

## Amina Grace Memorial Fund Partnership

The Amina Grace Memorial Fund announced a \$21,000, three-year partnership with the National Association for Down Syndrome (NADS), to support their Hospital and Congratulations Basket program.

Often when a child is born with Down syndrome, the diagnosis is delivered in a sad, somber way leaving the family feeling anxious

and scared about what the future holds. NADS strives to change the experience so that the diagnosis is filled with a more accurate and hopeful long-term perspective.

The NADS hospital speaker program strives to educate a variety of health care professionals that are points of contact with families during their pregnancy journey. The hospital program helps the doctors address the hard questions medical professionals face in breaking the news: how do they tell the parents in a positive and supportive way? Who should be present? How do they provide families with hope? The NADS program provides current information about Down syndrome and gives the medical personnel a vision of what it is like for families to raise a child with Down syndrome. When a baby with Down syndrome is born, the hospital staff refers the family to NADS so they can receive their Congratulations Basket.

The Congratulations Basket program is so important to set the right tone of celebration with families. "We are thrilled to support NADS in this important program as it is a gift for the families to know their child is valued and they will have more blessings than challenges along the way," says Maura Cullen,

Co-Founder of the Amina Grace Memorial Fund. These baskets are delivered to families by a NADS trained parent mentor either at the hospital or later, whenever the time is right for the new family. These mentors will congratulate, celebrate, provide emotional support, give direction on resources and help the families understand that there is no reason to limit the possibilities of their child. The basket is full of items that are appropriate for any new baby and provides connections and referrals for service to help them navigate their Down syndrome journey.



AMINA GRACE  
MEMORIAL FUND

### About Amina Grace Memorial Fund

Amina Grace Memorial Fund is a non-profit whose mission is to create lasting acceptance of people with Down syndrome and to provide resources to organizations that support those with Down syndrome and other differing abilities. To learn more visit [www.aminagrace.org](http://www.aminagrace.org).



To learn more about the  
**Hospital and  
Congratulations  
Basket Program,**  
see page 5.

## UPCOMING EVENTS

**February 28-March 1**  
DSAIA Leadership Conference -

**March 8**  
NADS Bowl A Thon

**April 25**  
More Than Down Syndrome  
Workshop

**June 25**  
NDSC Convention

**August 8**  
NADS Conference

**November 1**  
NADS Fashion Show

**MARCH 8**



BOWLERO IN NAPERVILLE

Register at  
[nads.org](http://nads.org)

**AUGUST 8**

**SAVE THE DATE!**



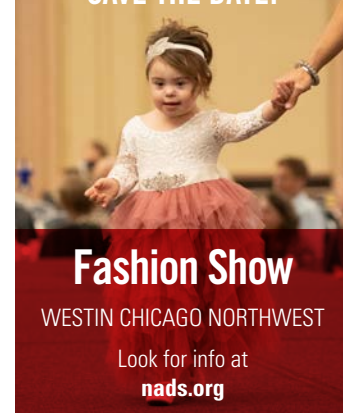
**Conference**

SAINT IGNATIUS COLLEGE PREP

Register at  
[nads.org](http://nads.org)

**NOVEMBER 1**

**SAVE THE DATE!**



**Fashion Show**

WESTIN CHICAGO NORTHWEST

Look for info at  
[nads.org](http://nads.org)

## NADS by the Numbers\*

**38**

Baby Baskets Delivered

**22**

Medical Presentations

**703**

Medical Presentation Participants

**35**

Public Awareness Presentations

**3,292**

Public Awareness Participants

\*July 1-December 31, 2019



Self Advocates working hard at the Buddy Walk

## Self Advocates in Action

**S**elf Advocates in Action (SAIA), formerly PAC, selected the new logo when they launched the new name at their Planning and Pizza Party held in September. They have been busy since that initial meeting!

They participated in The Buddy Walk which was held on Sunday, October 13, 2019 at the Bolingbrook Golf Club. Self-Advocates volunteered their time helping sell raffle tickets and assisting in various stations such as games, popcorn, photo booth and the bouncy house.

At the end of the month, our Self Advocates assisted with the Fashion Show greeting guests, selling raffles, introducing speakers at the podium and collecting donation envelopes.

Most recently, SAIA partnered with Phil's Friends, making up and sending out care packages. Phil's Friends is a Christian non profit organization established to support and provide hope to those affected by cancer. In addition, Phil's friends has been regularly donating extra items of blankets, bears and toys in which they receive a surplus of to help with our new families and the Congratulations

Basket and Hospital Program. Some of these toys and fleece blankets have also been given to the grandparents and siblings as a welcoming gift.

