NADS hosted its biannual conference this August 11th at St. Ignatius College Prep in Chicago. The theme for the conference was “Creating Lifelong Learners” with the goal to engage more professionals and educators at our amazing event.

Keynote speakers Katie Driscoll (Founder of Changing the Face of Beauty) and Kayla McKeon (Global Ambassador for National Down Syndrome Society) kicked off the day’s event in the morning. Over 25 organizations and businesses were represented at our Exhibitor Hall, which allowed parents, professionals, and caregivers to learn more about resources and organizations within our community. We were very proud to have Down In The Southland, Gigi’s Playhouse, Ups for Downs, and the National Down Syndrome Society participating as exhibitors along with 20 other organizations/businesses who supported the day as exhibitors.

**NADS 2018 Conference Wrap-Up** Peggy Delaney

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**UPCOMING EVENTS**

**Sept 11**
Trainer: Peggy Delaney, NADS
Clearbrook
1835 W. Central Road
Arlington Heights IL 60005
4:00-5:30 PM
FOR Early Intervention Specialists
RSVP to Susan M. Roderick,
Clearbrook, Director of CHILD Therapy And Support Services at
847 385 2621
sroderick@clearbrook.org

**Sept 21**
NADS PAC Dance Extravaganza
Itasca Park District
6:00 – 9:00 PM

**Oct 28**
NADS Fashion Show
Donald E. Stephens Convention Center, Rosemont
10:30
Get tix at nads.org

**SEPTEMBER 22**
Deadline to Order Yard Signs
GET YOUR DOWN SYNDROME AWARENESS MONTH SIGN
Get yours at nads.org/shop

**OCTOBER 28**
NADS Fashion Show
SAVE THE DATE
OCTOBER 28
Get tickets NOW at nads.org

**MARCH 10**
BOWLATHON & Family Fun Day!
SAVE THE DATE!
BOWLERO IN NAPERVILLE
More at nads.org

**Smile! [and help NADS]**
Designate the National Association for Down Syndrome when you shop on Amazon! Go to smile.amazon.com on your computer or mobile device and select NADS as your charity of choice. Amazon will donate a portion of the purchase price to us. It’s that simple!

amazon smile
We were thrilled to have 20 presenters supporting our “education sessions” throughout the day. Presentations had an array of topics such as:

- What you (and your family) need to know about “A BETTER LIFE EXPERIENCE” – ABLE!
- Navigating Nutritional Concerns Through Infancy and Toddlerhood
- Understanding and Improving Behavior – A Sensible Approach
- Special Needs Legal and Future Planning
- The DS Biobank: Accelerating the Advancement of Research
- Physical Therapy Considerations for Children with Down Syndrome
- Stages of Reading Development
- Sibling Support
- DRS Transition Services: Who, What, When, and Where
- What Happens with The Bus Stops Coming?

Presentations were facilitated by many amazing individuals from a variety of organizations such as Advocate Children’s Hospital, Sibling Leadership Network, Protected Tomorrows, Down Syndrome Achieves, Illinois Department of Human Services Division of Rehabilitation, and the Illinois State Treasurer Department.

This was the first year that our conference was able to directly hand out Professional Development Credit for Illinois teachers, Early Intervention specialists, and Early Childhood educators. We partnered with Illinois Early Intervention, the Illinois State Board of Education, and Gateways to Opportunity to ensure all professional attendees would have the opportunity to learn more about our community while also meeting professional development goals.

Our Teen and Adult program was very exciting this year. Our attendees had a fun-filled day of activities that included an Improvisation Workshop with Stand Up For Down founder Rob Snow, Yoga Session with Angela Rodrigues (Owner, Kinestraining), Light Saber Stunt Training with E.D.G.E. of Orion and Constellation Project founder Orion Couling, and a Dance Training/Party with Holly Lindsay.

