



# Down Syndrome News

NEWSLETTER OF THE



Special 2018 Year-End Extended Edition

## Introducing The National Down Syndrome Congress Center for Outreach & Education

2018 has been a monumental year for the National Down Syndrome Congress and a year of growth for our organization. The NDSC extended beyond our normal reach to provide support to communities across the country that may not have therapies, programs, and resources readily available.

The National Down Syndrome Congress realizes that not everyone has access, whether because of employment, location, transportation, or socio-economic barriers, to the quality programs and resources they need for their family member with Down syndrome. This year, the NDSC has embarked on a mission to bring critical education and support to areas with significant health disparities through The NDSC Center for Outreach & Education.

This Center, our largest initiative since the launch of our Annual Convention, partners the NDSC with organizations across the country to provide outreach to underserved rural, tribal, and urban communities. In addition, we will be changing school systems nationwide, by taking our acclaimed Educator Conference on the road.

In the past 5 months, we have served close to 300 families in West Michigan and Bakersfield, California (which included translation services for rural Spanish-speaking farmers) through Rural Outreach Summits. In addition, we already have requests for Rural Outreach programming from Alabama, Alaska, Arizona, Connecticut, Georgia, Ohio, Iowa, Indiana, Illinois, Virginia, and West Virginia and anticipate that requests will double within the next 12 months.

## You Can Help Us Change Lives!

Help us make a difference in 2019! There are so many families across the country in need of support and that's where you can be our partner. To see all that the NDSC Center for Outreach & Education will provide, and to make a 2018 Year-End donation, log onto our website at [www.ndsccenter.org](http://www.ndsccenter.org). Click Support, Join, Be Involved, and then click Year End Giving.



### In this issue:

Letter From the President.....	2
New Board Members.....	3
We Reached for the Stars .....	4
Awards and Honors .....	5
LuMind RDS Clinical Trials Network.....	6
Self-Advocate Spotlight .....	7
NDSC Movers and Shakers.....	8
NDSC in Action .....	9
2018 Convention Photos .....	10
Get Ready for #NDSC2019 .....	14
Meet Our New Staff Member ...	15
Lifetime Membership .....	15
Shop for NDSC Gear.....	16
2018 Convention Recordings ...	16
What's Happening in Washington, D.C.....	17
Get Involved with NDSC.....	18
NDSC en Español .....	19

# Letter From the President



Dear Families,

The NDSC team did an outstanding job, bringing a one-of-a-kind convention to Dallas! We had inspiring keynote addresses from Dan Habib and J. Frank Stephens, an impressive array of workshops, and many opportunities to dance and meet new people. I think that all the attendees left feeling educated, prepared to advocate, empowered and inspired. We are already working hard on next year's convention and I am so excited that you'll be coming to my hometown — Pittsburgh, PA.

Of course, we are working on a lot of projects outside of the convention too. We have launched our Rural Outreach Program and announced our new Silver Star Lifetime Membership level. In addition, in 2019 we are taking the Educator Conference on the road and are planning a great lineup of Parent Webinars. Don't hesitate to reach out to the Center if we can help you in any way.

Take care,

Kishore

## Your Opinion Matters

As the staff and Board of Directors begin making decisions for the future of our organization we are calling on you to provide feedback and share your opinions. To help guide our 2019 goal setting and strategic planning, we are conducting a survey which will provide you with an opportunity to share your thoughts on the programs and services we offer. Your feedback will help guide us as we move forward.

Thank you in advance for your input. We value and appreciate your assistance as we move into our 47th year

as one of the world's leading sources for Down syndrome information, advocacy, resources, and support. The link to the survey can be found in an email sent to all constituents on November 21, 2018. If you did not receive the "Your Opinion Matters to Us" email in your email inbox please check your junk or spam folder or email [ndsc@ndsccenter.org](mailto:ndsc@ndsccenter.org).

All individual confidentiality will be maintained. Please complete the survey by January 4, 2019.

## Down Syndrome News

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### Mission

The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

### Vision

The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

### Statement of Policy and Disclaimer:

This newsletter reports items of interest relating to Down syndrome and provides a forum for others. The NDSC does not promote or recommend any therapy, treatment, etc. NDSC will not espouse any particular political or religious view. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. The National Down Syndrome Congress works to educate, advocate and empower. We are the leading national resource of support and information for people seeking to learn about Down syndrome.

The editor reserves the right to make corrections as are appropriate and in accord with established editorial practice in material submitted for publication. Submitting an item to the editor to use in DSN gives permission to do so.

### Reprints From DSN:

We invite editors of other newsletters to reprint items from *Down Syndrome News*, provided proper credit is given to the source. Please delineate clearly the material you are reprinting and indicate that it comes from *Down Syndrome News*, newsletter of the National Down Syndrome Congress, 30 Mansell Court, Suite 108, Roswell, GA 30076, [ndsccenter.org](http://ndsccenter.org)

Please note that for material which the DSN reprinted with permission you must contact the original source.

