

Newsletter for supporters of the National Association for Down Syndrome

April 2020

NADS News

Bowl-A-Thon & Family Fun Day

Thank you to everyone who joined us this past Sunday for the NADS 35th Annual Bowl-A-Thon and Family Fun Day!

Nearly 80 bowlers and many other non-bowlers attended, including a large group of NADS self-advocates who bowled and/or volunteered at the event. Together with our fall fashion show, this serves as a major NADS fundraising event in support of our many vital programs. To date, the event has raised over \$32,000, with many pin pledges and donations still coming in!

There were over 40 exciting gift baskets taken home by winners of our choice raffle and three grand prize winners of large denomination Amazon gift cards. Congratulations to all of the winners and thank you to those in our community who contributed the gift basket items!

We truly appreciate the businesses and families who sponsored the event as well as the bowlers who did significant fundraising.

We hope to see you again next year at this fun fundraiser!



COVID-19 ANNOUNCEMENT

Please note, due to the rapidly changing situation regarding COVID-19, some changes have been made after the newsletter was printed. The **More Than DS Retreat has been postponed** in the interest of public safety. NADS Leadership is assessing our ability to hold the Conference and will provide an update as soon as possible. The content regarding the Conference offerings will go unchanged. Please follow us on social media for real time updates. Paper copies will not be mailed in the interest of safety for all. For any questions regarding programming, please contact Linda Smarto at lsmarto@nads.org.

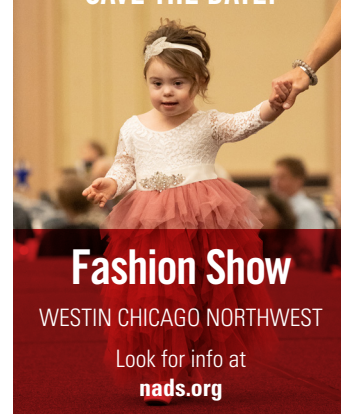
AUGUST 8

SAVE THE DATE!



NOVEMBER 1

SAVE THE DATE!



NADS by the Numbers*

50

Baby Baskets Delivered

29

Medical Presentations

809

Medical Presentation Participants

44

Public Awareness Presentations

3,708

Public Awareness Participants

*July 1, 2019 - March 1, 2020



Antioch Fire Department

Over the past few years, we've expanded our community outreach from hospitals and schools to now fire and police departments. Sometimes, it's one of our families who makes the initial contact to begin the process. Recently, we were asked to present to the Antioch Fire Department by one such family. Melody and Casey Zika live in Antioch, IL, along with their children, the youngest of whom has DS. Veronica is 4 yrs. old and already known in Antioch as a "Hometown Ambassador." What a wonderful welcome we received in mid-February!

Red Shift Battalion Chief Tim Taylor, the Training Director for the Antioch Fire Department, invited us to present over a 3-day period in order to reach as many emergency personnel in their department as possible. Chief Taylor and Captain Diana Horton also sent invitations to surrounding community fire departments who could benefit from the training. We had one of our largest turnouts yet, with 19 emergency personnel showing up the first day!

We were also joined by Melody and her daughter, Veronica, to give their perspective as community members. Melody was able to personalize the information as a local parent and Veronica spent the time demonstrating

her flexibility, friendliness and emerging verbal skills.

Afterwards, we received some outstanding feedback and the Chief promised to invite NADS back each year. He was adamant that no fire fighter or EMT should be ignorant of the best practices we presented when working with individuals with Down syndrome. A very big "Thank you" goes out to Chief Taylor, Captain Horton and all of the personnel who joined us for the presentations. We will be happy to return anytime.

If you would like your local fire or police department to get this free training, please contact us at 630-325-9112 or ismarto@nads.org.

Sibling Love

By Hannah Spenadel

I was only two years old when my brother Jacob was born, and I was too young at the time to understand what a diagnosis of Down syndrome would entail. Having a younger brother with Down syndrome hasn't always been easy, but Jacob has enriched my life in so many ways, and I am so lucky to share this journey through life with him.

