

Ryan Tazioli

NADSNews

Newsletter for the National Association for Down Syndrome

July, 2016

NADS Conference: "Next Steps"

Our conference is coming up on October 1, and we hope you will plan on joining us. Here are some highlights:

Keynote Speakers

Dr. Cathy DiVincenzo, "Family Matters: We All Have Special Needs"

Dr. DiVincenzo will share from her experiences as a pediatrician and as a parent. She is the mother of triplets, one of whom (her son, Scott) has Down syndrome. Her practice at Kids First Pediatric Partners also includes a number of children with Down syndrome. Her presentation will explore her family, their life and her family's approach to raising a child with Down syndrome.

Actor and author, Marcus Sikora, will be our Self-Advocate key note speaker. Marcus has acted with local and national companies and recently released his first book for children, *Black Day: The Monster Rock Band*. Marcus and his mother, Mardra, will give a presentation about his life and his many creative activities.

New Workshops

Our conference will include many popular topics from past years, such as toilet training, communication skills, inclusion, employment, and residential options, but we have also added some new workshops:

Friendships to Last: Fostering and Sustaining Positive Relationships in Intermediate and Middle School

Jennifer Naddeo, PhD, Director Special Education, District 54 Schaumburg, IL

How can we embrace opportunities within our schools to build and sustain friendships regardless of developmental differences? This session will offer structures and strategies to foster friendships among students with and without disabilities, especially in the critical years of grades 5-8.

Storytelling as Advocacy

Mardra and Marcus Sikora

Mardra and Marcus Sikora are a mother-son storytelling team.

Both published authors, they have discovered the power of stories to teach, to advocate, and to open conversations.

NEXT

STEPS
2016

Mardra will talk about how she and Marcus came to write together, how they've entered the world of advocacy, and what Marcus teaches her (and others).

Also, included in this session, you will be treated to the animated short, *Black Day: The Monster Rock Band* by Marcus Sikora, a fun story about "a boy who wants to be in the band." Marcus will share his thoughts on the



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NADS Conference

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project and answer your questions. If you're looking for creative ways to start the acceptance and difference discussion, and/or if you're wanting tips on sharing your own story(s) for a positive impact, this is your session.

Fire Safety and Emergency Training

Mike Falese, Bartlett Fire Chief, Bartlett Fire Department, Bartlett, Illinois

This presentation will discuss awareness of how fires start: cooking, candles, fire places, and other behaviors. Additional topics will include other emergency situations (chest

pain, seizures, choking), the proper steps to call for help, and the types of response and resources that will assist.

Using Mobile Technology for Independence and Community Living

Pat Politano, PhD, CCC-SLP, ATP

UIC Institute on Disability and Human Development Chicago, Illinois

Dr. Politano will discuss all the apps people with Down syndrome and their families are using. Topics include: creative ways smart phones and tablets are being used to stay connected with friends and family;

communication of new ideas; shopping; listening to music, etc.

The Down Syndrome Information Act

Peter Smith, MD, MA
Associate Professor of Pediatrics University of Chicago Medicine

This presentation will provide up-to-date reports and discussion of the Down syndrome Information Act.

Editor's Note: Watch out for our conference brochure, arriving in your mailbox soon! It will have all the details you will need to register. Online registration will also be available later this summer.

Invite Your Teachers to Learn about Our Disability Awareness Presentations!

Nancy Goodfellow

One of the workshops offered at this year's conference will detail the new disability awareness presentations that NADS offers to schools. Self-advocate Michelle Anderson will share what it is like to have Down syndrome, just as she does when speaking to students. Public speaker Nancy Goodfellow will describe how their presentations teach children about all disabilities, encouraging understanding, acceptance and inclusion. The pair will share their experiences from presenting to over 4,500 students in various school districts, ranging from 2nd to 8th grade. Teachers will receive practical tips for teaching disability awareness in their own classrooms.

Here are some responses to past presentations:

"Hearing from Michelle was the best part! The kids were able to better understand what it is like for a person to have a disability and were able to see that she is just like them."

— 4th grade teacher

"Your candid answers to the kids' questions and open attitude helped with perspective and was an invaluable resource."

— 3rd grade teacher

"I loved that you talked about how we can't always see a disability or difference on the outside. I also loved that students were able to have an open conversation about this topic in a safe, positive way."

— 4th grade teacher

"We had a great conversation when we came back to our room about understanding others."

