyes. When he got to us, all I could say was, "Annie, Fai un bacio per la Papa" ("Give our Pope a kiss"). And he smiled an immense smile and said in surprise, "You'll give me a kiss?!" And then he kissed both of her cheeks and held her shoulders and put his hands on her head and her belly. He prayed over her and then he took my hand and prayed with me. And as tears streamed down

my face, all I could choke out was a simple "Grazie."

A few days later I sat down and wrote this letter to him.

*Dearest Pope Francis,*

*You don't know me, but as you kissed my daughter's cheeks and held her face in your hands, I felt as if you did.*

*Just three years ago, my husband's job for Loyola University Chicago's John Felice Rome Center took us from Chicago, the only home I had ever known, and brought us to Rome. On the day before we moved we found out we were expecting our first child. I was very frightened to be having my baby so far from my family and loved ones.*

*Around the twentieth week of my pregnancy, the doctors told me they found an abnormality in my umbilical cord and suggested genetic testing for Down Syndrome. When I asked what difference testing would make I was told, "You don't have much longer to legally terminate this pregnancy." How could anyone think I didn't want my precious child? You often preach*

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or visit [www.nads.org](http://www.nads.org)

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## Dearest Pope Francis *Continued from page 1*

of the importance of truth, so here I would be lying if I said I wasn't terrified. I prayed every moment that my baby would be born without a "defect."

The day of her birth is one of the most shameful days of my life. As soon as she was laid on my body, I knew she had Down syndrome. I was so devastated for her future, and for ours. The unimaginable thought, "I don't want her," crossed my mind. I questioned God's plan. I turned away from him.

But my beautiful Annie has taught me I was wrong. She's taught me so many things in her first two years. She's shown me God's love and grace and presence. Now I see what a true blessing my Annie is and I couldn't imagine my life without her or her extra chromosome. She brings so much light and love into the lives of everyone she meets. I am not sure I will ever be

able to forgive myself for thinking otherwise the first days of her life.

That is why as you held my hand in yours, all I could choke out was a simple "Grazie." I was so ashamed that I ever thought of her life as less than perfect. I was crying and praying for all the Annies that are terminated. They are God's angels that don't make it here because of fears of a harder life. Annie has taught me that different and harder can be better. She may not walk yet and may never talk the "right" way, but she is, already only at the age of two, an example of how to love others and bring out the best in them. This is what really matters.

Holding Annie in my arms and your hand in mine, I was overwhelmed with gratitude for all God has given me. God is so good. I feel as though I don't deserve to be so blessed, to be the recipient of such a gift as my

little girl. And to have been touched by God through you and her at the same time was the most humbling experience of my life.

You have said, "Francis of Assisi tells us we should work to build peace. But there is no true peace without truth." I am trying to find my peace by sharing my Annie with the world and telling our story.

Thank you for being the greatest example of love and acceptance, for inspiring us all to use our God given gifts to bring good to our world, for bringing so much hope in times of despair.

I fear it is impossible to express how loved you are, our dear Papa Francesco.

We will never forget that day and the incredibly humbling experience of meeting the Pope. And we keep looking forward to all the wonderful surprises and experiences our Annie brings into our lives!

## CAMPS & PROGRAMS

### Camp-N-Play Lekotek at the Chicago Botanic Garden

Lekotek is offering a nature-inspired day camp at Chicago Botanic Garden for children with special needs aged 3-8 and siblings. The camp will be held August 10-14. Parents are also welcome to attend. For more information, call 773-528-5766 x407 or go to [www.chicagobotanic.org/camp/plantplay](http://www.chicagobotanic.org/camp/plantplay).

### Brookfield Zoo Camp

The Chicago Zoological Society has begun a new partnership with the National Inclusion Project on how better to serve campers with special needs. Their summer Zoo camp program, which is ACA accredited, educates children ages 4-14 about animals and the natural world. One week camps are offered throughout the summer. For more information, go to [www.czs.org/Brookfield-ZOO/Learning/Zoo-Camp](http://www.czs.org/Brookfield-ZOO/Learning/Zoo-Camp).

### Special Needs Dance Program

DancEsteem is a dance program for children with special needs offered by DancEncounter Dance Studio in Geneva. The studio will be holding a series of open houses in August for students and their families who may be interested in the DancEsteem program. Weekly classes will be offered in the fall. For more information, contact Lain Avery at 630-232-1221 or go to [www.dancencounter.com](http://www.dancencounter.com).