There are many interests that Jacob and I share. We enjoy reading comic books together and going to comic conventions. In October, we went to Ace Comic Con, where we met two of the Avengers: Brie Larson (Captain Marvel) and Chris Hemsworth (Thor)! We both love to travel to new places and have gone on many trips together over the years. We've traveled far and wide, visiting other countries, including Australia, Canada, Israel, Italy, and Mexico. Our most recent trip was to Las Vegas for

Jacob's twenty-first birthday. I still find it hard to believe that he's already twenty-one and can legally drink now! He loves Elvis, and we got to see an Elvis tribute show there. Watching him joyfully dance and sing along throughout the entire show while dressed up as Elvis was the highlight of our trip.

Despite the many challenges Jacob has faced throughout his life, his determination and ability to work through them never ceases to amaze me. He graduated from high school in 2017 and is now in the final year of his transition program. Jacob currently holds two jobs and is taking two classes at the College of DuPage. He is also a self-advocate in the National Association for Down Syndrome's SAIA (Self-Advocates in Action) group. In addition, he creates artwork for Creative Souls, acts in musicals, works out, and enjoys spending time with family and friends. I am so proud of everything that he has accomplished!

Jacob has always been my foremost support system as well as the driving force in reminding me that I am capable of overcoming any challenges. He inadvertently taught me to be a more patient person, which has been a very beneficial skill for me to have. Empathy is one of Jacob's most admirable qualities. He is always genuinely concerned about the well-being of others, whether they're a family member, a friend or a complete stranger. His infectious smile and laughter can light up any room that he walks into.

Jacob has helped to shape me into the person that I am today, reminding me every single day of the undeniable power of unconditional love and acceptance. I would never trade



Jacob in Las Vegas with Elvis

having him as my brother for having a brother without special needs. In fact, if he didn't have Down syndrome, it's unlikely that we would've formed such a strong, unbreakable bond. Although we sometimes bicker and get into arguments as all siblings do, this doesn't change how much we care about each other. There is no greater privilege in my life than being Jacob's sister.

Birth Call By Chris Newlon

I received my daughter's diagnosis when I was 25 weeks pregnant. She is the last of our 5 children and I assumed the pregnancy would be like the other four. It all seemed to change with the diagnosis. Along with the Down syndrome diagnosis, we were told she would need to have GI surgery within her first 48 hours of life and heart surgery within her first year. My husband, Shaun and I spent the next few months preparing her older siblings and ourselves for our new baby.

After a longer than normal labor, Rebecca arrived with a hearty cry to let us know she was going to be a strong one! The doctor we had planned and met with to do the bowel surgery was out of town, so she was transferred to Chicago Children's Hospital (as it was known at the time) when stable. I left the hospital at the same time to be with her. The surgery was a success, but the recovery took longer than expected.

Instead of being discharged within a week, Rebecca was kept in the NICU for almost 3 weeks. I spent the time with her, doing nothing but pacing,

pumping breastmilk and missing my other kids. She struggled with weight gain the entire time. We celebrated every 1 ounce weight gain. After 26 days, she was given the green light to go home.

One of the things that kept my sanity during that time was a call I got from one of the trained volunteers from the National Association for Down Syndrome. I remember exactly where I was standing on the unit, who was around me and how it felt to have someone who didn't know me personally reach out to me. She introduced herself, let me know that she was a parent of a child with Ds too, and she was willing to answer any questions, share stories and most of all, listen. We spoke briefly but I took her name and number to use when things settled a bit.



I never called her back and I don't remember her name. But for 16 years I've silently thanked her for giving me the strength to get through that rough time period, for letting me know others were (and still are) here for me when needed and that NADS will always be my go-to resource on this journey with our fabulous daughter.

OT Tips by Katie Frank

Just thinking about chores can make you groan. However, do you know that chores can benefit the physical and mental health and well-being of individuals with Down syndrome? Chores help individuals develop responsibility and independence and once added to their routines can be a valuable experience. Chores provide opportunities to practice developmental skills such as fine motor strength and coordination, motor planning, visual perception, organization, and following instructions. Chores are a great way to naturally provide proprioceptive input and help regulate our sensory

systems, which can improve attention and behavior. When done well, chores also help support a strong self-esteem. Suggested chores include washing and folding laundry, putting away dishes, wiping down counters and tables, vacuuming or sweeping floors, collecting and/or taking out the trash/recycling, cleaning the bedroom, and helping with cooking tasks. If you think your loved one with Down syndrome may have difficulty adding chores to his/her routine, consider incorporating visual supports to make the transition easier. Often times, adding the chore(s) to the weekly or monthly calendar can help the individual incorporate them into the routine. Additionally, to motivate a person with Down syndrome to complete non-preferred tasks (i.e.



chores), consider using a reward system to earn preferred things like time on the iPad, a special outing, or an opportunity to FaceTime a friend or family member.