— 5th grade teacher

"It is important to validate everyone's feelings, both those with and without disabilities. You did a great job of giving our students strategies for socializing with and assisting students with disabilities while also empowering them to achieve independently."

— 5th grade teacher

Editor's Note: This workshop may be of interest to parents who would like to learn more about our public speaking program as well as to teachers. Spread the word at your child's school!

Gwen Olimene at the NADS Fashion Show

Gwen was welcomed into the Olimene family a little earlier than expected, at 35 weeks, and spent the first month of her life in the NICU. Despite the additional medical challenges of a premature birth and the emotional challenges of an unexpected Down syndrome diagnosis, Gwen's parents always thought of her as a blessing. Their reaction was partly colored by having experienced

her a companion who could share many of her interests. The siblings are close and love to do things together. According to her mother, Gwen is "fearless," and wants to do everything better and faster than everyone else. They sometimes teasingly call her "Diva."

Given Gwen's outgoing personality, she was a natural for

Given Gwen's outgoing personality, she was a natural for the NADS Fashion Show.

the grief of losing their first daughter, and so when Gwen arrived, they thought of her as their little angel who had been given to them. Once past the medical challenges of the first year, Gwen began to thrive, and her parents enjoyed watching her develop into the vibrant child she is today. Her mother's sisters live nearby, and Gwen benefited from having lots of young cousins around. She also soon became a proud older sister to her younger brother, A.J.

Gwen is now an active four-year old, who loves dancing and being outdoors and at the park. Her parents installed swings and slides in their basement so that Gwen could remain active during the winter. Her mother, Kara, describes Gwen as the "tomboy of the family," and so having a younger brother gave

the NADS Fashion Show. At last year's event, she was accompanied by her aunt Mallory, who works with people with special needs and has been a big support to their family. Gwen loved walking down the runway, being the center of attention and waving to everyone in the audience. And when Steve Gotsis performed a One Direction song from her favorite video, she could not help but dance along. Gwen's family was thrilled to see her shine at the Fashion Show. Kara was afraid Gwen might have a temper tantrum or not want to walk, but Gwen was in her element.

Looking back on these last four years, Kara reflects on how lucky they have been with Gwen's experience so far. They are particularly grateful for



Gwen's Early Intervention therapists, who have continued to provide feedback, support, and informal help even after Gwen transitioned out of EI. Kara's advice to other parents is if they find people like Gwen's EI therapists, they should hold on to them!

Kara also thinks about Gwen's future and hopes to be able to provide her daughter with the tools and skills to be as independent and happy as possible. Judging by her radiant performance at the NADS Fashion Show, Gwen is well on her way!

Editor's Note: If you are interested in having your child participate in the 2016 NADS Fashion Show or would like to help out with the event, please contact the NADS office at 630-325-9112 or email fashionshow@nads.org.

On the Topic of... Trusting Your Instincts Nancy Goodfellow

When we first met with the IEP team for junior high, the administration convinced us that an Instructional Social Studies placement would be most appropriate for Lily. I didn't necessarily agree, but they made the point that her inferential and comprehension skills for Language Arts were weak and she would need those skills for Social Studies. Rather than arguing with them, especially when we'd just finished a heated discussion about whether or not she belonged in the self-contained classroom, we agreed to the Instructional Social Studies class. After all, she'd still be studying the same curriculum as her peers, just at a slower pace and in a smaller class.

However, that wasn't what happened. We learned halfway through sixth grade that Lily was in a class with peers who were in sixth, seventh and eighth grade, and as a result, they were studying the eighth grade curriculum. The class was not challenging her, and although we're always happy to see her get good grades, the A+ she was receiving was a reflection of how easy the class was for her and how little was being

asked of the students. We decided to keep her in the class for the year and look into switching for seventh grade. When we had her IEP in the spring, we were told that she would most likely have a new teacher for seventh grade and the placement was still appropriate. So we again agreed to the instructional

There will be times when we need to concede to the professionals regarding our children, but there are also times when we need to trust our instincts.

placement. It was the second time I should have trusted my instincts.

