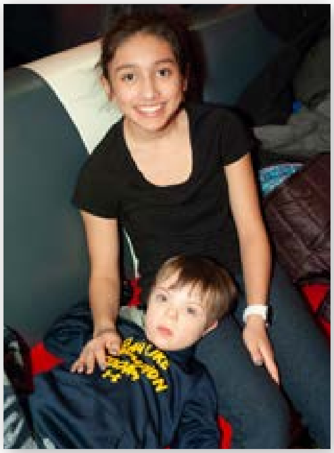
Newsletter for supporters of the National Association for Down Syndrome

Summer 2019

NADS News

Bowl-A-Thon Family Fun Day



This Year's Bowl-A-Thon Best Yet!

Our 34th annual Bowl-A-Thon, chaired by board member Joel Spenadel, was a terrific success, with over 100 bowlers participating in an afternoon of bowling, delicious food, great door prizes and a fantastic silent auction.

The event was held at Bowlero in Naperville which served as a great location for our event. We had a grand raffle with first prize being a big screen television, second prize Cubs tickets, and the third prize an apple watch.

This year's event was our best yet, and raised over $35,000 for NADS! Many of these funds were raised by our bowlers, who received pledges from their families and friends to participate.

All funds raised help us continue to provide programs and services to the Down syndrome community in Chicagoland and beyond.

Special thanks to all our wonderful volunteers, self advocates, board members and staff who worked so hard to ensure that the event was a success.

We are especially thankful to our sponsors, which include Apex 6

This year's event was our best yet, raising over $20,000 for NADS. These funds help us continue to provide programs and services to the Down syndrome community.

We can't wait for next year's event. Stay in touch for further details regarding our 35th Bowl-A-Thon!

See Bowl-A-Thon photos on page 2

OCTOBER 27

2019 Fashion Show

More information at **nads.org** | **Questions? fashionshow@nads.org**

We need models and sponsors! Contact **fashionshow@nads.org** for information!

NADS Impact this Fiscal Year!*

49
New Baby Baskets Delivered

12
New Hospitals Added to Basket Program

774
Medical Professionals Reached

831
Educators Reached

4,005
Community Members Reached

32
Received Bi-Lingual Support

34
New Familes Received Assistance

*July 2018-June 2019

Smile! [and help NADS]

Go to **smile.amazon.com** and designate the **National Association for Down Syndrome** when you shop online! Amazon will donate a portion of the purchase price to us. It's that simple!

amazonsmile

Bowl-A-Thon Family Fun Day Photos

Breaking Barriers in Young Adult Literature

By Peggy Delaney

Today, young adult literature has created some of the best reads available. Young adult/teen literature is more popular than ever.

A few years ago, I began reading more teen literature as my oldest son evolved into more complex reading. I was really surprised to see books on library and school reading lists that had main characters and secondary characters that had differing needs. It was also exciting to see that there were many new authors who were creating characters and story lines that my son, Charlie, could identify with as a sibling and friend of many who have differing abilities.

Wonder, by R.J. Palacio, is "top read" on most 4th grade reading lists. Wonder became a huge hit when it was turned into a major motion movie with Julia Roberts. It certainly opened the door to authors creating more inclusive characters that reflect the true diversity of families, classrooms, and communities.

There are a slew of other fantastic books that either focus on a character with differing abilities, or have secondary characters with Down syndrome, Autism, or other different abilities. Out of My Mind, by Sharon M. Draper, is a "must read" on many 6th grade reading lists. Its main character is an 11 year old girl named Melody, who has Cerebral Palsy and uses a wheelchair to navigate her surroundings. Her story is riveting and a fantastic read.

Slider, by Pete Hautman, and Inkling, by Kenneth Oppel, are recent releases. Both stories have secondary characters with disabilities who are siblings to the main character. In Slider, David has a brother Mal, who has Autism. In Inkling, Ethan has a sister Sarah who has Down syndrome. It was really refreshing to see that the themes of Slider and Inking do not revolve around Mal and Sarah's disabilities.

The historical fiction novel about the Chicago Fire, The Diary of Pringle Rose – Down the Rabbit Hole by Susan Campbell Bartoletti, tells an adventurous story of Pringle and her brother Gideon, who has Down syndrome. Again, the story is not about Down syndrome, but about Pringle and Gideon's harrowing journey to Chicago in 1871.