The most recent SAIA event was a Bowling Party sponsored by the Spenadel's on Sunday, January 19th. Self Advocates had a great time bowling and generously donated gift cards, raffle and auction items

to be used at the upcoming Bowl A Thon. On the horizon, Self Advocates will donate their time to help NADS get ready for the Bowl A Thon by packaging auction items and materials needed for the day of the event!

If anyone has any questions, please contact Linda Smarto at [lsmart@nads.org](mailto:lsmart@nads.org)



Having fun at the SAIA Bowling Party

### Smile! [and help NADS]

**G**o to [smile.amazon.com](https://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!

**amazon**smile





## Dual Diagnosis

**F**or 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.

On Saturday January 25th participants braved the snow to learn about “Pharmacologic Interventions to Address Behavior” at the Adult Down Syndrome Center. The speaker, Dr. Meghan O’Neil from Lurie Children’s Hospital Down Syndrome Clinic facilitated a fantastic presentation for all in attendance.

**There will also be a session on Saturday April 25** with the topic to be determined. For more information, please contact NADS staff member Linda Smarto at [lsmarto@nads.org](mailto:lsmarto@nads.org) or NADS board member and ADSC staff member Katie Frank at [katherine.frank@advocatehealth.com](mailto:katherine.frank@advocatehealth.com).



## Our 14th Annual Fashion Show — A Stellar Success!!

By: Co-Chairs, Erin Komacki and Jen Hora

**N**ADS 14th Annual Fashion Show, “A Star is Born” was held last Sunday in Rosemont, Illinois at the Donald E. Stephens Convention Center. The event, which included 39 amazing models (some traveling from Michigan and Virginia!) and over 500 attendees, helped raise over \$65,000 for our programs and services to the Down syndrome community.

We are so grateful to ABC-7’s Stacey Baca, who emceed the event, our donors, sponsors, attendees, and especially our models, who made the event such an uplifting and beautiful event. Click here to see the link to the ABC-7 television coverage: [NADS ON ABC-7](#)

Thanks to all who supported NADS and our models this year! See the Family Album on page 6 for more photos!

**Mark your calendars for the 2020 Show on November 1st at the Westin Chicago Northwest in Itasca.** Details will be released late Spring 2020.

**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](https://nads.org/contact-nads)**

## 2020 NADS Conference

### 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](http://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/](http://www.nads.org/events/2020-nads-conference-creating-lifelong-learners/)



## NADS Conference Expands To Serve Teen Siblings!

**N**ADS is excited to announce that the Creating Lifelong Learners Conference (August 8, 2020) will offer a Sibling Conference! We are so thrilled to expand our platform to include 12-18 year old siblings. Siblings will attend a separate track of education facilitated by Tara Conley from Supporting Illinois Brothers and Sisters.

S.I.B.S. is an established Illinois non-profit serving siblings across the lifespan. S.I.B.S. champions siblings of people with disabilities in Illinois, offering solidarity and relevant resources to enhance the quality of life for siblings and families alike.

Registration is open on the NADS website at [www.NADS.org](http://www.NADS.org). The Sibling Conference will be facilitated as a peer gathering which will include open and lively conversations, recreational and educational activities, and will give siblings a chance to meet with other teens their age with similar family dynamics.

Our 2018 CLLC survey had overwhelming enthusiasm for NADS to host a sibling track. We are thrilled to have fostered a partnership with S.I.B.S. to provide this programming during our conference. Now the entire family can enjoy the day at the Creating Lifelong Learners Conference. We will have tracks for parents and educators, teens and adults with Down syndrome, and now teen siblings! We hope to see you on August 8th at St. Ignatius College Prep!