## BOWL-A-THON

# 2015 Bowl-A-Thon

Thank you to everyone who bowled at this year's Bowl-A-Thon. We are grateful for your participation and commitment, which helped us raise more than \$70,000 for NADS. We would especially like to recognize the individual bowlers and teams who obtained the most pledges:

### Individuals

Gina Rotondi = \$8178  
Chris Hebein = \$7063  
Julia Smarto = \$2140  
Kristin Malkowski = \$1850  
Kenny Clayton = \$1200  
Emily Jackson = \$1120

### Teams

Jacob's Crew = \$6485  
Schubie-Doos = \$3465  
Kerry & The Big Dogs = \$3315  
Kaya's Krew = \$1915  
Team Lily = \$1400  
Sami's Super Strikers = \$1325  
Brogan's Bowling Buddies = \$1275  
Team Jane = \$1270  
D.A.D.S Group = \$1080  
Mallory's Team = \$1055  
Team Regan = \$1050  
Champions for Cameron = \$993  
Dale's Dream Team = \$870  
Team Hannah = \$600  
Dillon's Strike Machine = \$500

### 2015 Bowl-A-Thon Lane Sponsors

### NADS PARTNERSHIP PROGRAM

Wee Speech

### PLATINUM-\$2,500

Litchfield Cavo LLP

### GOLD-\$1,000

Jennings Chevrolet and Volkswagen, Inc.  
Barbara Rodgers  
James and Theresa Unnerstall

### SILVER-\$500

Therapy Yoga Gymnastics Rocks

### PEARL-\$250

Cary Firefighters Association  
Down in the Southland  
Evanston Family Dental Associates  
Gary & Shawn, Inc.  
Life's Plan, Inc. Trust Services  
Papanicholas Coffee Company  
Suburban Pediatric Therapies  
Tom and Karan Unger

### BRONZE-\$100

Amish Furniture Shoppe  
Laura and Scott Brashear  
Elk Grove Graphics  
Sac Pac, Inc.  
Specs4Us  
Al and Teresa Unnerstall  
The Waters Dental Group

### Door, Choice, & Raffle Prize Donors

Thank you to the individuals and businesses who donated items for our Door, Choice, or Grand Raffle Prizes. A complete list is posted on our website: [www.nads.org](http://www.nads.org).



## EVENT

### Bible Bingo Fundraiser for NADS

September 26  
8:00 p.m.  
Royal George Theater,  
1641 N. Halsted,  
Chicago, IL  
[www.nads.org](http://www.nads.org)  
(see order form on page 11)

## Special Olympics Patrick Crawford

My daughter, Katia, has spent the better part of her 9 years being dragged along to older siblings' travel soccer games, basketball tournaments, and various other sporting events, but since the beginning of 2015 the tables have been turned, with Katia's Special Olympics competitions



Katia Crawford

driving much of the family schedule. First in January, it was the Special Olympics district basketball skills competition held at Warren High school, where Katia won a silver medal for her ball handling skills. Then on May 3rd, Katia's brothers and extended family members trekked up to Lake Zurich High School to watch her earn a Gold

medal in the 50 meter run and a Bronze medal for the standing long jump. Katia's Gold in the 50 meter race extended her Special Olympics track and field season for a few extra weeks and allowed her biggest fans, older brothers Sean and Aidan, to help her prep for the Special Olympics Summer Games.

While our family has known several Special Olympians and celebrated their successes from afar, this was our first opportunity to attend the Summer Games in Normal, Illinois. It was truly a moving experience for our family to watch Katia during the Opening Ceremony as she carried the banner, for the newly established

Wilmette Community Stars Special Olympics squad, into Hancock Stadium on the campus of Illinois State University.

The Summer Games is Special Olympics Illinois' premiere sports competition with more than 4,000 athletes and Unified Partners competing in 6 different sports, along with 1,600 coaches, 2,000 volunteers and 3,300 family members. That totals almost 11,000 people who attend Summer Games annually. While Katia loves attention and was excited that we drove in the night before to attend the opening ceremonies, on Saturday morning before her event she confided to her entourage of siblings, cousins, aunts, and uncles that she was nervous. That nervous energy was quickly converted to a big smile when her name was announced as the bronze medal winner. It was an amazing experience to see the number of volunteers and families focused on supporting the athletes of all ability levels while celebrating and promoting the Special Olympics ethos as articulated in the oath, "Let me win. But if I cannot win, let me be brave in the attempt."