### Board of Directors:

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Valerie Williams

*The Annual Membership meeting was held Friday, July 13, 2018, in Dallas, TX. During this meeting, members were updated on the work of the Congress over the past year and new officers were elected to the Board of Directors.*

## The New Faces on Our Board of Directors

At our mid-year board meeting, we elected new board members, as well, we welcomed a self-advocate who was elected by her peers and Mitch Rothholz and Sean Smith were both elected to a second term.

**Zachary Carroll** is a long-time NDSC Convention attendee and volunteer, having served as a leader of the Brothers & Sisters Conference for several years. A Corporate Strategy Senior Associate living near Washington, D.C., Zach helped to start the regional chapter of Capital One's business resource group for associates with disabilities. In addition, he has volunteered with both Special Olympics and Best Buddies. Zach has an adult sister, Lainey, who has Down syndrome.



**Andrea Holmes, RN, BSN, CMSRN**, of Dalton, GA, and her husband, Shaun, are parents of seven-year-old Gavin, who has Down syndrome. Professionally, Andrea serves in several roles at Chattanooga,



Tennessee's Memorial Hospital. Previously, she served as president of the Chattanooga Down Syndrome Society. Andrea has also moderated an NDSC Sharing Session for Parents of Only Children at two prior conventions.

**Megan Smulski**, of Pittsburgh, PA, serves as Associate Athletic Director, Major Gifts at the University of Pittsburgh. She and her husband, Anthony, have two children, including three-year-old Cameron, who has Down syndrome. Megan is a Board Member of the Down Syndrome Association of Pittsburgh.



**Mary Warm**, of Kansas City, MO has attended the NDSC Convention's Youth and Adult Conference for many years. She works in Early Childhood Education, after completing a post-secondary program.

As we welcome the new members to NDSC leadership we want to thank the Board of Directors members whose terms have come to an end. Many thanks to **Carole Janine Guess, Raymond Jancso, Nadine Maes, and Jessica Smart** for their service to the NDSC. Each was presented with Board Service Awards while in Dallas.



# We Reached for the Stars

Dallas was a welcoming host city and our families and friends had experiences that they will not soon forget. From start to finish, all four days were jam-packed with opportunities to learn from the very best lineup of speakers. The exhibit hall was filled to maximum capacity and attendees were able to network, socialize, and dance the night away!

A focal point of the convention was the Hall of Stars. Located in the main walkway that leads to the convention center, the exhibit featured beautiful stars, suspended from above, that were decorated by individuals, families, civic groups, affiliate organizations, and corporations.

This year also featured the first-ever Hall of Stars Art Exhibition and Auction. The nearly 110 art entries were narrowed down to 51 exceptional entries that were exhibited in Dallas. Entries were featured in a digital auction and 10 of the pieces were part of a live auction at the convention's Star-Studded Gala.



## 321 Dance!™

Always a highlight of Convention weekend, this year's 321 Dance!™ did not disappoint. With DJ WillPower spinning the tunes, everyone danced the night away in their best western wear.





# Awards and Honors

The Annual Awards Winner Dinner honored our many award recipients from various award categories, culminating with a lifetime achievement award for Judy Martz. Judy served as an NDSC Board President and Member, as well as an NDSC Foundation Trustee over her more than two decades of involvement!

Awards were presented to the following:

## **Employer of the Year Award – Topgolf**

*For using your core values to create meaningful employment for individuals with DS*



## **Education Award – KinderFrogs**

*For providing an exemplary early intervention program for preschoolers with DS.*

## **Outstanding Affiliate Organization Award – Down Syndrome Association of Greater Richmond**

*For creating partnerships and programs for the DS community.*

## **National Media Award – The Mighty**

*For promoting stories that matter.*

## **Exceptional Meritorious Service Award – Libby Kumin, Ph.D., CCC-SLP**

*With deep appreciation for empowering individuals with DS to communicate effectively.*

## **Sig Pueschel NDSC Service Award – Susan Goodman, JD**

*For devoting your career to advocating for people with DS.*

## **Convention Service Award – Texas Host Committee:**

Ashford Rise School of Dallas (YMCA)  
DS Association of Brazos Valley  
DS Association of Central Texas  
DS Association of Houston  
DS Partnership of North Texas  
DS Association of South Texas  
DS Coalition for EL Paso  
DS Guild of Dallas  
KinderFrogs  
East Texas DS Group  
Eva's Heroes  
Friends of DS Houston  
Galveston Houston Families Exploring DS  
Green Oaks School  
Pan Handle DS Guild  
Red River Valley DS Society  
Rio Grande Valley DS Association



*In appreciation for your outstanding support of the 2018 NDSC Convention.*

## **Pueschel-Tjossem Memorial Research Award – Joaquín Espinosa, PhD**

*For improving the lives of persons with DS through research.*



## **Christian Pueschel Memorial Citizen Award – Christopher Bennett**

*For changing perceptions about people with DS and what they can accomplish.*



## **President's Award – Down Syndrome Medical Interest Group - USA**

*For providing support to medical professionals caring for individuals with DS.*

## **Lifetime Achievement Award – Judy Martz**

*With heartfelt gratitude for over two decades of leadership with the NDSC and the NDSC Foundation.*