Other recently published books focus on main characters with various disabilities. Rain Reign, by Ann M. Martin, is about a young girl, Rose, who has Autism. The highly awarded novel The War That Saved My Life, by Kimberly Brubaker Bradly, has a main character, Ada, who was born with a malformation of her foot. Head Above Water, by S.L. Rottman, has a main character Skye, whose older brother, Sunny, has Down syndrome.

All these books should be available at your local library or independent bookstore. I enjoyed reading these books prior to having my son read them. It allowed us an opportunity to discuss the characters and the more complex feelings that the stories evoked. These books are great additions to school and home libraries. If your school library does not have these books available, please consider donating one in honor of Down Syndrome Awareness Day on March 21st. Happy Reading!

There are many fantastic books that focus on characters with Down syndrome or autism. Consider donating one to your local library!

Great book selections!

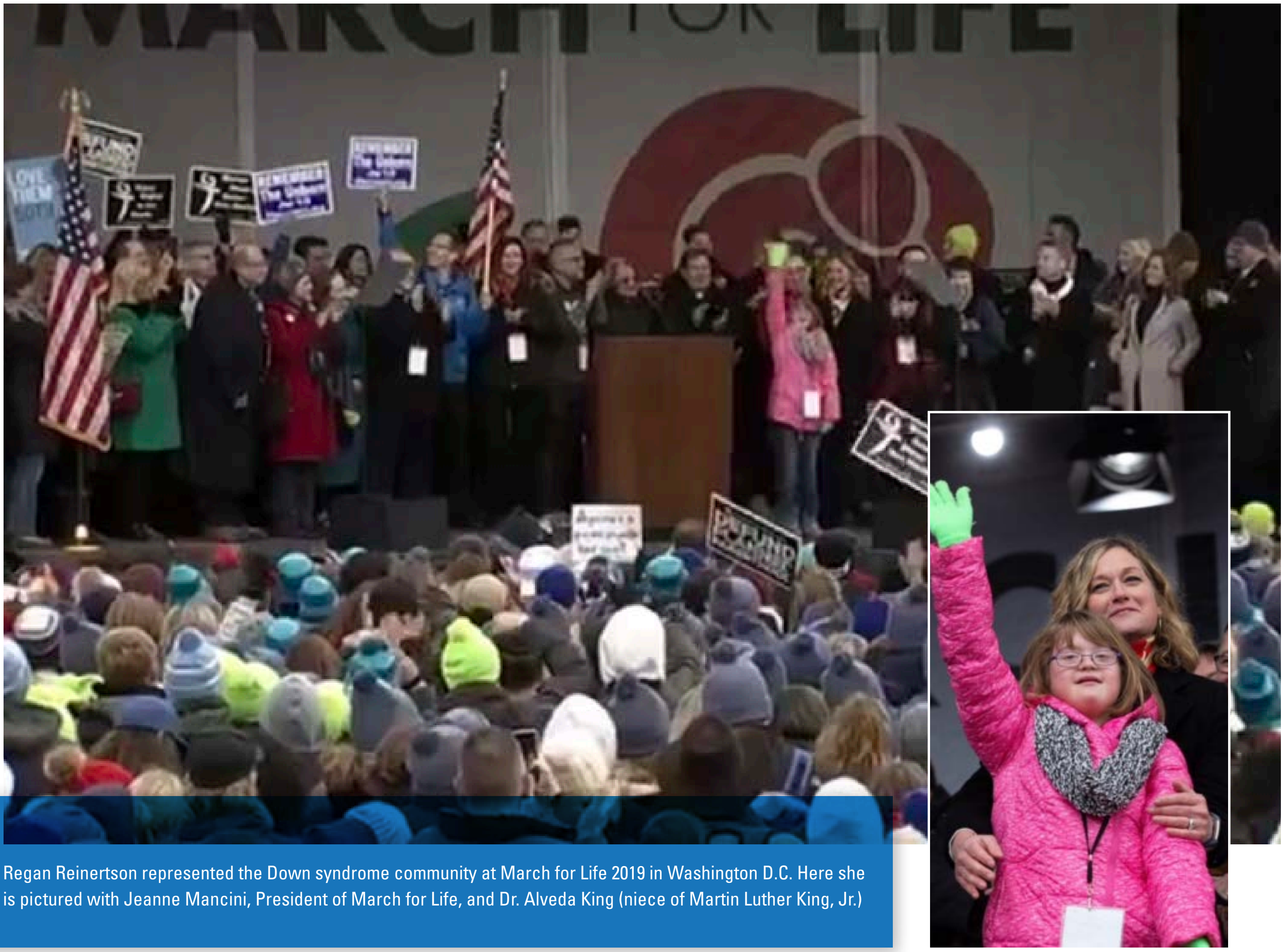
Want More News from NADS?