The day after our family trip to ISU, the Special Olympics Relay Across America came through

Chicago, allowing Katia and the Wilmette Stars to help the Flame of Hope make its way to Los Angeles, where the Special Olympic World Games are taking place later this summer. In May, the Flame of Hope was delivered to the U.S. from Athens, Greece and was split into 3 torches to be carried along 3 different routes from the East Coast to L.A. On Sunday, June 14 one of those torches came to Chicago and headed through from Wilmette, on the Evanston to Lake Forest route. Having the opportunity to carry the Olympic Torch and experiencing the Wilmette community celebration of their newly established Special Olympics team is something that our family will always cherish, and I don't think Katia's brother's minded a bit that they have taken over her role as super fan, at least for the time being.

### EVENT

#### 13th Annual Chicagoland Buddy Walk

Oct. 11

Bolingbrook Golf Club  
chicagolandbuddywalk.org

## New Parent Support Volunteers

Welcome to the new volunteers who recently went through our Parent Support Training on May 2 or our make-up training session on June 6. Our new parent support volunteers are: Liz Daly, Juliette DeNova, Natalie Garner, Don and Jessica Hubert, Erin Komacki, John and Maggie Lay, Julie Martin, Graham and Mandy Traynor, Erin Wolaver, and Stephen and Peggy Yogya. We appreciate their willingness to help other families and are delighted to have them as part of our Parent Support Program.

## Have you ever met an Olympian? Anne Reinertson

'Have you ever met an Olympian?' those were the words the communications director asked the group gathered at the Plainfield District 202 Board of Directors Meeting. Regan proudly raised her hand and stood up and said 'ME'! WOW. How many typical children get to be recognized at their district's Board Meeting let alone our daughter with Down syndrome. We are truly blessed to be in a district where ALL students are honored for their achievements.

Regan was given an award by the Board President for her achievements in Special Olympics. She competed at the State Level on June 12th at ISU! This is her first year with Special Olympics. Regan is a Rhythmic Gymnast. She not only received the Silver medal for her overall performance at her first competition, but she took home GOLD in her rope competition to qualify

her to compete at the State Level.

The best way to describe the Special Olympics experience so far is 'uplifting.' I get goosebumps just thinking about her first competition. She was surrounded by so many family members, teachers, friends and strangers cheering her on! I have never been in a place where you can feel the love, acceptance and pure joy in the air. To see all the athletes during the opening ceremony is an experience EVERYONE should have on their bucket list. The human spirit shines through in all the athletes—the energy could light the world! It doesn't matter if Regan didn't medal that day. All that matters was Regan doing her best and enjoying the "anything is possible" spirit that penetrates these events. If you have ever thought about Special Olympics, I encourage you to give it

a try. Your athlete will gain self-confidence and a sense of accomplishment while training for months for the competition. The coaches are amazing; they devote so much time to the athletes, and we appreciate every minute of it. Regan is always asking to go to gymnastics! She loves her coaches and can feel their devotion to her and her sport. My niece Juliann is now a coach at University of Iowa for their Special Olympics swimming program, and I couldn't be more proud! She loves working with the athletes and gets just as much out of the experience as they do... if not more. I want to thank everyone in the organization for being so generous with their time. I am so glad that Regan has begun this journey with Special Olympics. The outcomes are helping her in so many aspects of her life.

The athlete's oath is...

"Let me win, but if I cannot win, let me be brave



Regan Reinertson

in the attempt." I think this says it all, not just for the athletes but us too.

## Speech Therapy Corner – Voice Laura Drower, M.S., CCC/SLP, C/NDT, Wee Speech

Voice challenges are one of the many issues that can negatively impact speech intelligibility in persons with Down syndrome. When we talk about voice we include: quality, pitch, loudness and resonance. Persons with Down syndrome may have difficulty in one or more of those areas. Their vocal quality can be hoarse or harsh. They may use a lower pitch and be more monotone in speaking. Volume is often loud with little variation. They may be hypo or hyper nasal. The reasons for these issues vary. Persons with Down syndrome may have allergies, reflux or frequent upper respiratory/sinus infections with drainage that can impact the vocal folds. They may yell a lot or use a harsh vocal onset when speaking. Tonsils and adenoids may be enlarged and overall muscle tone in the head and neck may be low.

Voice challenges can be addressed in several ways. An ENT (Ear Nose Throat) doctor can evaluate the vocal tract to determine if there are nodules or other problems that can be repaired or remediated. A GI (gastrointestinal) doctor can assess reflux. A pediatrician, allergist or general practice doctor can diagnose and treat allergies, sinus and upper respiratory problems. A speech pathologist specializing in the field of voice disorder can then address the quality, pitch loudness and resonance issues to improve the voice for increased intelligibility.

Recently, there was a story in the news about a young lady with Down syndrome who used a vocal coach to improve her singing voice. A vocal coach is typically a music-based professional who works on the use of the voice for singing. They may focus on enunciation and breath support to promote a higher quality singing voice and those skills may lead to improved intelligibility in speaking.