## RESEARCH AND CLINICAL STUDIES

# LuMind Research Down Syndrome Foundation Launches the Down Syndrome Clinical Trials Network

Established in 2004, LuMind Research Down Syndrome Foundation (LuMind RDS) has awarded more than \$18M in research grants to fund groundbreaking projects at top academic institutions and biopharmaceutical companies leading to more than \$50M in concurrent funding from the NIH, industry and other sources. LuMind RDS-supported research has led to the discovery of 10 therapeutic targets, the development of 3 Down syndrome-specific assessment scales, 15 interventional and observational clinical trials with more than 1300 participants and the initiation of several consortia.

With a combined \$3M commitment from the Alana Foundation and biopharmaceutical companies H. Lundbeck A/S and AC Immune SA, the LuMind Research Down Syndrome Foundation (LuMind RDS)

is launching the Down Syndrome Clinical Trial Network (DS-CTN) across several sites in the United States. LuMind RDS issued awards to the following 11 clinical sites: Advocate Health (Chicago, IL), Barrow Neurological Institute (Phoenix, AZ), Case Western Reserve University (Cleveland, OH), Cincinnati Children's (Cincinnati, OH), Duke University (Durham, NC), Emory University (Atlanta, GA), Kennedy Krieger Institute/John Hopkins (Baltimore, MD), Massachusetts General Hospital (Boston, MA), UC Irvine (Irvine, CA), Rush University (Chicago, IL) and University of Kentucky (Lexington, KY). DS-CTN will leverage research best practices and data collection to accelerate clinical trials and to deepen the knowledge about Down syndrome. While initially focused on adults, the network will expand over time to include adolescents and children.

*"In the next 2-5 years, clinical trials with promising drugs and interventions may be underway that will eventually provide families with more options to improve the health and independence of their loved ones with Down syndrome," said, Hampus Hillerstrom, CEO of LuMind RDS, "DS-CTN is*

*modeled on the most successful clinical trials networks (such as Cystic Fibrosis Foundation's Therapeutics Development Network) and will include clinicians who are experts in providing care for individuals with Down syndrome. They will be patient-focused and enable the rapid enrollment of volunteers for industry and publicly funded clinical trials. We are very thankful to Alana Foundation, H. Lundbeck A/S, and AC Immune SA for their support and confidence as well as all the people involved in launching this effort."*



*"DS-CTN will allow the rapid advancement of new treatment options and facilitate the safe clinical evaluation of the most promising treatments and interventions. For people with Down syndrome, who have not been a research priority in the past, and for their families, having treatments and interventions to improve sleep, speech, cognition and prevent early Alzheimer's onset is long overdue and the DS-CTN network will speed up such progress," says Hillerstrom.*

For more information about Down syndrome research, please visit [www.LuMindRDS.org](http://www.LuMindRDS.org) and contact LuMind RDS at [JoinOurMission@lumindrds.org](mailto:JoinOurMission@lumindrds.org) to get involved.

Original Release: November 1, 2018

Marly Chevrette | LuMind Research Down Syndrome Foundation  
[mchevrette@lumindrds.org](mailto:mchevrette@lumindrds.org)

# SELF-ADVOCATE

## Spotlight: Chess Mitchell

Chess Mitchell is the National Down Syndrome Congress Administrative and Social Media Assistant. He assists with office duties such as building Family Care, Adult Sibling, and Advocacy Toolkits for Self-Advocates. Chess also writes the NDSC Movie Reviews. Before finding his home at the NDSC Chess tried out several jobs over the years. He has worked at a movie theatre as a ticket taker, at Toys R Us, Target, PetSmart and Chick-fil-A. Chess also spent time as a grocery stocker, but once he started working at NDSC, he found a place where he could blossom. He LOVES the opportunities afforded to him by his coworkers and his coworkers say that Chess brings a certain undeniable life to the NDSC Center. He brings a smile to the face of all that he meets. He is funny, kind, loving, and smart, while at the same time stubborn and laser focused when he is on a mission.

Along with his position at the NDSC Chess also works at Top Golf, where he has many other great experiences and opportunities. This past Fall Chess was invited to Arizona by executives at Top Golf to be a feature in a video to be used company-wide that showcases his talents and the company's inclusive atmosphere.

Chess has been a trailblazer his entire life. When Chess was very young his parents decided that a traditional childcare setting like they were using for their younger son was what they wanted to try for Chess. Chess was one of the first children with Down syndrome to be included in the chosen daycare setting. The teachers in the typical class had no experience with children with Down syndrome and were amazed at the help they received from the therapist who came to work with Chess and saw the benefit for ALL of the kids in the classroom. (This was a novel concept in 1985). This was such a new concept that the local paper ran an article highlighting Chess and his younger brother Jay.