Sign up to receive news, stories, resources, event information and more... all in your email inbox!

To Join the NADS Email List, Go To:

nads.org/contact-nads

March for Life, Washington, DC, March, 2019



Regan Reinertson represented the Down syndrome community at March for Life 2019 in Washington D.C. Here she is pictured with Jeanne Mancini, President of March for Life, and Dr. Alveda King (niece of Martin Luther King, Jr.)

Kelly Neville Truly Sparkles

Special Sparkle was created to assist Kelly (at left) in leading a fulfilled and productive life after school came to an end for her. She had a part time job at a dentist's office, but there was still a lot of time to fill during the week. Once we got started, we realized how much awareness and education needed to be done to educate people about Down syndrome, achievement, success, and abilities. So many people questioned how Kelly could make her beautiful items. We started having her make things at craft shows to demonstrate her abilities. We created a website, Facebook page, and Instagram profile to bring awareness and promote her business.

During this time, we also became more involved with NADS and took the training to become public speakers, where we could educate and bring awareness to many different groups about both Down syndrome and Kelly's life.

We were thrilled when NADS started the basket program to provide new parents with a basket full of congratulations, celebration and information. We wanted to be a part of this new venture to provide some positive snapshot of their child's future by giving them one of Kelly's bracelets. While we tell new parents to just focus on their babies we know that every mom and dad wonders about the future. Hopefully our little bracelet and story of our business will help them realize the future is bright!

— Karen Neville, Kelly's mom

NADS Impacts Nation Family

I contacted NADS when I had recently received the news from my amniocentesis that my baby girl did indeed have Down syndrome. From just 15 weeks, I knew in my heart that she would have it, so I instantly went into research mode. I simply didn't know where to begin when it came to what information to start with. Our main priority was her health, and what to do to manage it and the potential health risks she may or may not encounter. I was told to reach out to Facebook forums, which are all filled with so many insightful and helpful people with relatable issues. However, I would be lying if I said it couldn't get overwhelming at times.

From there, one of the moms I made friends with mentioned to contact NADS. This would be the first organization that I would actually contact. They instantly emailed me back, and sent me some information in the mail. It really saved my sanity. It laid out Down syndrome in such a simple and easy way, it made everything seem so much more manageable. Even our two older children participated in learning more about the diagnosis. NADS truly jumpstarted our journey to understanding everything we need to, and answering any questions I would have.

Maddy is now 6 months old and we could not be more smitten with her. We are so blessed to be on this new journey. Thank you NADS for being so supportive in our journey, and all the other families I'm sure you've saved too.

(Left to right) Kylee, Maddy and Elijah Nation

Mrs. Levengood and Nathan

11-year old Touched By Teacher's Amazing Attitude

Recently we received a request from a mom, Maria Winkler, for a card her son could give to his teacher indicating a gift was donated to NADS in honor of her. While speaking with Maria, she stated that this teacher, Lyndsay Levengood, is one very gifted teacher. She teaches math to fifth grade students, but has incorporated her personal and professional life lessons into the classroom activities in the Brandywine Heights Area School district in Topton, PA. She utilizes an online program, Empatico, to connect her students with those across the globe in order to learn about others who may be different from themselves. She invited them to make connections outside of their comfort zone and understand that different isn't bad or scary, it's just not the same.

But it was her personal interactions and experiences with her brother Guy, who has Down syndrome, that made the biggest impact on an 11 yr. old student of hers, Nathan Winkler. Mrs. Levengood didn't have to go far in order to give a life lesson to this young student. Guy works at the school in food services and has become an integral part of the student and staff environment. He is appreciated by everyone who interacts with him. As Nathan's mom said, "We are truly blessed to have them both in our lives!"