The voice can have a great impact on intelligibility in persons with Down syndrome.

Voice goals can become a part of an overall treatment plan for improved intelligibility that may already include articulation and language goals. Talk to your school-based or private SLP (or both!) to see if voice goals are appropriate for your loved one with Down syndrome.

## NADS Fashion Show

Our 10th Annual NADS Luncheon and Fashion Show will be Sunday, October 18, 2015. The NADS Fashion Show Committee is looking for volunteers to plan and organize the upcoming fashion show featuring models with Down syndrome. Please email [fashionshow@nads.org](mailto:fashionshow@nads.org) or phone 630-325-9112 if you are interested in volunteering and having your child participate in this year's fashion show.

### Avery at the Fashion Show

Gretchen Connors

The first time we entered the Rosemont ballroom, we were only spectators. We had heard of the NADS Fashion Show but were convinced it was not for Avery. This first visit confirmed our fears. Avery was uneasy and anxious to leave. Avery seems to be prejudiced against ballrooms, stadiums, arenas etc - any place that requires designated seating and lengthy exits. Echoing acoustics, high ceilings and rooms with no windows can be a nightmare for those with sensory integration issues. Also, forced close proximity and resulting obligatory small talk are not her fortes. Last year, armed with contingency plans (i.e. iPad, bagels and favorite cousins), I was ready to do battle once again with Avery's sensory issues. However, this being our third attempt, there was nothing to fight. Avery walked into the Rosemont as if she owned the place. She sat at the table for the entire lunch and greeted everyone warmly. She waited for her designated time to walk the catwalk. She performed a cheer and danced on stage, not as the old cliché goes as if no one's watching, but rather as if she expected them to.

If it hadn't been for the chocolate cake that some angel/genius had placed on each table, we wouldn't have made it into the room. It was a temporary victory: as soon as the slice of cake was gone, so was Avery. The next year, in an effort to engage her, I signed Avery up as a model. She seemed a little less anxious but would venture to any part of the convention center except the ballroom. She rode the escalators several times and loitered in the lobby. Myla, Avery's persuasive sister, could not convince her.

The problem with waiting your child out, is that the rest of the world does not stop. Avery's scheduled time as a model had arrived. In an act of desperation, her father carried her in

on his back. Gail, who was in charge of the show, wondered aloud if Stephen would carry her across the catwalk on his back. Stephen's reply was as it always is: if she needs me to, I will.

Suddenly, at the foot of the catwalk stairs, Avery slid off of her dad's back, took her sister's hand and strutted her way across the stage. Avery fancied herself the Lady Gaga of the Down syndrome circuit. Why wouldn't everyone want to be carried in? All the guests at our table had tears in their eyes.

Last year, armed with contingency plans (i.e. iPad, bagels and favorite cousins), I was ready to do battle once again with Avery's sensory issues. However, this being our third attempt, there was nothing to fight. Avery walked into the Rosemont as if she owned the place. She sat at the table for the entire lunch and greeted everyone warmly. She waited for her designated time to walk the catwalk. She performed a cheer and danced on stage, not as the old cliché goes as if no one's watching, but rather as if she expected them to.

As Avery's mother, I have often sought the advice of others who have gone before me. Searched for sure footing on an uneven path. Sometimes, though, I worry that the path I want is the one of least resistance. Finding a way to make the world easier for my daughter. Perhaps Avery doesn't want easier. Maybe she doesn't want a path at all. She may very well be content to trample through the woods in order to find her way home. But they are her woods. And she is at home on that stage in a way I could not have foreseen three years ago. The NADS Fashion Show has given her not only the time and the platform, but also a reason to shine.



Avery Connors at the NADS Fashion Show

### Parent Support Group

Parents who are looking for a local support group may be interested in one which started several years ago for those who have a loved one with a disability. They meet the first Wednesday of each month from 12-2 on the 2nd floor of the Community Bank of Elmhurst at 330 W. Butterfield Rd (where Butterfield and Spring Rd intersect) and bring in speakers periodically. The group includes several parents who have adult children with Down syndrome. New members are welcome. For more information, contact Shirley at [Slpanda2@sbcglobal.net](mailto:Slpanda2@sbcglobal.net).

## Show Them How Special You Are!

Jenni Von Tobel, Director of Programs, Special Gifts Theatre, Inc.

From Annie in *Annie* to Peter Pan in *Peter Pan*, Erin has played a variety of roles in her 9 years at Special Gifts Theatre (SGT). She has a passion for acting and upon meeting her, her enthusiasm and flair for the dramatic prove that, for her, stage fright is not an issue. Listening to her talk about being part of SGT, however, it becomes apparent that the acting is secondary.