## Basket and Hospital Program

**T**hanks to the generous partnership with the Amina Grace Memorial Fund, the Basket and Hospital Program has gone through an overhaul to launch with brand new baskets and protocol in 2020. On January 4th, Baby Basket Volunteer Coordinators met at the NADS office to drop off their basket inventory and pick up new standardized baskets. The NADS Staff and Board Members, Erin Komacki and Katie Wood, met in the office to make over 70 baskets for the upcoming year. The Baskets are

### NADS IS NOW DELIVERING BABY BASKETS TO FORTY HOSPITALS WITHIN THE CHICAGO METROPOLITAN AREA.

now blue and white, in line with NADS colors and has the NADS logo on each one. NADS is moving towards gender neutral baskets to optimize the program materials and inventory needed. Inside the baskets are hand knit blankets, diapers, wipes, a baby floor mirror, toys, stuffed animal or stuffed "lovey," NADS Onesie, additional baby soft goods, resources for other Down syndrome organizations, Early Intervention materials, a sign language baby book, children's book, resources and books about Down syndrome and information about the Amina Grace Memorial Fund. Thanks to the generous donations from Kelly Neville and Special Sparkle, the mothers have a beautiful bracelet attached to each basket. These baskets are provided in both English and Spanish.

NADS is now delivering Baby Baskets to forty hospitals within the Chicago Metropolitan area. This rapid expansion is due to the hard work from the Programs Team, with Linda Smarto leading the charge. Without the dedicated Basket Coordinators and Basket Delivery Volunteers, we would not have been able to make this happen. This group of volunteers is dedicated to the program and will deliver baskets within 24 hours of a referral to get this needed information into the hands of new families and provide support, often prior to hospital discharge. Within this group of volunteers are bi-lingual parents that deliver baskets and provide assistance in Spanish.

Due to this expansion, Karen Neville, joined the Programs Team as the Basket and Hospital Outreach Coordinator to dedicate her efforts exclusively to this program. Karen will manage referrals, coordinate with volunteers, track inventory and continue scheduling and presenting within our hospital network. Prior to Karen's employment with NADS, she was a long-time dedicated volunteer and supporter of the organization. Karen can be reached at [KNeville@NADS.org](mailto:KNeville@NADS.org).



Learn more or refer  
a family at:  
[www.nads.org/refer-someone](http://www.nads.org/refer-someone)



# NADS FAMILY Album





## From the President: 2019 Wrap Up and The Year Ahead

The National Association for Down Syndrome had a great year in 2019. This would not be possible for the wonderful volunteers, supporters, donors, staff and Board members that give back to the organization. We are so thankful for everyone that lends both their time and treasure to help the organization flourish.

2019 brought tremendous program growth with the same upward trajectory projected for

This past fall we added Hannah Spenadel to the Development Team as the Development and Communications Assistant. Hannah comes to NADS as a recent graduate of the University of Illinois with a strong background in Social Media Management, Writing and Communications. She is the sister of Self-Advocate, Jacob Spenadel. Jill Sterling recently parted ways with the organization. We appreciate everything she has contributed and wish her luck in her future



**Katie Wood,**  
President – Board of Directors

### WE ARE LOOKING FOR PROFESSIONALS OF VARYING BACKGROUNDS TO JOIN US

2020. With two weeks still left in calendar year 2019, we have presented to 38 medical facilities totaling 1,204 attendees resulting in 62 Congratulations Baskets. This is only possible with our wonderful Program team. Linda Smarto, Director of Programs and Advocacy, has been instrumental in working within the community and with the Board to grow programming reach. In addition to the Family Support and Resource Coordinator, Chris Newlon, NADS is excited to welcome a familiar face of the community, Karen Neville, to the Program Team. Karen will work as the Basket and Hospital Outreach Coordinator focusing on growing and maintaining organization of the Congratulations Basket and Hospital Program. Chris will continue to support families with resources and provide resources and presentations through various education channels.

endeavors. Mike Finelli started in January as the new Development Manager. Mike comes to us with years of experience in both the for profit and non-profit sectors. We are excited to have him join the team.

The Board of Directors is now halfway through their fiscal year operations. Planning for the upcoming Bowl A Thon and Family Fun Day, Creating Lifelong Learners Conference and Fashion Show are underway for 2020. The operational compliance with the new Advisory Board is also complete. Invitations to join the Advisory Board will mail in early 2020. We are looking for professionals of varying backgrounds to join us this upcoming year. If you know anyone interested in learning more about the Board of Directors or Advisory Board, please contact Katie Wood at [kwood@nads.org](mailto:kwood@nads.org).



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



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

Katie Wood, President



Self-Advocates In Action (SAIA) partnered with Phil's Friends, making up and sending out care packages.

## 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** - And 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-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 the NADS office at **630-325-9112** with any  
questions.



**National Association of Down Syndrome**

1460 Renaissance Drive, Suite 102 | Park Ridge, IL 60068

#### Disclaimer Policy Statement

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.