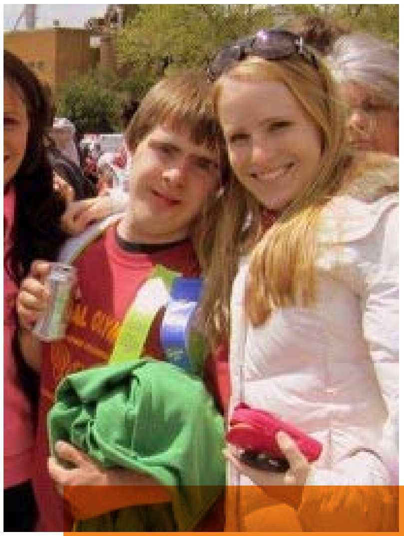
Nathan felt that Mrs. Levengood truly cared about him and each of his classmates. She made it a priority to teach them more than math; she taught them about diversity, empathy and kindness, too. She cares deeply about her students' successes, not only in math, but as people!

SHE INVITED THEM TO MAKE CONNECTIONS OUTSIDE OF THEIR COMFORT ZONE AND UNDERSTAND THAT DIFFERENT ISN'T BAD OR SCARY

Nathan's thank you note says it all:

Mrs. Levengood, Thank you for always having my back and teaching me all of the important things I need to know. You always inspire me to be the best student and the best person I can possibly be. You are the best teacher in the world. I will always remember this year. Instead of a gift I donated $100 to the National Association for Down Syndrome in honor of Guy. I thought this would be a good way to say thank you for the best year ever. Love, Nate.

Thank you Maria and Nathan Winkler, for your generous donation to NADS. And thank you, Lyndsay Levengood, for sharing your life and your brother Guy, in order to positively shape others to be their best selves!



Mrs. Levengood and her brother Guy

Handwriting Without Tears

Katie Frank, PhD, OTR/L
Registered Occupational Therapist
Adult Down Syndrome Center

Is printing letters a challenge for your child with Down syndrome? There are many physical reasons printing can be challenging for a child with Down syndrome. An individual might just not be developmentally ready to print his/her name yet. Many pieces need to be in place in order to learn how to print! First, you need to be able to copy the following shapes in this order: I, -, o, +,/, square, \, x, and triangle. How can you help your child learn these shapes? I have found the Handwriting without Tears program to be a great way to teach someone with Down syndrome how to print. It uses a multi-sensory learning approach (i.e visual, tactile, auditory, and motor components), which is always great for a person with Down syndrome. It also teaches the capital letters first! This is because all of the capital letters are the same size, whereas lower case letters either fit between the lines or extend above or below the lines on the paper, which can be confusing. The letters are taught in the order of the learned pre-writing shapes mentioned above. Therefore, letters like L, F, E, H, T, and I are taught before letters like A, W, X, Y, and Z. Each capital letter is made with any combination of the following four components (big or little lines and big or little curves). This developmental readiness approach is different from how many schools teach handwriting, which can be phonetically or even alphabetically. The program also has curricula to teach cursive handwriting as well as keyboarding! For more information, refer to www.lwtears.com.

So what happens if your child still has trouble printing? Perhaps the teacher can use other tools to help the child communicate their understanding of the material. For a spelling test, for instance, the child could use a keyboard or letter tiles or blocks to spell the words if he/she cannot physically write the words. It is important for teachers and therapists to be creative when supporting learning in individuals with DS until motor skills develop because a lack of fine motor skills does not correlate to a lack of learning or understanding in the classroom.

New study details development of functional skills based on age

Sue McGreevey,
MGH Public Affairs

When expectant parents learn their child will be born with Down syndrome, they invariably have questions about what this diagnosis will mean for their son or daughter and for the rest of their family. When will their child be able to walk, to speak clearly, to care for most basic needs? Will he or she be able to hold a job, to live or travel independently? A new study from investigators at MassGeneral Hospital for Children (MGHfC) and colleagues in the Netherlands is providing answers to some of those questions.