"I've learned so much at SGT," she says. "I've learned to forget about the mistakes I make and to always be myself."

In theatre, we often say be true to your character in reference to the specific role someone might be playing. How would Peter Pan react in this situation? What would Cinderella be thinking right now? Would the Lion really be that brave or would he be more fearful? Act like that. Act in whatever manner is true to your character.

Erin, like many of our students, has been able to transfer that skill to her own life.

"I try to be true to myself all the time. I know that it's ok to be different than other people. In fact," she says, "it's awesome."

That's what SGT is all about – celebrating the differences that make each of us unique. Erin is an excellent example of someone who knows what her own personal character is made of and is proud to let it shine. This year, as Peter Pan, she choreographed her own solo complete with a cartwheel at the end! Of course, she brought down the house with applause as the audience recognized the hard work that she put in every week. Having been part of SGT for nearly a decade, she has taken on the role of supporting some of our younger students who may have fears about being in the spotlight in front of an audience.

When asked what she would tell



Erin as Peter Pan

someone who might have stage fright or be scared to try something new, she says, "Do it. Go out there and show them how special you are."

We couldn't have said it better ourselves.

Are you interested in being part of SGT? Registration is open at all our locations. Go to [www.specialgiftstheatre.org](http://www.specialgiftstheatre.org) for more information about classes and events.

### EVENT

**NADS Hispanic Disability Fair**  
**Saturday, October 24**  
 Chicago, IL  
 Contact [durhausen@nads.org](mailto:durhausen@nads.org) for more info

### New Public Speakers

Congratulations to the new speakers who were trained at our recent Public Speaker Training: Juliette DeNova, Jenny DiBenedetto, Natalie Garner, Debby Hanrahan, Julie Martin, Dale Ramsburg, and Stephen Yoga.

## DS Awareness Yard Signs

Order your Yard Sign to help support awareness for National Down Syndrome Awareness Month!

- 100% of all proceeds go to NADS
- Fundraiser by NADS & KinderCare
- Yellow & Blue Signs are 24 X 18
- Cost \$16/each

A great way to spread awareness! We are hoping to see schools, churches, neighbors, family, friends, and local businesses purchase and display our signs in October!

Let's SHOUT IT FROM THE ROOFTOPS that our children are loved by our community.

### ORDER FORM

Due by September 9th

Name: .....

Email: .....

Phone Number: .....

Desired Pick-up Location .....

You can find a list of locations at [www.nads.org](http://www.nads.org) or call the NADS office for options.

Number of signs: .....

Total \$ Amount of Order: (\$16/per sign) \$ .....

Orders can be placed via the NADS website ([www.nads.org](http://www.nads.org)) or via Check.

Checks should be made out to: National Association for Down Syndrome (NADS)

Please mail your order forms to:

**National Association for Down Syndrome [NADS]**  
 1460 Renaissance Drive, Suite 405  
 Park Ridge, IL 60068

- An email will be sent once your order is ready for pick-up.
- Please contact NADS if you have questions: 630-325-9112
- Signs are being produced by SignCo – Anthony Perna – THANK YOU!
- Orders should arrive at pick-up locations by September 28th.



Megan Niklas

## Megan Niklas Speaks at Gigi's Gala in Cleveland

Jeanne Niklas

Megan Niklas delivered a motivating, informative and heart-felt keynote speech to the guests of the 2015 Cleveland Inaugural Gala in Cleveland Ohio on May 9th at the Crown Plaza Hotel.

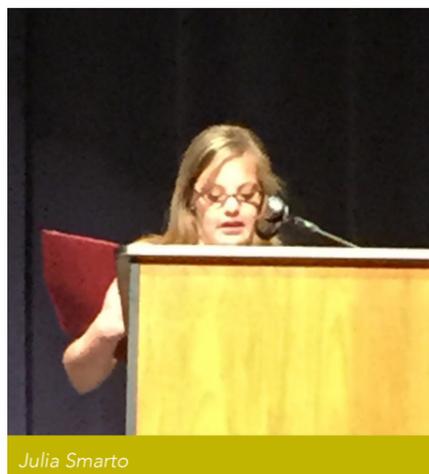
Megan attended GiGi University and graduated in the first class in June of 2013. She then served a six month internship at Gigi's Hugs and Mugs, which she completed in June, 2014.

Megan's message to the enthusiastic audience praised them for their hard work in bringing Gigi's to Cleveland.