Chess' family moved several times while he was growing up but when the Mitchells moved to Atlanta. Chess knew he was where he belonged. He quickly

blossomed beyond his parents' wildest dreams. Chess quickly made friends and learned of "Just People", a place where Chess participated in the Social Day Program. This quickly evolved to Chess' adamant desire to move out from his parent's home and into his own apartment. In 2006, Chess moved into an apartment with 2 of his best friends. He has since changed roommates and locations but has maintained residence with his friend "JP" the entire time.

Although Chess' parents have asked him to move to Florida, where they now reside, (they even tried to bribe him with large screen TV's, frequent visits to Disney World and even most recently, the opportunity to go back to college at the University of Central Florida Inclusive Education Program) Chess has decided that he does NOT wish to move to Florida. He said that he is living his best life right where he is and he cannot give up the great life that he has in Atlanta.

Chess texts, FaceTimes, and talks on the phone daily, with his family — sometimes several times a day! And while Chess' parents are sad that he is not living as close as they would like, they are IMMENSELY proud of his decision and his ability to self-advocate. When asked to comment on Chess' journey, his mother said, "I often tell new parents who are still processing the Down syndrome diagnosis, that they should be careful what they wish for. Thirty-five years ago, all we wanted was to know that Chess would grow up to have friends, and a job that he loves, and a place to live where he is happy. We NEVER intended it to be over 600 miles away!"





# NDSC Movers and Shakers!

## Advisory Council Member Receives Distinguished Award

Madeleine C. Will (pictured in the lower right of the photo), a member of the NDSC Public Policy Advisory Council and the founder and current Interim President of the Collaboration to Promote Self-Determination (which NDSC is one of the leading members), received the distinguished 2018 "Special Recognition Award" from the Association of University Centers (AUCD) on November 13, at the AUCD Convention Awards Celebration. This award is presented annually to an individual who has had a significant impact on the quality of life for people with disabilities. Madeleine was recognized for the body of her work that has had an enormously positive impact on people with disabilities, their families and the networks that serve them.



## A Decade of Dedication



Over the years many volunteers, board, and staff members have worked tirelessly to make the NDSC Annual Convention a place where the Down syndrome community comes together. This year marks our tenth convention with Convention Director Coleen Popp at the helm. Her passion, focus, drive, and creativity are a marvel to behold. To our attendees, each year everything falls seamlessly into place. But, the truth is that there are thousands of details and complexities that arise from each new location and each new program; and, believe it or not, unwelcome surprises that have to be handled on the fly. No matter what arises, Coleen remains unruffled and leads our team to a quick and appropriate resolution. She is the first to deflect any praise onto the rest of the team — and it's true that producing the Convention takes a village — but every successful team needs a great leader and we are so blessed to have Coleen as ours.

At the Star-Studded Dinner and Gala, Executive Director, David Tolleson presented Coleen with a gift of appreciation for her decade of service and unwavering commitment to NDSC.

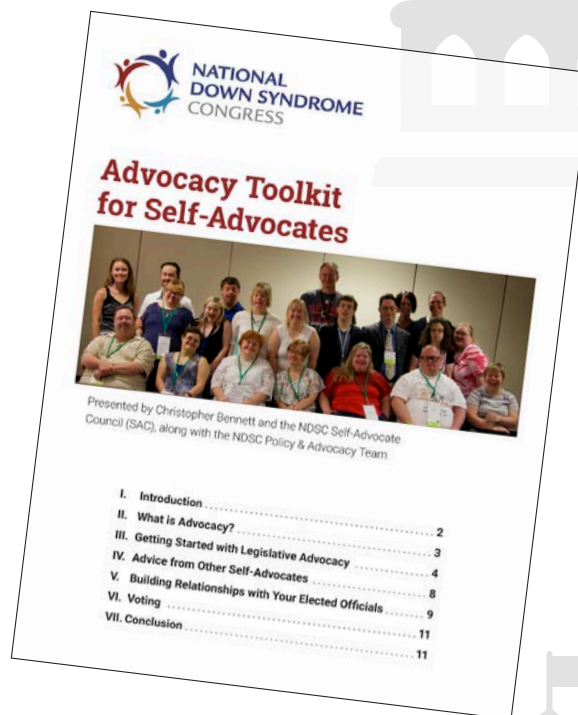


# NDSC in Action

## Advocacy Training Day

Our first Advocacy Training Day was a huge success with over 175 participants. It was a packed room full of eager advocates who are just beginning their policy journey. Lead by the NDSC Policy & Advocacy Team, Stephanie Smith Lee, Ricki Sabia, and Heather Sachs, sessions included basic government processes, panel discussions, interactive activities, and calls to action.