Within the first six weeks of seventh grade, we knew it was time to make a change. The Social Studies class was now following the sixth grade curriculum, and the class was not only easy for Lily, but boring her. I contacted her Learning Behavior Specialist to discuss the issue and she agreed the class was not challenging Lily. She said that she would talk to the teacher about making some changes to the assignments, but after two weeks, no changes had been made. We then had many meetings to discuss the pros and cons of

changing Lily's placement, I observed the class that she would potentially move to, and staff observed Lily in each of her classes and documented the percentage of time she was on task vs distracted. It came as no surprise that Lily was off task the most during Social Studies. Although the staff never said whether

they thought Lily should move to the general education class or not, they expressed concerns about the size of the class and the requirements. But I was determined to follow my gut this time. My instinct was that Lily would succeed. We just needed to give her the chance to do so.

Lily moved to the new Social Studies class just before Thanksgiving. She was thrilled to be with her friends, and the class and teacher soon became her new favorites. Any concerns I had about the teacher were quickly put to rest. Although he had never taught a child with Down syndrome before, he was more than willing to try. He contacted me on a regular basis to pass along the information he was teaching in class. He sent PowerPoint presentations and told me which slides he covered in class that day. He sent handouts in advance and asked for my opinion regarding the amount of material she should be expected to learn. He allowed me to

be an active participant in making any modifications to Lily's assignments and tests, and most importantly, he was willing to try when I said "test her on all of it." As a result, Lily took the same tests as all of the other children and earned an A in his class.

On the last day of school, I dropped off gifts to each of Lily's teachers, therapists and assistants. When I handed him his gift, I told him how much I appreciated his efforts to communicate and collaborate. I let him know that I had sent an email to the vice-principal and principal to tell them how wonderful he had been and that Lily's success in the new placement was due to his willingness to fully include her in his class. I told him that I wished all teachers could be like him. To which he replied, "Frankly, I wish all students could be like Lily."

There will be times when we need to concede to the professionals regarding our children, but there are also times when we need to trust our instincts. Lily's Social Studies placement was a good example of when I should have remembered that I am the expert when it comes to my child. If I truly believe she can succeed at something, it is my responsibility to let her try.

FUNDRAISING

7th Annual Designer Genes

We are grateful to the Alzamora family for their continued generosity to NADS. Not only did Sarah serve on our board and share with us her creativity and her experience, her family also held their Designer Genes fundraiser for the seventh year, raising more than \$22,000 for NADS. We deeply appreciate all that Sarah and her family have done for NADS!

Parent Tips for Better IEP Meetings

Teresa Unnerstall

My 20 year old son, Nick, has Down syndrome and autism. While driving to his IEP meeting last Monday, it occurred to me that he only had one more of these next year. With 15+ IEP meetings under my belt, I have learned a lot about how to become an effective advocate for my son. IEP stands for "Individualized Education Plan." An IEP is done for a student who has special needs. These meetings are held each year to update the student's current level of functioning, progress and goal planning for the following year. There was a time when I was terrified and intimidated by IEP meetings. Here are some things I've learned to make an IEP meeting be effective and run smoothly.

Here are my top 10 parent tips for better IEP meetings:

- Establish communication with all the teachers, therapists, and other key members of the IEP team via email. Send a communication notebook back and forth in your child's back pack. Attend conferences, open house events and if you can, chaperone at field trips and volunteer in the classroom. All of these things will help to build a relationship with the staff and make you feel more comfortable.
- Designate one notebook for all meetings, conferences and trainings related to your child. Keep a folder for the current IEP and progress reports. Review these prior to the meeting.
- After you review your child's goals, make notes for the support teacher/case manager of what you'd like to see for the upcoming year using an "IEP planning form". See the Resources box above to obtain a form.
- Request a copy of the IEP draft (including present level of academic functioning, and all proposed goals) to review BEFORE the meeting. Go through this with a fine tooth comb making notes in red ink of any questions you have or things you would like to see added.
- Learn your child's educational rights. See the Wrightslaw link listed above.
- Don't hesitate to ask questions and seek clarification.
- If you feel unsure or overwhelmed, bring an advocate from your local support group or a seasoned IEP parent to the meeting.
- Keep in mind that according to the law, schools do not have to offer the best, they have to offer what is "most appropriate" for your child.
- The child should be the center of focus at the IEP meeting. A parent's dream for their child may not be what the reality is. Keep an open mind to this.
- You know your child the best. You are a huge part of the team, speak up!
- If you have serious doubts or concerns about the

Resources:

IEP Planning Form for Parents:

http://www.greatschools.org/pdfs/2200_21-IEPplanning.pdf?date=3-11-02

Special Education Rights: www.wrightslaw.com

IEP, ask to take it home and review it further. You are NOT required to sign it if you disagree or have any uncertainties. You only need to sign that you attended the meeting. Put any concerns that you have in writing and return them to school with the unsigned IEP. You can request another IEP meeting.