"Today is a great day, because with the opening of Gigi's, here in Cleveland, families who have a child with Down syndrome can come and meet other families who have a child with Down syndrome—they can exchange experiences, information, ideas, and things tried. Children can meet new friends and siblings can meet other siblings. The path to tomorrow can be filled with support, experiences and celebrations to share." Megan's message was personal, sincere, informative and most encouraging to all who attended.

It was a wonderful evening and one that left everyone with a big smile and a happy heart.

Editor's Note: Megan is one of NADS' Self-Advocate Public Speakers.



Julia Smarto

## Julia Smarto presents to U-46

Julia was asked to speak at the end of the school year U-46 Administration breakfast Friday, June 5th because she has been a student of U-46 (2nd largest district in the state of Illinois) since the age of 3. She was introduced by the Chief Executor, Tony Sanders, who introduced her as their very own student and NADS Self-Advocate Speaker. There were approximately 200 administrators from the district present, and after her presentation, they rose to their feet with a standing ovation.

## Enhancing Lives Through Design

Sami Nerenberg, Director, Design for America

Help make better solutions to enhance the lives of those affected by Down syndrome. Are you a parent, sibling, or educator of someone with Down syndrome? Or an adult, teenager or child with Down syndrome? Then Design for America (DFA), based at Northwestern University, wants to talk to you. DFA is a national network of college students who use creative problem solving for local and social good. This August they'll be doing a 48 hour design project with over 80 college students from 29 universities and they need your help to share your stories (Friday Aug 7th) and offer feedback (Sunday Aug 9th) on the students' concept. To get involved, please contact their director, Sami Nerenberg: [sami@designforamerica.com](mailto:sami@designforamerica.com), 847-467-4695 for details.

## Back to School Resources

Looking for tips on how to prepare your child for the new school year? Here are a few articles which may give you some ideas to try:

- *Back to School* ([www.dsagsl.org/back2school/](http://www.dsagsl.org/back2school/))
- *10 ways to help your child with special needs make a positive start to the school year* ([www.chicagoparent.com/magazines/special-parent/summer-2014/school-days](http://www.chicagoparent.com/magazines/special-parent/summer-2014/school-days))
- *Special Needs Tweens: How to ease the transition to Middle School* ([www.chicagoparent.com/](http://www.chicagoparent.com/))

[magazines/web-only/2015-march/middle-school-transitions](http://www.dsagsl.org/wp-content/uploads/2014/04/All-About-Me-Booklet.pdf))

You may also be interested in the *All About Me* booklet developed by the Down Syndrome Association of Greater St. Louis, which you can use to introduce your child to new teachers. It is available at: [www.dsagsl.org/wp-content/uploads/2014/04/All-About-Me-Booklet.pdf](http://www.dsagsl.org/wp-content/uploads/2014/04/All-About-Me-Booklet.pdf).

## I Love College

Bridget Brown, NADS Self-Advocate and Board Member

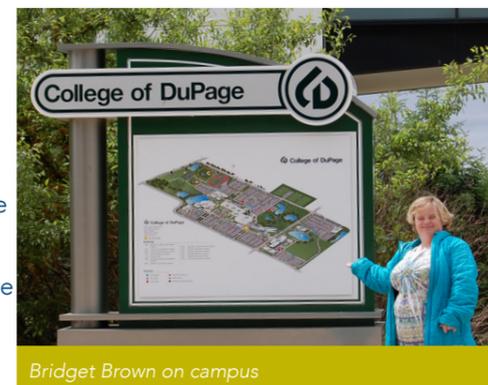
One of my big dreams has always been to go to college. I love school! Now I attend College of DuPage and I am having a great experience. I am officially a college student and I feel like I have accomplished a lot.

The main thing I am working on is passing the reading test. I have to pass that test before I can enroll in many of the general education classes. I was discouraged at first but I figured a way to go to college while working on my reading test taking skills.

I have taken excellent classes from many different categories that include:

- Vocational Classes specifically for people with disabilities
- Pre College/general college classes that don't require a reading placement test
- Literacy classes that are small groups where I work on the reading and test taking skills needed to pass the test.
- And Adult/community education classes that offer a variety of classes with interesting topics.

First, I learned how to get around the school and now I feel confident and can be there alone. I met with a couple counselors who work with people with



Bridget Brown on campus

disabilities and they helped me figure it all out. I learned how to get on the college web site and connect to Black Board where all my grades are kept. I can communicate with my teachers on this site also. I use this to submit my assignments for my classes. I figured out how to use the center for access and accommodations. I go there to get the adaptations I need so I can be successful. I even took the PACE bus to school with friends one semester. I really loved that experience even though I was a little nervous in the beginning.