"More and more parents are opting for prenatal testing during their pregnancies, and if they learn about a diagnosis of Down syndrome, they want to know real-life answers to such questions," says Brian Skotko, the Emma Campbell Endowed Chair on Down Syndrome at Massachusetts General Hospital (MGH), director of the MGH Down Syndrome Program, and senior author of the study published online in American Journal of Medical Genetics Part A. "Contrary to some public beliefs, people with Down syndrome never stop learning, and functional skills can still be attained and improved well into adulthood."

While previous studies have looked at the development of specific skills by people with Down syndrome, most of them have been small, and several were based in countries where limited support services can restrict the potential of children with Down syndrome. The current study combines the results of surveys taken of more than 2,600 families in the U.S. and the Netherlands.

The U.S. survey, sent in 2008 and 2009 to families involved with six nonprofit Down syndrome organizations across the country, asked parents to rank their child's functional abilities in 11 areas — walking, eating, speaking, grooming/personal hygiene, reading, writing, preparing meals, working at a job, dating, traveling independently, and living independently. They were also asked whether their child had significant health problems or educational/learning difficulties. The same questionnaire — with some subtle differences due to translation from English into Dutch — was administered online in mid-2016 to families recruited through the Dutch Down Syndrome Foundation. For both groups, the family members with Down syndrome ranged from younger than 5 to older than 40, with the largest numbers in the youngest age groups.

> "Contrary to some public beliefs, people with Down syndrome never stop learning, and functional skills can still be attained and improved well into adulthood."
>
> —Brian Skotko

From the standpoint of major functional milestones, the results indicated that most people with Down syndrome in the U.S. could walk by 25 months of age, speak reasonably well by age 12, maintain personal hygiene by 13, and work independently by 20. By the age of 31, 49 percent were reading reasonably well, 46 percent could write reasonably well, 34 percent were living independently, and around 30 percent could travel independently. Dutch parents reported largely similar results. In both groups, learning challenges were reported more often than health problems, and reports of serious health problems in individuals with Down syndrome increased as they grew older.

An associate professor of pediatrics at Harvard Medical School, Skotko said, "Now we have guideposts — based on the responses of thousands of parents — that can help clinicians know when children may be falling behind their peers with Down syndrome and, when necessary, refer parents to additional supports, resources, and therapies." He also notes that recent advances in social, educational, and medical supports for people with Down syndrome should lead to even greater improvement in the acquisition of functional skills.

Skotko added, "Here in the U.S., there have been 'wrongful birth' and 'wrongful life' lawsuits filed either by parents of children with Down syndrome or on behalf of the children themselves, claiming that parents were not given information allowing them to terminate a pregnancy or that the child is living a life of suffering. These headline-grabbing lawsuits center around basic questions, such as what a person with Down syndrome can reasonably be expected to achieve. Such discussions should be centered around accurate information, rather than wild, outdated speculation, and we hope our research will help give clearer answers to those questions."

The lead author of the American Journal of Medical Genetics Part A paper is Gert de Graaf of the Dutch Down Syndrome Foundation; additional co-authors are Susan Levine of Family Resource Associates in Shrewsbury, N.J., and Richard Goldstein of Boston Children's Hospital.

The study was supported by grants from the Fred Lovejoy House-Staff Research and Education Fund, the Joel and Barbara Alpert Endowment for the Children of the City, the Tim White Foundation, and the Harvard NeuroDiscovery Center.

What Services Does NADS Provide?

NADS has been promoting the welfare of individuals with Down syndrome of all ages since 1961.

We offer innovative programs that promote health, advocacy, education, research and public awareness.

NADS supports all persons with Down syndrome in achieving their full potential.

Services We Provide

NADS is proud of its history and expertise in providing direct support and information to new parents of children born with Down syndrome. After birth, our trained professionals continue to provide emotional support, resources, referrals and education to families and caretakers, which includes medical professionals and community personnel.

Support from Diagnosis to Birth and Beyond

- Welcome baskets to new parents in 35 area hospitals (baskets include gifts, books and information to welcome the new baby)
- Connect new parents to services that address specific concerns
- Provide trained parent support volunteers
- Host a D.A.D.S. Program (Dads Appreciating Down Syndrome)
- Offer continuing education at our NADS Biennial Conference for parents, educators and others interested in the issue of Down syndrome

Community Outreach & Awareness

- Provide speakers at hospitals, schools and other organizations to increase awareness and acceptance of people with Down syndrome
- Provide materials, newsletters and membership options to the community to promote awareness and understanding of Down syndrome
- Work with the Partnership Advocacy Council (PAC), a service leadership organization led by adults with Down syndrome
- Host events to celebrate and involve donors, supporters and individuals with Down syndrome

Lillie-Grace Sherwood, 2 years old, from Middlesbrough, England

Why support NADS?