- IEP meetings don't have to be a scary thing. Do your homework

beforehand. If you are prepared and keep the lines of communication open, then they can run quite smoothly.

Editor's Note: Excerpted from Teresa's blog, *Down Syndrome with a Slice of Autism*, at <https://nickspecialneeds.wordpress.com/2014/03/17/blog-88-parent-tips-for-better-iep-meetings/>.

NEW BOOK & FILMS

Supporting Positive Behavior in Children and Teens with Down Syndrome

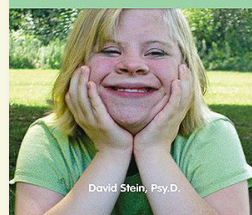
David Stein

Woodbine House, 2016; \$21.95

Dr. David Stein, a psychologist and Co-Director of the Down Syndrome Program at Boston Children's Hospital, provides many strategies for parents to help them manage behavior issues and maintain a positive relationship with their child. His suggestions, which emphasize how to be proactive and not reactive, draw on years of experience with neuropsychological testing and behavior therapy.

Supporting Positive Behavior in Children and Teens with Down Syndrome

The Respond but Don't React Method



I Don't Care

<http://sproutflix.org/all-films/i-dont-care/>

(14 min / narrative) A mother-to-be faces the high possibility of having a child with Down syndrome and befriends a family who share their experiences and guide her towards a different perspective.

Extra Ordinary

<http://sproutflix.org/all-films/extra-ordinary/>

(5 min / documentary) A glimpse into the lives of two young individuals with Down Syndrome living happy and fulfilling lives.

2016 Bowl-A-Thon

A big thank you to those who bowled at this year's Bowl-A-Thon, our largest fundraiser of the year. We would especially like to recognize the individual bowlers and teams who obtained the most pledges:

Individuals

Gina Rotondi = \$8205
Chris Hebein = \$7356
Julia Smarto = \$2145
Kristin Malkowski = \$1775
Emily Jackson = \$1340
Connors Family = \$1050

Teams

Kerry & The Big Dogs
= \$4413
Jacob's Crew = \$3789.44
Lamma's Lanes = \$2450
Schubie Doos = \$2395
LaChapelle = \$2100
The Lovebirds = \$1700
Kenny-Man = \$1410
Champions for Cameron
= \$1029
Brogan's Bowling Buddies
= \$990
Boot's Bowlers = \$810
Singla Strikers = \$800
Team Jane = \$785
Eli's Xtreme Team = \$715
Dale's Dream Team = \$670
WalknRollers = \$500
Kaya's Krew = \$200

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.

Matt LaChapelle and Gina Rotondi with Ronald McDonald



Erin Dominiak & Chris Hebein



Update on the ABLE Act

The Congressional lawmakers responsible for the ABLE Act have introduced three new federal bills to expand some of its provisions. The ABLE to Work Act (HR 4795/ S 2702) would allow individuals with disabilities who are employed to contribute additional amounts from their earnings (up to the federal poverty level) beyond the current annual maximum amount. The ABLE Age Adjustment Act (HR 4813 /

S 2704) would expand the group eligible to establish accounts by raising the limit for disability onset from 26 to 46. Family members who would like to roll over money from 529 college savings plans into ABLE accounts may also be able to do so if the ABLE Financial Planning Act (HR 4794 / S 2704) is approved. To follow the progress of these bills, go to www.govtrack.us.

The federal ABLE Act, which became law at the end of 2014, allows individuals with disabilities to save money in tax free

savings accounts (similar to 529 college savings accounts) without jeopardizing their eligibility for government benefits. It also authorizes states to develop their own ABLE programs. Since the passage of the federal legislation, the IRS has been developing federal guidelines for the accounts, and states have been developing their own laws to make ABLE 529A programs available to their residents. Ohio was the first state to finalize their program. Residents of Ohio can now open up

ABLE accounts through their state's version of the ABLE Act, known as STABLE. Nebraska, Tennessee, and Florida will all be launching ABLE programs this summer. Those in Ohio, Nebraska and Tennessee will be open to individuals throughout the United States, while the Florida program will only be open to Florida residents. For updates on the progress of the ABLE Act's implementation in other states, go to www.ndss.org/Advocacy/ABLE-Act.