I feel like I have learned so much since I started college. It is the best thing for me in my life right now. I hope to be a lifelong learner and always take classes at my community college. I have big dreams and I am working to make them come true one step at a time.



## Center Stage Dance Presentation

Linda Smarto and Self-Advocates Julia Smarto and Kelly Neville recently presented at Center Stage Dance Studio in Bloomingdale, where Julia and Kelly are members of the performing troupe, to promote Down syndrome awareness.

## New Partnership Advocacy Council

NADS started training and utilizing adults with Down syndrome in our public awareness and educational outreach efforts over two years ago. The program has been extremely successful but we wanted to find additional ways that individuals with Down syndrome can make an impact on our organization and to have a voice in what NADS is doing. Over the past year, under the guidance of Nancy Brown and Cheryl Crosby and a committee consisting of individuals with Down syndrome and NADS members, we developed the Partnership Advocacy Council (PAC).

NADS Partnership Advocacy Council is a service leadership organization led by adults with Down syndrome and works in partnership with the NADS Board. The PAC focuses on service, leadership, outreach and advocacy. Self-advocates will participate in NADS activities, plan and run their own events, form committees, promote awareness, and work collaboratively with the National Association for Down Syndrome.

The activities of our current self advocates will be integrated into the PAC. This new program will allow us to train additional speakers and will have activities for individuals who want to be involved in areas other than public speaking. All participants will expand their leadership skills to become caring leaders through service. This council is inclusive of all adults with Down syndrome (18 and older) who want to be involved. Please watch NADS News for PAC program updates and information on our fall kick-off event.

If you are interested in participating please contact NADS at 630-325-9112 or [durhausen@nads.org](mailto:durhausen@nads.org).

# family album



Richard Jegen



Carter Grant



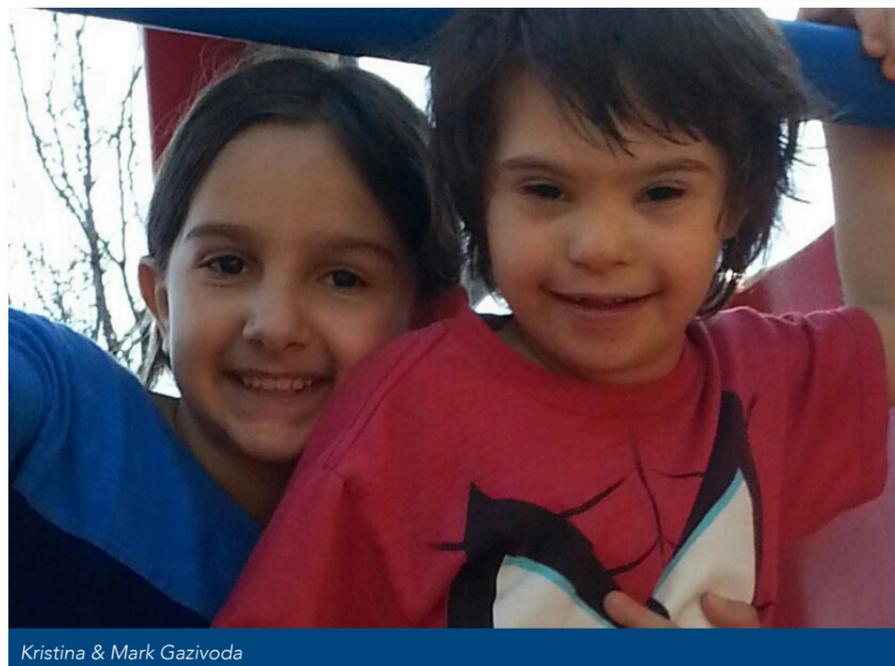
Joe Versaci and sister, Patti



Tommy Veach



Jack Delaney & Maddie Goddard



Kristina & Mark Gazivoda

## FUNDRAISING

### Donation from Miles Evans

We are grateful to Miles Evans, a local high school student with Down syndrome who is also an award winning photographer, for his generous

donation of three framed photos for our office. According to his family, "Miles picked up his first camera at age 7. Now a teenager, he continues to capture everyday moments through photography. Miles is especially fond of nature scenes. His photography business, Photos By Miles, provides him the opportunity to show and sell his work, learn life and job skills, and increase awareness of the abilities of people with special needs." One of the photos, "Chicago Skyline," was a selection in the 2014 VSA International Art Competition. Another, "Path of Inspiration," taken at the Morton Arboretum, was recognized by the Illinois PTA Reflections Art Program in 2014, and the third, "Tree Shades," was a runner-up in the Glen Ellyn Public Library Teen Art Contest in 2015. Stop by the office to see the photographs—or visit Miles on his Facebook page at PhotosByMilesE.