During the Advocacy Training Day, Christopher Bennett unveiled and presented his **Advocacy Toolkit for Self-Advocates**. For months before the convention, Christopher worked with the NDSC Policy and Advocacy team to create this useful toolkit that includes information on how a bill becomes a law, tips when meeting with legislators, ways to become involved, and much more. Each Advocacy Training Day participant received a hard copy. This toolkit contains valuable information for self-advocates or anyone interested in beginning advocacy. You can find a downloadable copy of the **Advocacy Toolkit for Self-Advocates** on the NDSC website under the Policy and Advocacy tab found at the top of the homepage.



## Educator Conference on the Road

In 2016, the NDSC presented its pilot Educator Conference at our Orlando Convention. This Conference provided educators with best practices, resources and other tools to effectively support their students with Down syndrome in the classroom. Each year since, at the NDSC Convention, professionals have participated in this specialized training, and are currently utilizing the skills they have learned to support thousands of students with Down syndrome and other disabilities in school systems across the nation, and internationally.

We realize that not all educators can attend our annual convention, so we are taking our Educator Conference on the road! The NDSC will present one-day Educator Conferences across the country for teachers, para-professionals, administrators, educational diagnosticians, and therapists who serve individuals with Down syndrome

and other intellectual disabilities. The curriculum is appropriate for both general and special educators. The specialized training covers reading intervention, technology innovation, and positive behavior strategies that promote meaningful inclusion in general education classrooms. Attendees will walk away with six continuing education unit hours and dozens of hands-on activities that have proven results for Kindergarten through 8th grade classrooms.

For more information visit [www.ndsccenter.org](http://www.ndsccenter.org). Click on the **NDSC Centers** tab at the top of the homepage and in the drop-down menus click **Center for Outreach and Education**.

# 2018 Convention



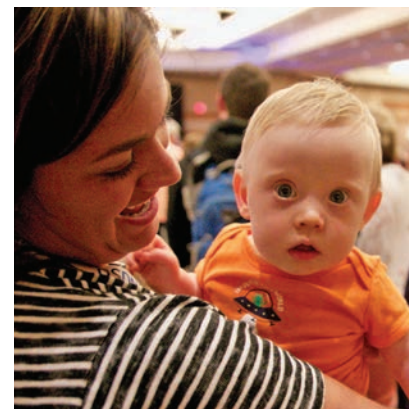
**"As always, NDSC organizes an amazing convention!! Thanks so much to everyone for the hours and hours put into organizing this! We appreciate it!"**

*– C. Griffith*



**"It was so educational, encouraging, and refreshing to our family. Also thank you for giving us access to all the workshops!! That is a huge gift! We are ready to sign up for next year!!!"**

*– L. Carver*



**"This has been amazing! It was a great event to the... this has been successful... could not..."**





been perfect,  
 From the cocktail  
 the gala and auction,  
 been a huge and  
 week for us, we  
 be happier!"

– John Poston, Daymark Living



"What an amazing experience!  
 I will never forget it and left  
 with so many new friends  
 and knowledge!"

– J. Dykstra





# Thank you to all of our 2018 Convention Sponsors

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Down Syndrome Association of Minnesota





# NDSC 2019 Convention Sponsorship Opportunities

The NDSC could not reach and serve the vast number of families that we do without the financial support of businesses and individuals, personally and professionally connected to our organization. These sponsorship dollars allow us to keep the cost of attending the NDSC Annual Convention at a minimum. In fact, sponsorship funds help keep the attendee costs at less than 50% of our actual convention costs.

NDSC Convention sponsors reach thousands of families, professionals, and service providers from the Down syndrome community. The 2019 Sponsorship Proposal includes sponsorship levels and opportunities for every budget and packages are customizable to suit the needs of your organization.

If you would like to discuss sponsorship options, contact NDSC Development Director, Kathy Edwards, at [kathy@ndsccenter.org](mailto:kathy@ndsccenter.org).

## We Need You!

### As We Prepare for World Down Syndrome Day 2019 We Need Your Photos & Quotes

We are gearing up for our 2019 "21 Quotes in 21 Days" campaign. We had such great feedback last year, that we will again be posting on Facebook, Twitter, and Instagram every day leading up to World Down Syndrome Day — then culminate with a slideshow on WDSO that we will share in the E-News and on all of our socials.

Are you a self-advocate with something to say? Send us your high-resolution photos, along with a quote, your name, city & state to [ndsc@ndsccenter.org](mailto:ndsc@ndsccenter.org). While we may not be able to use all the submissions in this campaign, you may see your photo on other social posts, in newsletters, or on the NDSC website!

## Do You Want to Be in the Spotlight?

Send us your original story or article and a picture and tell us why you think you should be considered for the next *Down Syndrome News* Self-Advocate Spotlight.