NADS would like to thank all the amazing Presenters, Exhibitors, Keynote Speakers, Volunteers, and Committee Members that helped make this event happen. Our greatest gratitude goes to all the attendees who came to learn more about our community and how to better the lives of our loved ones. When we gather together we know we can make a difference in our own lives and those around us.
Bentley Wayne Reese, of LaCrosse, Virginia, was born on March 7th at Henrico Doctor’s. We were aware that Bentley had Down syndrome and a heart defect as it was identified earlier in the pregnancy. Bentley was born with AV Canal Defect as well as a hole between the top two chambers and the bottom two chambers of his heart. These defects would not heal on their own and would require open heart surgery to repair. The hope was that he would be able to come home and have the surgery when he was approximately 3-4 months old. While every child is different, we did have some experience as our niece, Kirsten Lauren Reese, was born with Down syndrome and required open heart surgery when she was less than a year old. She has done well and recently celebrated her 24th birthday! However, after Bentley was born, the doctors decided he would not be able to be discharged. He wasn’t able to leave the Henrico Doctor’s NICU until he was transferred on April 26th to UVA in Charlottesville, VA. Bentley had surgery on May 14th and it was a success! He is home now and continuing to recover and get stronger. Our family decided to sell bracelets as a fundraiser while Bentley was in the hospital. One, we wanted to raise money for Bentley’s mom — Haley Lunceford — to use for expenses while she stayed with him in Charlottesville and to care for him now that he’s home. Secondly, $1 from the sale of each bracelet would be donated, in Bentley’s name, to The National Association for Down Syndrome. Lastly, we want as many people as possible to wear these bracelets in honor of, and in prayer for, Bentley and others with Down syndrome and congenital heart defects. The response was overwhelming and continues. It was such a great feeling to be able to pick up the cashiers’ check from our local bank for the donation and have Bentley take his picture with it.

#TeamBentley

Teen & Adult Conference

Saturday August 11th was the NADS Teen and Adult Conference. 25 participants rotated through a wide variety of workshops so that everyone got to do it all! Our Self Advocates (Ryan Burke, Julia Smarto, Bridget Brown, Kelly Neville, Jacob Shimanek, Rachel Giagnorio, Jacob Spenadel, Sarah Bak, Erika Kissel, Lindsey Pazerunas, Thomas Kouros, and Adrian Drower) were busy throughout the day introducing speakers for the main conference. We started the morning with Rob Snow’s incredible improv group. The participants got to use improvisation to learn about communication and social cues. Angela Rodriguez led a relaxing yoga class and everyone got to take home their yoga mat and a box of yoga cards to help them continue their practice. Our final morning session was a rousing dance class taught by Holly Lindsay. We broke for a tasty box lunch and watched some funny video shorts while we ate. After lunch we learned about the impact of media and advertising from Katie Driscoll and talked about the importance of self-advocacy with Kayla McKeon. We saved the wildest for last and ended our day by learning some lightsaber moves from Orion Couling. In the words of our participants the day was “super cool and awesome!”

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

Orion Couling gives lightsaber lessons to teens and adults
My Little Sister

Caroline Himli-Seelbinder, 10 years old

My little sister Laura has Down-Syndrome. That means she has an extra chromosome and is different and special.

I’ll tell you how she is different. Her nose is smaller and she can’t talk that well. People with Down-Syndrome’s eyes are spaced different. Laura has to wear glasses to help her see better.

People with Down-Syndrome have shorter arms and legs. That is how Laura and other people with Down-Syndrome are different!

Laura likes dancing and singing. She is actually in dance class just like my other sisters and I! She loves it!

Laura doesn’t like loud noises. She has to wear headphones when we go to dance competitions, the fair, etc...

How I describe Laura is funny, cute, helpful, nice, sassy and joyful! Laura is so cute when she is sleeping!

Laura has a lot of friends! There is this one girl at school and she is Laura’s best friend! They play alot together! And this girl loves to help Laura. Laura loves school! I can tell because this year when it was summer she kept asking school? School? School? Laura goes to summer school for either 1 or 2 weeks in the summer.