Social Security Disability Benefits & Down Syndrome

Deanna Power, Director of Community Outreach at Social Security Disability Help

If you or a loved one has been diagnosed with Down syndrome, you know that your family has more expenses than the typical American family. From additional medical bills, costs of medications, and the expenses of physical therapists, people with Down syndrome often find themselves needing financial assistance. Fortunately for you and your family, help may be available. The Social Security Administration (SSA) offers resources for people with Down syndrome.

What disability benefits are available?

The SSA offers two forms of disability benefits, but the one that people with Down syndrome typically qualify for is called Supplemental Security Income, or SSI. SSI benefits are for people of all ages who haven't worked before, including children.

SSI benefits have strict financial eligibility qualifications. Parents' income will be evaluated whenever a child under the age of 18 applies for SSI benefits. This means that if you or your spouse makes a living wage, your child with Down syndrome will not be eligible for SSI benefits. The SSA has an online chart that shows exactly how much your family can earn per month while still qualifying.

Once a child with Down syndrome turns 18, the SSA will not take parents' income into consideration anymore, even if your child still lives at home. Many families with a child who has Down syndrome find that their child qualifies after turning 18.

An adult with Down syndrome cannot have more than \$2,000 in assets, which include cash, stocks, or life insurance.

How does my loved one medically qualify with Down syndrome?

Every time the SSA receives an application for Social Security disability benefits, it will compare the applicant's medical records to its medical guide called the "Blue Book." The Blue Book will list what test results

or records are needed to medically qualify for disability benefits.

Down syndrome is listed in both the childhood and the adult versions of the Blue Book.

This listing states that both children and adults with either Trisomy 21 or Translocation Down syndrome will medically qualify with simply a diagnosis. To qualify, you will need to be able to show a laboratory report of a karyotype analysis signed by a physician, or an unsigned karyotype analysis with treating physicians' records.

How does my loved one qualify with Mosaic Down syndrome?

The SSA's Blue Book listing only covers non-Mosaic Down syndrome. This is because many people with Mosaic Down syndrome do not experience the same physical or cognitive limitations as those with Trisomy 21 or Translocation Down syndrome.

Qualifying with Mosaic Down syndrome is not as straightforward, but it is still possible. You will either need to show that your loved one "matches" another Blue Book listing.

To match another Blue Book listing, you will need to prove that your loved one's Mosaic Down syndrome has complications that are already listed in the Blue Book and that affect working ability. Some Down syndrome complications that are listed in the Blue Book include:

- Heart defects
- Sleep apnea
- Cognitive disabilities
- Seizures
- Hearing or vision loss

Because every person with Down syndrome is completely different, you should work with your physician to look over the Blue Book and

The SSA offers two forms of disability benefits, but the one that people with Down syndrome typically qualify for is called Supplemental Security Income, or SSI.

determine whether or not your loved one would qualify.

How do I start the application process?

Every SSI applicant must make an appointment at a local SSA office. There are multiple offices in every state, so there is usually at least one office nearby.

Before your appointment, be sure to review the Adult Disability Starter Kit, or the Child Disability Starter Kit if you are applying on behalf of a child under the age of 18. These guides will outline everything you'll need to apply, from pay stubs to personal documents.

Finally, about 65% of claims are denied. If your claim is denied due to financial eligibility, it is not advisable to appeal the claim. There is unfortunately nothing your family will be able to do if your income is too high. Most families have more success after their child turns 18.

If your child has Mosaic Down syndrome and the claim is denied due to medical eligibility, there is a thorough appeals process available, and you should continue the claim! Most applicants are awarded benefits at later stages of the application process.

With any luck, your loved one's claim will be approved quickly.

Editor's Note: This content was provided by Deanna Power, Director of Community Outreach at Social Security Disability Help (www.disability-benefits-help.org). She first started working with people with disabilities through Best Buddies in college, and now helps people of all ages receive disability benefits.



Chris Hebein Celebrates 30 Years as an Altar Server

Chris Hebein recently celebrated 30 years as an altar server at St. Nicholas Church in Evanston. When he first became an altar server at St. Nick's in 1986, he was 13 years old and Fr. Bill Flaherty was the pastor. The first time he served was at the 7:30 am Mass – the day the Chicago Bears won their one and only Super Bowl. Initially he thought he would continue to serve until the Bears won another Super Bowl, and here we are 30 years later, and Chris is still serving, and the Bears have not won another Super Bowl!