21+ More Than Down Syndrome

For years, NADS has been offering services for families of loved ones with Down syndrome plus an additional diagnosis like autism spectrum disorder and ADD/ADHD. While the services have changed over the years, the commitment to serve these families remains. NADS has partnered with the Adult Down Syndrome Center (ADSC) in Park Ridge to bring in speakers to share valuable information regarding these More than DS diagnoses. In 2019 presentations were offered on sensory processing, caregiver self-care, and functions of behavior and ABA therapy. Jonathan Rauwerda, a behavior therapist, will be talking about practical strategies to address behaviors. In preparation for this presentation, Jonathan would like to know about specific behaviors that you want to make sure he addresses. The session will cover all ages and families do not have to be patients of the Adult Down Syndrome Center to attend. Unfortunately respite care is not able to be provided.

Due to the pandemic, this session has been postponed. For more information, please contact NADS staff member Linda Smarto at lsmarto@nads.org or NADS board member and ADSC staff member Katie Frank at katherine.frank@advocatehealth.com.

**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



CREATING Lifelong Learners!

Family • Educators • Community

The National Association for Down Syndrome will hold its bi-annual conference on **August 8th at St. Ignatius College Prep** in Chicago. The Creating Lifelong Learners Conference (CLLC) helps educate parents, caregivers, siblings, service providers, and educators – all in one

conference! CLLC provides a unique opportunity for our community to gather together and connect with each other.

At CLLC parents will learn how best to help their children acquire the skills that will enable them to lead fuller, more independent lives. Teens

and adults with Down syndrome will have an opportunity to socialize and work with professionals on skills that support a healthy and engaging adult life. Professionals and educators will learn about Down syndrome and how to best support students in their school environment.

Registration and information is now available at **www.NADS.org**. We hope to see you on August 8th.

August 8th NADS Conference Agenda

7:30 – 8:45

Registration Open – Registration tables will be open until 11:00 AM.

Exhibitor Hall Open

8:45 – 9:45

Opening Keynote address

10:00 – 11:00

Session 1 Presentations (10 presentations during this time slot)

Sibling Workshop begins (session will continue until 12:15)

Teen/Adult Conference begins (T/A Conference proceeds until 3:30)

11:15 – 12:15

Session 2 Presentations (10 presentations available during this time slot)

12:15 – 1:15

Complementary Box Lunch Provided (Sibling Workshop breaks for lunch – lunch is attended with parents in Tully Hall).

Teen/Adult Conference do lunch together in McLaughlin Hall

Exhibitor Hall Open

1:15 – 2:15

Session 3 Presentations (10 presentations available during this time slot)

Sibling Workshop begins (session will continue until 3:30)

2:30 – 3:30

Session 4 Presentations (10 presentations available during this time slot)

3:30 – 4:00

Exhibitor Hall Open

Education Table available for teacher/educator Certificates

Sibling Workshop and Teen/Adult Conference Conclude at 3:30

Register NOW!

www.nads.org/events/2020-nads-conference-creating-lifelong-learners/

Meet our Keynote for the 2020 Creating Lifelong Learners Conference: Karen Gaffney

NADS is excited to announce our Keynote for the 2020 Creating Lifelong Learners Conference (August 8th at St. Ignatius College Prep in Chicago)! Karen Gaffney will be opening our conference with a message that celebrates how anything can be accomplished with positive expectations and a strong will to overcome limitations. NADS is thrilled to also have Karen support our Teen/Adult program (available to teens and adults with Down syndrome ages 15 and up) during the conference. She will conduct workshops for our attendees and spend the day with them to further her message of "anything is possible!"