Laura’s favorite food is spaghetti, and her favorite color is red. Her favorite number is 8. She loves cookies! Sometimes people don’t know what Laura is saying. I know exactly what she is saying most of the time! When my mom doesn’t know what she’s saying she asks me and I know what she’s saying! It’s like we are twins!

Laura is 8 years old and her whole name is Laura Johanna Himli-Seelbinder. Her birthday is June 17th 2010.

My favorite thing to do with Laura is wrestle! She wins all the time. She is really strong! I also like doing tickle fights with her!

How people with Down-Syndrome are the same as other people is their feelings and emotions are the same. Also they like doing the same things and their senses are the same.

Laura prefers cats over dogs and loves chickens and ducks!

Laura is awesome! Everyone should have a friend who has Down-Syndrome!

Movie: Far From the Tree

Linda Smarto, NADS Director of Programs and Advocacy

Andrew Solomon, Ph.D., New York Times best selling author is an award winner writer and lecturer on politics, culture and psychology, winner of the National Book Award. The Far From The Tree documentary, based on his book which began showing in select theatres throughout the Unites States on July 20, 2018. The film explores the struggles and triumphs of being different.

Andrew Solomon was most recently interviewed with Megan Kelly from the Today Show and has also worked with Katie Couric, Ted Talk and so many others. It was truly a privilege to represent NADS and moderate the post screening of Far From The Tree on Saturday, August 18, 2018 at Chicago’s Landmark Century Centre Cinema.

I was happy to have three of our NADS Self-Advocates (Adrian Drower, Kelly Neville and Julia Smarto photographed) with their families there to join us. Complimentary books were given to the audience and following the Q&A, Andrew met with the viewers, signed his books and welcomed photographs.

It was a “Feel Good, Must See” movie for all. I have to say from a parent’s perspective, I think Andrew Solomon was “on point” in making this documentary. I found it to be very empowering, uplifting, inspiring, emotional, realistic, funny, relatable and respectful. What I liked most about this film, is it will definitely help promote education, awareness and inclusion for all.

If you have a chance to see it, I would highly recommend it. The show begins and ends with Emily Perl Kingsley (wrote Welcome to Holland) and her 41 year old son, Jason Kingsley, who has Down syndrome.
Ryan Burke
NADS Board Member & Self Advocate

Ryan Burke has two significant attributes: he never quits and he never complains. These traits have led him in life to personal enjoyment, accomplishment, and an ambition to do even more.

Ryan has achieved many goals, but has new ones to achieve. He wants to drive, to have a credit card and to be a producer of a Broadway show.

From an inclusive grammar school education, Ryan became the first student with Down Syndrome to enter Notre Dame College Prep High School. Through four years, he was included in most high school classes, was on the swimming team and led the marching band. Ryan was also the first Burke Scholar graduate of Notre Dame.

After high school, Ryan was accepted into the ELSA Program at Elmhurst College. He graduated in June, 2017. College was his greatest challenge, both academically and in navigating the campus, his classes and activities by himself.

In his final year, Ryan participated in the “Teaching Together” program as an intern at Notre Dame College Prep. He was subsequently hired by Notre Dame and now works three days per week. His work includes general office, library and clean-up duties. With four empty days in the week, Ryan is searching for another job. Ryan may have the record for seeing “Mama Mia, the musical” nine times. His favorite city is New York, and his favorite street is Broadway. Once there, he insists on dinner at Ellen’s Stardust Diner, where the wait staff sing songs from musicals. Ryan also loves to travel with his family. He has been throughout Europe and the U.S. His next destination: Africa.

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Doctor’s Corner

Erin B. Dominiak, M.D.
Adult Down Syndrome Center, Director of Medical Education

As school is starting up again and the season is about to change, it’s a good time to think about transition of routine, including sleep. We recommend using visual calendars and checklists to keep organized and promote independence. Good health requires consistent and adequate sleep time. We recommend getting at least 8 hours of sleep per night (some people require more) and including this on the schedule. Be aware that “sleeping in” more than 30-45 minutes on the weekends may result in difficulty getting up in the mornings on Mondays. Please also be aware of the very high rate of sleep apnea in people with Down syndrome and talk to your medical provider about any sleep concerns; there are newer ways of diagnosing (home tests) and treating (Inspire implantable device) sleep apnea and even if some of the more involved treatments are not immediately pursued, there may be other advice that can help. Enjoy the end of summer and getting prepared for the transition ahead!