Send your original story or article to:

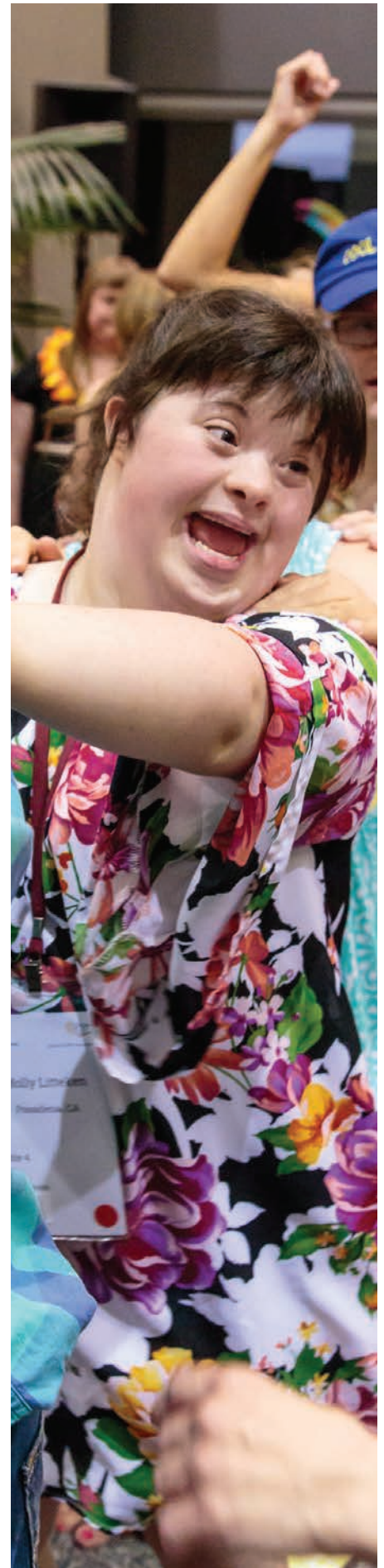
Editor, Down Syndrome News  
30 Mansell Court, Suite 108, Roswell, GA 30076

or

[ndsc@ndsccenter.org](mailto:ndsc@ndsccenter.org)

Please include your name, age, address,  
phone number, and email address.

Don't forget to include a picture!



# Get Ready for #NDSC2019 – Rivers of Opportunity!



## The 2019 NDSC Convention is Already Shaping Up to be an Event of Champions

Each year, thousands of people from across the globe attend the NDSC Annual Convention. For most, it's to hear the latest information from world-renowned experts. For others, it's a great vacation. However, for nearly all, there's the one-of-a-kind NDSC "giant family reunion" feeling that permeates the convention weekend.

The convention weekend is comprised of conferences, workshops, programs, and social events designed for parents, self-advocates, family members, professionals, and advocates. Because we offer something for everyone, pre and general conference workshops, Youth and Adult

conference, Brothers and Sisters conference, Kids' Camp, Advocacy Training Boot Camp, conferences and roundtables for professionals, Connection Receptions, dances and galas, registration for the event can sometimes be overwhelming. We have updated the About Convention page of our website to help attendees better navigate all that is available during our annual convention. Please take a moment to familiarize yourself with all of the conferences, workshops, and opportunities to engage with other families and professionals in the Down syndrome community prior to the open of registration on **March 25th**.



## Meet Our New Staff Member

In July, Matthew Fernandez was hired as the Multicultural Program Director for the National Down Syndrome Congress. Matt is a Cuban-American, born and raised in Miami, FL. A child of a Hispanic family, Matt has developed an understanding of Hispanic culture and looks forward to how he can apply that to his passion of working to help those who have or love someone with a disability.



Matt is responsible for delivering NDSC's programs and resources among numerous minority populations and generally promoting inclusion and diversity in the Down syndrome community. Additionally, he works with, develops, and supports NDSC's diverse network of affiliates and leaders, both domestically and abroad. Matt also oversees NDSC's Rural Outreach Program, partnering with local Down syndrome organizations across the U.S. to host a one-day conference, providing a full range of resources and services to populations that otherwise fail to receive adequate support.

Prior to joining the NDSC, Matt was involved with Best Buddies — an organization dedicated to establishing one-to-one friendships, integrated employment, and leadership development for individuals with intellectual and developmental disabilities. Matt was an officer for both his high school and college chapters. More importantly, Matt met his two best friends, John and Howard, both of whom have Down syndrome, through his involvement with Best Buddies. During his time working as an intern for Best Buddies, Matt helped with their conferences, special events, advisory boards, and development. Matt continues to volunteer for Best Buddies and was recently nominated as the Champion of the Year for Georgia as he works to help Best Buddies expand their mission there. Matt has also spent time with The Arc as a Supported Employment Specialist, where he helped numerous individuals with intellectual and developmental disabilities secure employment; and with the Special Olympics as a volunteer, and participant of their Play Unified movement.

During his time away from being a disability advocate, Matt enjoys spending time with family and friends, watching sports, and achieving his fitness goals. A graduate of the University of Florida, Matt received his degree in Education. He currently lives in Atlanta, GA and hopes to one day adopt a child with Down syndrome.