The direct support we provide to families is at the core of our mission in supporting all individuals with Down syndrome in achieving their full potential through programs such as:

- Parent Support
- More than Down syndrome Support
- Workshops
- Information and Referral
- Public awareness programs
- Education for Healthcare Professionals
- PAC—giving adults with Down syndrome leadership and service opportunities
- Newsletter
- Bi-annual conference

Learn more about NADS at **nads.org**

Four year old Morgan McEneany (above) of Naperville, Illinois and with her dad, Rob, and brother Colin (below).

Self-Advocates In the Community

Self Advocates pack food for the Northern Illinois Food Bank.

Game Night in June.

NADS Self Advocacy panels speaks at Ups for Downs Parent Education Night.

Decorating cards and boxes at Phil's Friends to be shipped to hospitals to help those battling cancer.

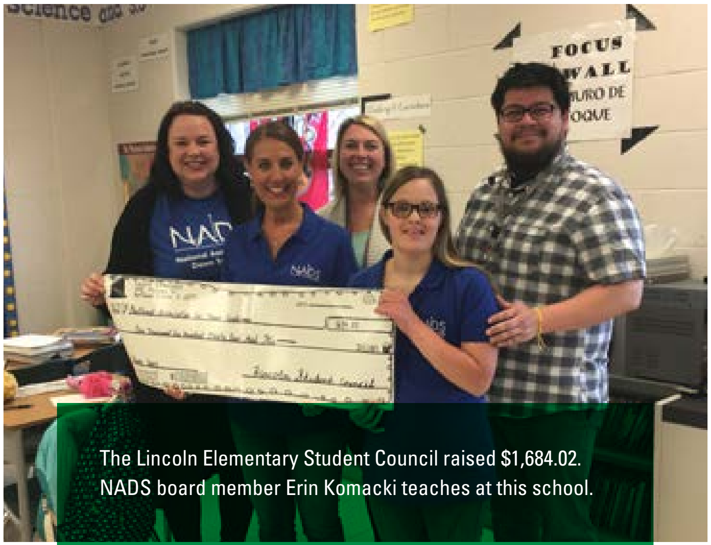
Our New Parent Speakers accompanied by 4 new Self-Advocates and 2 existing Self-Advocates and two Staff Trainers.

*Photo taken by and special thanks to Karen Neville who assisted in the Self-Advocacy training.

Thanks to our Supporters!

Designer Genes, sponsored by Komar Screw Corp., held on May 4, raised over $19,000 for NADS.

Trivia night, sponsored by the Zion Firefighters, raised $3,500 for NADS.



The Lincoln Elementary Student Council raised $1,684.02. NADS board member Erin Komacki teaches at this school.

The Alzamora family

Designer Genes

For the past 10 years, Komar Screw Corp., founded by Marvin Kocian and currently run by Stephen Kocian and Sarah Alzamora, has sponsored an amazing fundraiser known as the Designer Genes Celebration. Each year this fun and love-filled evening has benefitted the National Association for Down Syndrome and its programs. Sarah and Mike are the proud parents of Bobby and Maria and this event began soon after Maria's birth. Sarah is also one of the NADS Welcome Basket volunteers, delivering information, gifts and love in a basket to new parents in the Chicago area once a diagnosis is given. You have impacted many families over the past decade and will influence many in the years to come.

NADS FAMILY Album


Mary Washam, from Key West, FL, participating in the Special Olympics flag football game.


Tommy Veach, 13, and his parents, from Elmhurst Illinois He has three older siblings (sister and two brothers).


Meghan and Camden Roberson Ararat, North Carolina!


Suzana Clini, 11, from Cotia, São Paulo.


Kira Monroe, age 2, from Chicago Illinois


Miles is 19 and lives in Glen Ellyn. He attends the transition program through Glenbard District 87 and attends College of DuPage Vocational Skills classes through their Continuing Education program. He also works at Blackberry Market Cafe in downtown Glen Ellyn. Transition students also volunteer, participate in job training at various sites and attend social & recreational activities. He is pictured here attending his last day of class for the semester at College of DuPage!