When Fr. Bob Oldershaw became the pastor he developed a very special relationship with Chris – he often refers to him as his dance partner because the two of them have been performing great dance steps together throughout many Easter seasons, but especially at the Easter Vigil. The highlight of Chris' year is Holy Week, especially Holy Thursday and the Easter Vigil. This year he took a day off work on Good Friday so that he could participate in the Neighborhood Way of the Cross, and he asked if he could also help Jesus to carry the cross.

Chris has served Mass every week for many years - sometimes at the 4:30, sometimes at 9 and sometimes at 11 o'clock. It's a wonderful way to get to know the community. He has served at many weddings and funerals and other very special occasions, and he is always eager to help. Throughout the years we have had many presiders at St. Nicholas and Chris makes it his business to know which

priest has each Mass – perhaps he's thinking he could step in one of these days.

He also loves the social activities at St. Nicholas and he can be found helping with clean up after the rummage sale, attending Carnevale (and winning prizes) – one year he won \$3,000 at the winter Holiday Festival.

In addition to his involvement at St. Nicholas, for many years Chris has raised money for the National Association for Down Syndrome at their annual Bowl-A-Thon. Throughout the years,

many St. Nicholas parishioners and staff have supported him in these efforts and to date he has raised over \$170,000.

Chris also works 40 hours a week at Rotary International in Evanston as a mail clerk, and on April 26th he celebrated 23 years in his job.

Chris stays busy playing the piano, swimming at the YMCA, participating in a drama group at Piven Theatre, taking his dog for walks in the neighborhood, going out to eat, going on vacation and in general enjoying life every day.



New Virtual Down Syndrome Clinic at Mass General

Massachusetts General Hospital has received a \$2.1 million grant to establish a Down Syndrome Portal at Massachusetts General Hospital to address the health needs of individuals with Down syndrome. This "virtual clinic" will be able to provide healthcare information to individuals who do not have a Down syndrome clinic in their community and will also relieve some of the pressure on primary care physicians, who may not have many patients with Down syndrome and may find it difficult to keep up with new developments in Down syndrome research. The clinic is expected to launch next summer. For more information, see the article in the Boston Herald: http://www.bostonherald.com/news/local_coverage/2016/05/mgh_to_build_down_syndrome_portal.

UIC IDHD Accessible Research Summaries

The Institute on Disability and Human Development at UIC is making accessible summaries of their research available. The briefs are intended for a general audience, including individuals with disabilities and their families, and summarize research published in professional journals. Parents of younger children may be interested in the brief, "Developmental Milestones in Children with Down Syndrome," but the library also includes briefs on a wide variety of topics, including health issues, caregiving, employment, entrepreneurship, and transportation. They can be accessed at <http://ahs.uic.edu/dhd/facultyresearch/publications/#accessible>.

NADS PAC Service Project at Feed My Starving Children: An Interview with PAC member, Ashley McLeod

What did you do at Feed My Starving Children?

On our trip to Feed My Starving Children (FMSC), we packed food for babies in poor countries around the world. We packed 3 kinds of powder: potato, soy and sweet potato. The dry meals have a special formula of vitamins and minerals added to the powder to help babies grow. We measured out 1 cup of each, put in a plastic

where a 2 year old boy from Uganda weighed only 9 lbs. before FMSC food. Now, he is 4 years old and after eating the meals, he weighs 29 lbs and is thriving!

What are you learning through the NADS PAC program?

So far through the NADS PAC program, I am learning how to be a self-advocate, and helping others understand about Down syndrome.



The part I liked the best about this project is being able to serve those who are hungry.

bag, and weighed the bag on a scale. Then, another person seals the bags and gives it to a packer, who puts the bags in a box and it is ready to go. There were other groups packing food besides NADS. At the end of our 2 hr shift, we packed 126 boxes which is \$54,432 servings!

What did you like best about the project?

The part I liked the best about this project is being able to serve those who are hungry. It was fun working as a team and knowing that we're helping babies survive.

What did you learn by helping there?

I learned that a lot of babies get better because we feed them with the food we pack. If they don't get the right nourishment, many babies die. We watched a video

What do you like best about being part of NADS PAC?

The best part about being part of NADS PAC is being with old friends, making new friends, and being able to make a difference.

What else do you like to do?

I like to read, cook, swim, dance, and listen to music.

What are some of your hopes for your future?