## Silver Star Lifetime Memberships



Become a Silver Star Lifetime Member and enjoy all of the perks that go along with it. The only prerequisite is that you must be 60 years of age or older. As a Silver Star Lifetime Member, you will receive:

- Lifetime Membership in the NDSC, with regular benefits that accompany membership (Member pricing for the NDSC Annual Convention; mailed Quarterly Newsletter, "Down Syndrome News"; mailed Annual Report; NDSC Monthly E-News and Newline; "Ages & Stages" E-News (targeted information sent via email throughout the year); NDSC National Advocacy; and 1 Voting Member to attend the NDSC Annual Meeting held at the Annual Convention)
- A beautiful, framed print of our 2018 winning art entry from the Convention's "Reach For Your Star" art competition (over 110 entries arrived at the NDSC office from across the United States)
- Early registration for the NDSC Annual Convention, prior to opening to the general membership
- A Silver Star ribbon to display on a convention name badge, denoting "Lifetime Member"
- Invitation to our annual pre-gala Cocktail Reception at the NDSC Annual Convention
- An annual gift, designed by an NDSC Self-advocate

The cost for Silver Star Lifetime Membership is a one-time membership fee of \$1,500 (if you have already paid your membership for this year, your fee will be \$1,450). To enroll, please visit our website and click on the "Support, Join, or Be Involved" tab at the top of the page, in the drop-down menu hover over "Join NDSC or Renew Membership" then click on the "Lifetime Membership"

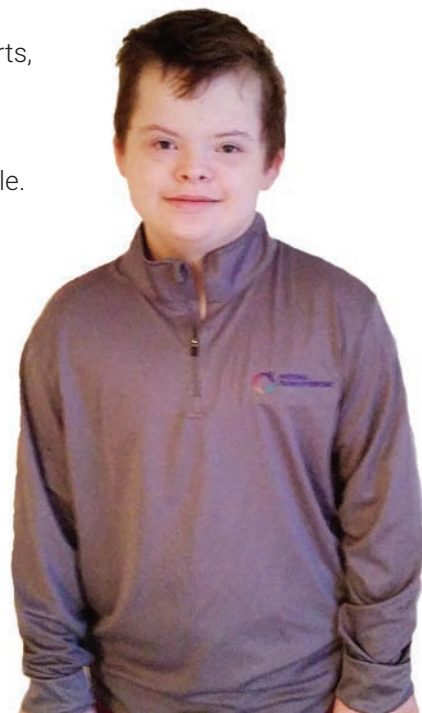
Questions? Please contact Kathy Edwards at 404-242-3640 or via email at [Kathy@ndsccenter.org](mailto:Kathy@ndsccenter.org).

# Shop for NDSC Gear

## You asked for it — You got it

Did you know that you can purchase NDSC t-shirts, jackets, sweatshirts, and even sleep pants?

Visit <https://squareup.com/store/NDSC/> to discover all of the great items that are available.



## Couldn't Make it to Dallas? You Don't Have to Miss Out on the Great Information.

Each year NDSC records a selection of general convention workshops and the plenary session. Don't miss an opportunity to hear self-advocate Frank Stephens' amazing keynote "Lives Well Lived" or filmmaker Dan Habib's inspirational message, "Disabling Segregation." Included in the package are 76 presentations by leading experts in the field of Down syndrome.

Recordings are hosted for NDSC by PlaybackNow. Current year conference recordings were included with current year convention registration. One access account for a Fast Pass is provided to the account holder of a registration that includes at least one general convention attendee.

For more details about the 2018 recordings or to purchase basic or upgraded packages visit our website, [www.ndsccenter.org](http://www.ndsccenter.org) — click on the "Annual

Convention" tab at the top of the home page, then "Workshop Recordings" in the drop-down menu.

For access to recordings included with convention registration — the account holder should go to PlaybackNow, Inc. and activate your account. You will need the email address and conference registration code associated with your registration. If you already have an account or have activated your new account, log in at PlaybackNow, Inc. using your email and password. If you forgot your password the login page includes a "Forgot Password" reset function.

For questions please contact [Jean@ndsccenter.org](mailto:Jean@ndsccenter.org).

### Get Social With Us!



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# What's Happening in Washington, D.C.

## Midterm Election Results Lead to Divided Congress

As a result of the midterm elections, the House of Representatives will shift from Republican to Democratic control in the 116th Congress, which will begin in January 2019. The Senate will remain under Republican control with an increased Republican majority. The party that has the majority of members in the House or Senate has substantial power to set the agenda, chair committees, and decide what bills will be considered for hearings and markups. The majority also has more members on each of the committees. The House has significant authority over appropriations and oversight of existing laws and regulations as well as oversight over the executive branch in general.

It is unknown exactly how this divided Congress will impact policy, but we believe that Congress will now be less likely to prevail in efforts to repeal the Affordable Care Act or to cut or significantly alter Medicaid. Continued ideological differences and partisanship could possibly lead to ongoing gridlock, but we are hoping instead that the new balance of power will lead to more bipartisan action.