From the President

As NADS nears the end of their fiscal year, we are eager to continue building on the momentum and positive change we've seen so far this year. The 2018 Fiscal year was a rebuilding year for NADS and we couldn't be prouder of the progress.

2018 Fiscal Year Programming Update

Programming is vastly expanding. With our fiscal year ending this June 30th, the Basket program has expanded to 34 hospitals with a 45% increase in basket deliveries over the same time period last year.

This year we expanded our language services by upgrading our website to provide translation in 10 languages and cultivating a diverse group of bi-lingual parent-support volunteers in 5 languages. We have ten dedicated Spanish speaking support volunteers in addition to volunteers speaking French, Cantonese, Polish and Italian. Our volunteers have been able to translate support calls and family support materials for over 35 families so far this year.

NADS CONTINUES TO PROVIDE PUBLIC AWARENESS THROUGH PRESENTATIONS THROUGHOUT THE COMMUNITY.

NADS continues to provide public awareness through presentations throughout the community. This fiscal year to date, we have presented to almost 700 attendees through Medical Outreach, which includes doctors, residents, other medical professionals and nursing students. We have presented to over 750 attendees through Higher Education Outreach, which includes service coordinators, student teachers, educations, case workers and therapists. Almost 4,000 attendees have been present at our Public Awareness presentations throughout the community. Most importantly, 58% of all of the Outreach was done or assisted by Self-Advocates.

BE SURE TO CHECK OUT THE NADS WEBSITE – NOW TRANSLATED INTO 10 LANGUAGES

As we continue fulfilling our mission, we are ecstatic to share that we've reached over 40,000 people through our in-person outreach efforts over the last five years! We are so proud of our ability to advocate for the Down syndrome community and continue educating and supporting through our programming!

Financial Update

Through this re-building year, the Board of Directors has been able to drastically cut non-program and non-critical general operating expenses from our budget. Some of the largest savings include staff-reorganization and the reduction in office space due to our move last August. We've completed a major overhaul of all expenses items, bringing almost every item to re-bid. We are proud of our fiscally responsible efforts as we prioritize critical mission specific programming!

Our membership supporters have grown 110% over the same time period last year. We are so thankful for our supporters that believe in the NADS mission and help us achieve it every day!

New in 2019

As we continue to grow and develop the organization, this upcoming fiscal year we will further expand our professional continuing education programming and programming for professionals that service and support the Down syndrome community.

Due to overwhelming feedback from our supporters, our traditional NADS News will go paperless this upcoming fiscal year. This change will not only allow NADS to become a greener organization but will allow the generous support we receive to be focused on programming. All supporters will continue to get our weekly E-Blasts and in addition will be notified when the NADS News is posted on the website. For those that are still wanting to receive paper, just please contact the office and they will put you on a mailing list.

We will soon be launching an Advisory Board, which will connect professionals from across the country to develop and advise the Board of Directors. We are in the beginning stages of inviting professionals to join the Advisory Board and plan on officially launching prior to the end of calendar year 2019.

Katie Wood,
President – Board of Directors

NADS

NADS News is a publication of the National Association for Down Syndrome (NADS).

For more information call or write:

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Park Ridge, IL 60068

630 325-9112
or visit **www.nads.org**

Jill Sterling, *Editor*
Katie Wood, *President*

There are so many ways you can help NADS!

Sponsor our events!

Get more involved with our Self-Advocate and PAC Programs! Contact Linda Smarto for details. Email Linda at **lsmarto@nads.org** for more information

Purchase items from our Amazon Wish List!

Host an event to raise critical funds for NADS!

Join a committee!

Also Consider These:

HONORARIUMS

Donating to NADS in someone's name is a wonderful gift to someone who has been helped by NADS.

MEMORIALS

Consider making a donation to NADS in memory of a loved one.

MATCHING GIFTS

Ask your employer if they're willing to match your generous donations to NADS.

MAKE A PLANNED GIFT TO NADS

When planning your estate, you can designate NADS as one of your beneficiaries. Call Jill Sterling at the NADS office at **630-325-9112** or e-mail **jsterling@nads.org** with any questions.

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