Someday, I would like to move out and live on my own with some roommates.

Editor's Note: For more information about the PAC Program, please contact Diane Urhausen at durhausen@nads.org.

NADS Welcomes New Board Members

Cheryl Crosby, Maggie Lay, and Carlitta Tucker-Powell are joining the NADS Board of Directors for 2016-17. We appreciate their willingness to serve and are looking forward to welcoming them to the Board.

We would also like to express our appreciation for retiring Board members Sarah Alzamora, Nancy Andrade, and Al Unnerstall. Thank you for your service and for all you have done for NADS!

Steve Connors will continue as President; Lucas Staib will become 1st Vice-President; Bridget Brown will remain as 2nd Vice-President; Anne Haddad will continue as Secretary; Katie Wood will continue as Treasurer; and Andrea Caruso, Erin Dominiak, Nancy Miner, Michelle Pusatera, Matthew Spiewak, Cara Tazioli, and Richard Weicher will continue as Directors.

UPCOMING EVENTS

NDSC Convention

July 21-24
JW Marriott Grande Lakes,
Orlando, Florida
www.ndsccenter.org



NADS Conference: "Next Steps"

October 1
Donald E. Stephens
Convention Center
Rosemont, IL
www.nads.org

Chicagoland Buddywalk

October 9
Bolingbrook Golf Club
2001 Rodeo Dr,
Bolingbrook, IL 60490
(630) 771-9400
chicagolandbuddywalk.org

2016 Statewide Transition Conference

October 27-28
Thelma Keller Hotel &
Convention Center
Effingham, IL
illinoistransitionconference.org

NADS Fashion Show

October 30
Donald E. Stephens
Convention Center
Rosemont, IL
www.nads.org

familyalbum



Kevin Mikan with his nieces



Taylor Kaiser



Eleanor Olsen



John Froemke with his niece



Tommy Veach



Self-Advocates: Elaine and Ryan Burke, Jeanette Reid and Kelly Wesolek, Ashely and Sue McLeod, Francesca and Anne Maddock, Marylynn and Cristina Cassata and Jennifer Brown and Jamie Jerominski



Public Speakers: Elaine Burke, Maggie Lay, Melissa Ciraulo, Jamie Mumber, Joyce Hansen, Pat Shimanek and Emilia Walasik

New NADS Public Speakers

NADS welcomes and congratulates all our newly trained speakers. Self-Advocates and their Coaches completed the first part of their training on April 10th, while other Public Speakers were trained on April 16th. Both groups joined together for a final combined training on April 25th.

The Self-Advocates who attended the training with their coaches were: Ryan and Elaine Burke, Cristina and Marylynn Cassata, Francesca and Anne Maddock, Ashely and Sue McLeod, Kelly Wesolek and Jeanette Reid, Jennifer Brown and Jamie Jerominski, and Sarah, Janice, and Scott Weinstein.

Participants in the public speaker training were Elaine Burke, Melissa Ciraulo, Melissa Cleary, Blair Covino, Jenny DiBenedetto, Joyce Hansen, Julia Kozel, Maggie Lay, Jamie Mumber, Pat Shimanek and Emilia Walasik. Linda Smarto conducted both trainings with the assistance of Julia Smarto, Nancy and Bridget Brown and Karen and Kelly Neville for the Self-Advocacy training and of Chris Newlon for the Public Speaker Training. Thank you to everyone who took part in the training!

2016 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.

Please fill out and mail the order form below, or you can order online at www.nads.org.

ORDER FORM

Due by September 7th

Name:

Address:

Email:

Phone Number:

Pick-up Location:

Number of signs:

Total (\$16/per sign) \$

Credit card payments will include a credit card processing fee.

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

Please mail your order forms to:

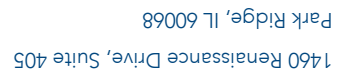
**National Association for Down Syndrome [NADS]
1460 Renaissance Drive, Suite 405
Park Ridge, IL 60068**

Please contact Peggy Delaney if you have questions: pdelaney@klcorp.com or 630-715-5315

Signs are being produced by SignCo
THANK YOU Anthony Perna!

Please designate the location you would like to pick-up your signs.

For a full list of locations, visit www.nads.org or call the office at 630-325-9112. You can also designate the NADS conference on October 1 as a pick-up location. Orders should arrive at locations by September 28th. An email will be sent once your order is ready for pick-up.



Membership Application

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

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Special Gift!