Miles Evans with NADS Executive Director Diane Urhausen

### Kentucky Derby Party Donation

Trish Clarke

On May 2nd 2015 we hosted our first Derby Party to honor a very special person in our lives, Anthony Forde. He has been an inspiration to us all and truly with such pride I can honestly say has taught us so much. We are honored and proud to have been part of Anthony's life and the many accomplishments he has achieved. Our thanks to you and Anthony for all the great work that you do.

—The Shaller and the Clarke Families

*Editor's Note: We are grateful to the Shaller and Clarke families for their generous donation of \$1,500.*

### 6th Annual Designer Genes Celebration

The 6th annual Designer Genes event was held Saturday, May 2 at Mickey Finn's Brewery in Libertyville and was once again a big success, raising over \$26,000 for NADS. We are grateful to the Alzamora family, who started the event more than 5 years ago in honor of their daughter, Maria, and have seen it grow each year, thanks to their creativity and dedication. Thank you to everyone who supported this event and helped to raise money for NADS.

## Bible Bingo at the Royal George Theater

**"Laughing from the very beginning and it didn't stop the whole night long."**

-- Fr. Nick Parker

**"Standing Ovation!"**

-- Rev. Joseph R. Horn

Come join us for a night out on **SATURDAY, SEPTEMBER 26** for a performance of **"BIBLE BINGO"**

at the Royal George Theater located at 1641 N. Halsted in Chicago

Doors open at @ 7:30 PM/Show time @ 8:00 PM

All proceeds go to NADS!

Cost of tickets is \$30.00 each

A great way to support Down syndrome awareness and have a fun night out!

Vicki Quade, creator of the hit comedy, *Late Nite Catechism*, brings to life a new comedy, *Bible Bingo: An Act of Charity...in Two Acts* which is an interactive show about the Catholic culture of fundraising and bingo.

### TICKET ORDER FORM

Due no later than September 18, 2015

Name: .....

Address:.....

Email: .....

Phone Number: .....

Number of tickets: .....

Total \$ Amount of Order (\$30.00 each): \$.....

Please make all checks payable to **NADS**.

**To order by mail:** mail your check and this Ticket Order Form to:

NADS  
1460 Renaissance Drive, Suite #405, Park Ridge, IL 60068

**To order online:** Order on the NADS website at [www.nads.org](http://www.nads.org) (credit card required)

- You will be contacted by email once your order is received.
- Tickets purchased in advance will be available for pick-up at the door the day of the event. Tickets will **not** be mailed.
- All Ticket Sales are final. No Refunds.
- Please contact Debbie Taus-Barth at NADS if you have any questions: [dtausbarth@nads.org](mailto:dtausbarth@nads.org) or (630) 325-9112.



We Need Photos!

Send your Family Album photos to NADS!

[shebein@nads.org](mailto:shebein@nads.org)



1460 Renaissance Drive, Suite 405  
Park Ridge, IL 60068

Change Service Requested

[www.nads.org](http://www.nads.org)

## Membership Application

Membership dues can be paid online at [www.nads.org](http://www.nads.org)

Name: .....

Address: .....

City: ..... State: ..... ZIP: .....

Phone (home) ..... Phone (work) .....

Email Address: .....  
 Please add me to the NADS e-mail alert list

**Category of Membership** (check one)  
 Parent:  \$25.00 (1 Year)  \$70.00 (3 Year) Child's birthdate ...../...../.....  
 Professional: \*  \$30.00 (1 Year)  \$85.00 (3 Year)

\*Please indicate professional involvement: .....

**Donation level:**  Contributor (\$100 +)  Benefactor (\$500 +)  Patron (\$1000 +)  
 Check if Renewal

Make checks payable to: **NADS** and send to:  
**1460 Renaissance Drive, Suite 405, Park Ridge, IL 60068**

The editor of this newsletter writes as a non-professional. NADS does not promote any therapy, treatment, institution or professional system, etc. The editor reserves the right to make any such corrections as necessary in accordance with established editorial practice in material submitted.

**Special Gift!**  
 A NADS Membership is the perfect gift for grandparents, aunts and uncles and even your child's favorite teacher!

**NADS GIFT MEMBERSHIP**  
 Please send a NADS gift membership to:

Name: .....

Address: .....

From: .....

Phone: .....

Relationship: .....

\$20 per recipient should be enclosed and sent to:  
**National Association for Down Syndrome (NADS), 1460 Renaissance Drive, Suite 405, Park Ridge, IL 60068**