Karen has been an inspiration to our community for over 20 years. Karen is the president of the Karen Gaffney Foundation, a non-profit organization headquartered in Portland, Oregon "dedicated to championing the journey to full inclusion for people with Down Syndrome and other disabilities."

In 2001, she became the first person with Down syndrome to complete a relay swim of the English Channel. Her 2007 swim across the nine mile span of Lake Tahoe became the subject of the documentary *Crossing Tahoe: A Swimmer's Dream*. In 2009, she swam across Boston



Karen speaking at TedX Portland

Harbor, a distance of five miles, to celebrate Down Syndrome Month in Massachusetts. She has also earned two gold medals from the Special Olympics, and completed 16 swims across San Francisco Bay, including the Escape from Alcatraz triathlon. In 2010, she received the Global Down Syndrome Quincy Jones Exceptional Advocacy Award.

In 2015 Karen Gaffney presented at TEDxPortland. Karen left Rose City and the world in awe with a captivating talk that explored the history, current state and progress of Down syndrome. You can view her TEDtalk under the title: *I have one*

more chromosome than you. So what? Karen Gaffney TEDxPortland

Karen Gaffney became the first living person with Down syndrome to receive an honorary doctorate degree when she received an honorary Doctor of Humane Letters degree from the University of Portland on May 5, 2013, for her work in raising awareness regarding the abilities of people who have Down syndrome.

Karen Gaffney graduated from St. Mary's Academy high school in Portland in 1997, and in 2001 she graduated from Portland Community College with an Associate of Science degree and a teacher's aide certificate.

Calling All Educators to Attend the 2020 Creating Lifelong Learners Conference!

As parents of young children with Down syndrome one common education goal we have is for our children to have teachers, therapists, and support team members who are well versed in current education and medical insight into caring for our kiddos. The 2020 Conference is the perfect place for Illinois educators to get that information!

NADS is an Illinois state-approved professional development provider authorized to issue professional development credit to Illinois licensed educators for license renewal purposes. Illinois educators that attend the conference will be able to collect 4 hours of ISBE Professional Development.

Be sure to also let your educators know that Illinois STARnet provides stipends for educators to attend professional conferences. Our conference falls under their mission of "providing opportunities for personal and professional growth for those who touch the lives of young children, ages birth through eight, with special needs." Teachers can submit for funding by contacting the following agencies:

- Cook County — <https://www.starnetchicago.org/family>
 - Grundy, Kankakee, Kendall, LaSalle, Will, or South Suburban Cook County — <https://www.swccase.org/starnet>
- Funding Assistance Form — <https://il02207139.schoolwires.net/cms/lib/IL02207139/Centricity/Domain/2075/Fellowship%20Form.pdf>
 - Northern Illinois — <https://www.starnetregionii.org/>
- Funding Assistance Page — <https://www.starnetregionii.org/funding-opportunities>
 - Northwest and Central Illinois — <http://starnet.org/home/fellowships-2/overview/>
 - Southern Illinois — <http://roe.stclair.k12.il.us/starnet/content.php?q=Funding&PHPSESSID=23f0c354a00cd02cefd8b876278ae4b5>



NADS FAMILY Album



Fun is in Fashion!



Student Athletes Give Back

On February 25th, the Stevenson High School Hockey Association (SHSHA) donated their time to help the National Association for Down Syndrome (NADS). Adlai Stevenson High School, located in Lincolnshire Illinois, is the only High School in the state of Illinois to recognize an Ice Hockey team as an official School Sport. As such, the Stevenson Hockey players are required to not only abide by USA Hockey rules, but IHSA rules, qualify academically as a student athlete and abide by the school academic and athletic code of conduct. The unique partnership that SHSHA has with Stevenson High School's Athletic Department, specifically with Tricia Betthausen -- Athletic Director, is very beneficial to the growth and success of the Stevenson Hockey Program. Outside of the players being dedicated to their studies and their sport, they make time throughout the season to give back to various non-profit organizations.