Memantine Research Study

Linda Smarto

On Tuesday, July 17th, some of our NADS members attended the Memantine Research Study that Sandy Pazerunas organized and Ups for Downs hosted. Dr. Alberto Costa of Case Western Reserve School of Medicine, presented and gave a wonderful and informative presentation. Dr. Costa shared memantine’s effects on learning and memory in older teens and young adults with Down syndrome.

The memantine research study has been approved by the University Hospitals Cleveland Medical Center Institutional Review Board (IRB). The study will include 100 participants with Down syndrome, ages 15-32 years. In partnership with the Advocate Medical Group Adult Down Syndrome Center and Dr. Brian Chicoine, the study would require visits to Cleveland Clinic and potentially one visit with Dr. Chicoine at the Adult Down Syndrome Clinic in Park Ridge, Illinois.

If you are interested and didn’t have the chance to attend, please contact the study coordinator, Melissa Stasko, at melissa.stasko@case.edu.

Get More Doctor Tips & Recommendations

Did you know that the Adult Down Syndrome Center and Dr. Chicoine have an E-Newsletter? You can sign up by going to this link: http://eepurl.com/c7uV1v. Sign up to receive emails with information on health topics for adolescents and adults with Down syndrome, updates about research and education, and information about upcoming programming. The ADSC sends 1-2 emails per month that include information on the above topics.

They also have resources and information about programming on their Facebook page and website. The links are below.

Facebook: www.facebook.com/adultdownsyndromecenter
Website: www.advocatehealth.com/health-services/adult-down-syndrome-center

If you have any questions regarding sign-up, please contact Laura Chicoine at Laura.Chicoine@advocatehealth.com or (847) 318-2368.
We are excited to be in the planning stages of the 13th Annual NADS Fashion Show, Shine Bright Like A Diamond, which will be held on Sunday, October 28th from 10:30-2:30 at the Donald E. Stephens Convention Center in Rosemont. While many aspects of the show will stay the same, we are excited about some of the fun and new aspects of the show! If you are interested in being a model, we are looking for individuals of all ages to participate. Models can be escorted down the runway, so babies are always welcomed! Please contact fashionshow@nads.org for information on how to become a model by September 1st. If you are interested in attending the show, tickets are now on sale now! $65 for adults & $40 for children 10 and under, $600 for tables of 10 and $1,000 for a runway table. Please visit www.nads.org to purchase tickets. Online orders are the only way to obtain tickets. We are also looking for volunteers to be a part of our Fashion Show Committee, so if you are interested in helping, please contact us! We are looking forward to welcoming back past families as well as new faces. Together we can spread the word of how individuals with Down syndrome shine bright like diamonds! Hoping to see you all in October!
OT Tips
Katie Frank, PhD, OTR/L

Did you know that we have been using sensory strategies at the Adult Down Syndrome Center to address mental wellness? Individuals we see come in with anxiety, sometimes in general and sometimes because of impending medical procedures. Our OT has been using trials of various sensory strategies to help address their anxiety. For instance, we had a patient at the clinic who needed to get his blood drawn. Mom reported that her son often requires two security officers to assist him with a successful blood draw. He met with the OT for about 30 minutes before his blood draw. She tried some joint compression and vibration. Ultimately he laid down on the exam table under a weighted blanket for about 15 minutes. The OT asked Mom to report back to her after the blood draw to see if anything was different as a result of the sensory input. Less than 30 minutes later, Mom was standing in the OT’s office saying that her son walked into the room to get his blood drawn, held out his arm, allowed the phlebotomist to draw blood, and even held the cotton ball down so a Band-Aid could be placed on his arm. Security even questioned why they had been called. Mom was so surprised that the blood draw had been such a success! It seems logical that calming techniques such as joint compression and the weighted blanket should work, but that doesn’t always mean they do. In this case, our patient received adequate amount of sensory input to calm his body enough to tolerate having his blood drawn. These techniques may also work for dental appointments, haircuts, and shots to name a few. If your loved one has anxiety with procedures, perhaps mention it to your OT to see if there are sensory strategies that can be implemented. As always, Katie is available at the ADSC if you have any questions!

Meet Matteo

My name is Mario Matteo Zurita, everybody calls me by my middle name Matteo. I am 5 years old. I have 2 younger brothers Milan is 3 years old and Marcus is 3 months old. My parents are from Ecuador and we speak Spanish and English in our home. I understand both languages! I love to learn, play, dance, walk to the park and play there, go to the Children’s Museum, and swim. I was born with Down Syndrome and I have been very healthy. I also wear glasses and sometimes get ear infections. I can say over fifty different words, but my words are not always easy to understand. I use other ways to communicate. I use many different signs and sometimes combine signs to make phrases. I also use an Accent communication device to express my ideas and interact with my friend and grown ups.

I’m just starting kindergarten this fall and I’m really excited to learn and meet new friends and ready to rock my extra chromosome!

So Proud
Jamie Mumber

My daughter, Grace Sanchez, is going to be starting her second year of high school! Last year was her first year at Belvidere North and I was a nervous mom about releasing my daughter into a great big high school that treats her like any other student. They gave us her schedule and I felt like we were walking miles trying to find each classroom. She’d brought all kinds of fun stuff to put in her locker (shelving, magnetic mirror and pencil holder, etc.) After finally finding her locker, it became apparent her actually operating the combination lock was going to be quite the challenge. Over and over again we tried and she just couldn’t do it. I sought out the principal and was told an aide would be available to help her.

Fast forward to this year and school orientation for her second year at the high school — after just the second try, I was standing in the hallway in tears because she successfully opened her locker! She closed it, tried again, and there again it opened. SO PROUD!!

I am so grateful for my daughter who continually reminds me how special even the smallest accomplishment can be!
Have you seen the Adult Down Syndrome Center Facebook page and website?

We share information about a variety of health topics related to Down syndrome, ADSC news, and upcoming events.

Like us on facebook by going to: www.facebook.com/adultdownsyndromecenter

Visit our website at: www.advocatehealth.com/luth/health-services/adult-down-syndrome-center

Check out our resources:

Watch Videos...
Sign up for our email list...
and more!

Questions or feedback? Please contact Laura Chicoine, Project Manager, Research and Education, at (847) 318-2368 or laura.chicoine@advocatehealth.com
FAMILY Album

We Want YOUR Photos!
Send your Family Album photos to NADS!
info@nads.org

Natalie H. and her family
Giuliana R. and her mom Angela

Jack B.

Allison H. and brothers Naethan and Lucas

Jane K.
Where is NADS going?
Katie Wood, President – Board of Directors

Over the past several months since Diane Urhausen’s sudden departure “Where is NADS going?” I want to be clear with everyone that the direction of the organization has not changed. Since January, the Board of Directors has taken the opportunity to dive deep into the internal office processes of the past and build an even deeper understanding of the past day-to-day operations. During this period, the Board has found many areas of improvement in both daily office tasks, operational efficiencies and administrative based cost-saving measures. The Board of Directors is committed to implementing meaningful and impactful change which will further the organization’s ability to serve the Down syndrome community and their families.

Since January, we have worked diligently to build a staff that is committed and capable of furthering the organization’s mission. Linda Smarto stepped into the role of Director of Programs and Advocacy. She is excelling in her new role, expanding program reach and families impacted by the organization. Linda sits on many committees and is working very closely with the Board on implementing changes where necessary. Chris Newlon, our Family Support and Outreach Coordinator, has provided resources to many new families, implemented additional structure in the Basket Program and updated many resources. Chris also spends time matching Spanish-speaking families with our dedicated bilingual volunteers to provide ongoing parent support.