Earlier this season they spent their time at Libertyville, Illinois' Feed My Starving Children, by capping the evening off breaking the Feed My Starving Children facility record of the most meals packed in one session. The teams have also spent time at Bernie's Book Bank in Lake Bluff, Illinois, sorting, stickering and packing books for underserved children in the Chicagoland area. Hockey Director



JV and Varsity Stevenson Hockey Players, supervised by Coach Dan, with the packed boxes and signs from their evening volunteer efforts

and Varsity Head Coach, Tom Wood, states, "I'm really proud of our players coming together to help such wonderful causes. I try to express to my players the importance of giving

"IT'S SO IMPORTANT TO GIVE TIME TO WORTHY CAUSES LIKE NADS AS THEY MAKE THE WORLD A BETTER PLACE."

back to your community. The most important part of coaching our players is teaching them how to be a caring and responsible adult when they finish their playing careers."

On this volunteer night, members of the Junior Varsity and Varsity hockey teams came together at their home rink, Twin Rinks in Buffalo Grove, Illinois, to help NADS get ready

for their annual public awareness campaign. Yard Signs, sharing information about World Down Syndrome Day (March 21st) and Down Syndrome Awareness Month (October), provide a visual reminder of the Down syndrome community and lets the public know where they can locate resources about Down syndrome. This doubles as a critical fundraiser for the organization helping provide the funds to further the mission. During this evening the teams assembled boxes, packed yard signs and stakes and taped them, so they were ready to ship from the NADS office. This saved NADS numerous staff hours, allowing them to focus their efforts elsewhere within the Down syndrome community. Varsity Assistant Coach Dan Wood said, "the kids were great! We offered the opportunity as voluntary

and so many stepped up to help! It's important that we work with the kids to give back to the community." The players are looking forward to next year's boxes and other ways they might be able to help NADS and other nonprofit organizations in the future. Tom Wood states, "It's so important to give time to worthy causes like NADS as they make the world a better place. Even volunteering for one day can make an impact on other people's lives. I'm glad we were able to have such a large turnout for the event."

If you are interested in purchasing a yard sign or donating to NADS, please visit www.nads.org. More information about the Stevenson High School Hockey Association and the Stevenson Hockey Program can be found at www.stevensonhockey.org.

Get Your Yard Sign!

Since 2014, NADS has been creating yard signs that celebrate awareness and advocacy during World Down Syndrome Day (March 21st) and Down Syndrome Awareness Month (October).

In 2018, NADS expanded the yard sign fundraiser to encompass shipment of signs to anyone living outside of the Chicagoland area. In 2019, yard signs were ordered from individuals in 19 states across the United States!

NADS would like to thank Steve Kozle, Vice President of Printastic, for his generous donation to our annual Yard Sign fundraiser. This year, Steve Kozle generously offered to support our fundraising efforts by donating 500 signs to NADS in an effort to help boost our fundraising goal! His support will allow NADS to raise more funds that help support our programs.



Yard signs are available for at home delivery at nads.org!



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

For more information call or write:

National Association for Down Syndrome

Suite 102
1460 Renaissance Drive
Park Ridge, IL 60068

630 325-9112
or visit www.nads.org

Katie Wood, President

Who to contact at NADS

- **Linda Smarto** (lsmarto@nads.org) - **Director of Programs and Advocacy** - Any program related inquiries
- **Chris Newlon** (cnewlon@nads.org) - **Parent Resource and Outreach Coordinator** - Any resource related questions or inquiries about public speaking
- **Karen Neville** (kneville@nads.org) - **Basket and Hospital Outreach Coordinator** - Any questions or requests related to the Basket and Hospital Program
- **Mike Finelli** (mfinelli@nads.org) - **Development Manager** - Any Development or Fundraising inquiries
- **Hannah Spenadel** (hspenadel@nads.org) - **Development and Communications Assistant** - Questions regarding donation record, event registrations, social media or E-Blast content
- **Deb Kracik** (dkracik@nads.org) - **Bookkeeping and Office Assistant** - Billing, invoicing, donation processing and general event related requests
- **Katie Wood** (kwood@nads.org) - **President, Board of Directors** - Any general organization questions or concerns



There are so many ways you can help NADS!

Sponsor our events!

Get more involved with our
Self-Advocates in Action 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 the NADS office at **630-325-9112** with any
questions.



National Association for Down Syndrome

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The editor reserves the right to make any such corrections as necessary in accordance with established editorial practice in material submitted.