As the Board of Directors has continued to make strategic changes, we parted ways with Roselia Correa (Hispanic Outreach Coordinator) and Debbie Taus-Barth (Development Coordinator) in July. They both dedicated many years to NADS and we are grateful for how they’ve impacted the community. NADS has been and will continue to serve the Hispanic Community and expand our presence into Chicago proper and beyond the Chicago suburbs. Chris Newlon and Linda Smarto are working with our bilingual volunteers and identifying opportunities to partner with community organizations to expand this reach. Deb Kracik continues to work as NADS’ Bookkeeper and Office Assistant processing all financials, assisting the Programs team with materials and being the first point of contact for many.

The Board of Directors is very excited to introduce Jill Sterling as our new Development and Communications Coordinator. Jill joins NADS with 25 years of experience in Development, Communications and Public Relations, of which the last 13 years has been spent working in the Not-for-Profit sector. Jill’s background includes working with the Ronald McDonald House Charities in both Development and as the Director of Public Affairs for 11 years. She is most proud of raising the over 30 million dollars needed to open the largest Ronald McDonald house in the world, located right here in Chicago. She also spent 2 years working at WINGS as their Manager of Communications writing newsletters, annual reports, developing branding strategies and coordinating all media relations. We are very excited to have Jill join the NADS family and look forward to everyone meeting her.

Moving forward, below is a list of a few new and exciting enhancements:

- Full-color print newsletter for NADS members that request it. There will also be an option to receive an electronic version of the same newsletter right to your email! Please make your selection when renewing your NADS membership at www.nads.org/membership
- The online NADS merchandise shop has launched. All merchandise can be purchased online and will ship directly to you or your family and friends. Visit www.nads.org/shop
- Everyone on NADS email list will begin to receive a monthly e-Blast with updates on events, programs, resources and more! If you’re not already receiving emails from NADS, you can join the list at www.nads.org/contact-nads
- Our events will continue to feature updated looks, locations and other exciting enhancements
- The Adult Down Syndrome Center (ADSC) and National Association for Down Syndrome (NADS) are partnering to offer new programming to support families of loved ones with a diagnosis of Down syndrome plus a secondary diagnosis (i.e. autism, ADHD etc.). Please complete this survey if you have previously participated in the More than DS Retreat sponsored by NADS or have a loved one with more than DS.

SURVEY LINK: www.surveymonkey.com/r/WL8MPKC

Your responses will help inform new programming. Replying to this survey does not commit you to participate in these sessions. There are 7 questions and the survey should not take more than a few minutes to complete. Thank you in advance for your participation.

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

www.nads.org

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Make checks payable to NADS and send to: 1460 Renaissance Drive, Suite 102, Park Ridge, IL 60068

NADS Member: $50.00 (Annually recurring) Receive NADS News & NADS E-Blasts
NADS Patron: $10.00 (Monthly recurring) Receive NADS News & NADS E-Blasts
NADS Benefactor: $250.00 (Annually recurring) Receive NADS News & NADS E-Blasts

Category of Membership (check one):
- NADS Member
- NADS Patron
- NADS Benefactor

Phone (home):

Phone (work):

Email:

Address:

City:

ZIP:

State:

Name:

Consider This:

MATCHING GIFTS:
- Consider donating to NADS in memory of a loved one. Ask your employer if they will match your generous donation to NADS.

MEMORIALS:
- NADS has been helping others for over 20 years. Consider giving a donation in NADS’s name in memory of someone who has been helped by NADS.

E-MAIL LIST:
- Please add me to the NADS e-mail list.

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 will match your generous donation 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 to learn more.

JOIN NADS online at www.nads.org... or use the mail-in form below...

Don’t let this be your LAST ISSUE OF NADS News?

BECOME A NADS MEMBER NOW at www.nads.org!