## Sign up to receive our Action Alerts!

Receive timely, accurate information from the NDSC Policy & Advocacy Team and to magnify your voice. Signing up is free and takes less than one minute. On the NDSC website click on the "Policy & Advocacy" tab at the top of the homepage. In the drop-down menu click "Take Action & Stay Informed" — simply provide your name, email, address and zip code. NDSC will not share your personal information and will use it for advocacy communication purposes only.



## Get Involved – Let Your Voice be Heard – Join NDAC

The National Down Syndrome Advocacy Coalition ("NDAC") is a member service of the National Down Syndrome Congress ("NDSC"). NDAC is a grassroots advocacy service that is designed to educate individuals with Down syndrome, their family members, and other allies about policy issues and give them the advocacy tools and techniques they need to effectively engage with their legislators to advocate for change.

NDAC aligns with NDSC's purpose since its founding in 1973: to promote the interests of people with Down syndrome and their families through advocacy, public awareness, and information.

With this program, we bring together advocates of all abilities and levels of experience from across the country that have a passion for the Down syndrome community. Through NDAC's education, training

opportunities, and engagement on social media, we are cultivating a broad coalition of advocates who will be able to effectively engage with lawmakers, agencies and other key decision makers to promote policy change. This program works to involve and engage more advocates, including individuals with Down syndrome, their parents and other allies who support our community.

NDAC Members are advocates of all abilities and levels of advocacy experience. Anyone can become an NDAC Member by filling out the application and agreeing to the terms of membership found on the NDSC website under the Policy and Advocacy tab at the top of the homepage.



# The National Down Syndrome Congress Has Partnered With Kroger Community Rewards

The National Down Syndrome Congress is pleased to announce our partnership with more than 900+ Kroger and Kroger Family stores to allow our members, as well as their families and friends, to support the NDSC when shopping at their local Kroger stores, simply by using their Kroger Plus Cards. Using your Kroger Plus Card to support the NDSC does not affect your other Kroger programs such as Kroger Fuel Points. In order to support the NDSC through the Kroger Community Rewards Program supporters must have a registered Kroger Plus Card account online to be able to link their card to the NDSC.

Below are instructions for registering your Kroger Plus Card to partner with the NDSC.

## If you do not have a Kroger Plus Card:

- You can obtain a Kroger.com account by creating one online at [www.KrogerCommunityRewards.com](http://www.KrogerCommunityRewards.com) and clicking "Create an Account" or at any Kroger store.

## If you have a Kroger Plus Card but have do not have an existing Kroger.com account that you wish to link to the NDSC/Kroger Community Rewards Program:

- Visit [www.KrogerCommunityRewards.com](http://www.KrogerCommunityRewards.com)
- Click "Sign In".
- Follow the prompts to create an account.
- Once you have finished entering your information check your e-mail inbox and click on the link within the body of the e-mail to activate your Kroger account.



## If you have a Kroger.com account that you wish to link to the NDSC/Kroger Community Rewards Program:

- Visit [www.KrogerCommunityRewards.com](http://www.KrogerCommunityRewards.com)
- Click "I'm a Customer".
- Enter your email address and password then click "Sign In".
- In the "Find an Organization" field enter National Down Syndrome Congress
- Click "Enroll"

# All Kinds of Heroes Golf Tournament

Now in its second year, the National Down Syndrome Congress "All Kinds of Heroes" Golf Classic is excited to announce our 2019 Grand Marshall — Rachel Wilson.

The National Down Syndrome Congress invites you to join us for the 2nd Annual NDSC "All Kinds of Heroes" Golf Classic to be held on World Down Syndrome Day, March 21, at the beautiful Legacy on Lake Lanier Golf Course. Proceeds from the 2019 tournament will support educational programs for people with Down syndrome, their families and the professionals that serve them, provide free materials for communities, families and educators, new parent packages, rural outreach programs, and disability training programs for first responders.



The 2019 event will include golf, breakfast, lunch, dinner/awards party, a raffle, unlimited beverages of all kinds, in a "Bottomless Yeti," contests, and a chance to win a beautiful 2019 boat at one of our four Hole-In-One tournament holes! The event will also include a Fire Ball drop from the aerial ladder of a fire truck, for a cash prize!

Join our "HEROES" — firefighters, police officers, military, teachers and individuals with Down syndrome — in this special day as we putt with a purpose!

For more information, to register to play, or to view sponsor opportunities visit [www.ndsccenter.org](http://www.ndsccenter.org), click the "Support, Join, Be Involved" tab at the top of the home page, then click "Golf Tournament" in the drop-down menu.



# ¡Conozca a nuestro nuevo miembro del personal!

**Matthew Fernandez** es el Director del Programa Multicultural para el Congreso Nacional de Síndrome de Down (NDSC). Matt es un cubanoamericano, nacido y criado en Miami, FL. Hijo de una familia inmigrante, Matt ha desarrollado una comprensión de la cultura hispana y mira hacia delante cómo puede aplicar eso a su pasión de trabajar para ayudar a quienes tienen o aman a alguien con una discapacidad.



Matt es responsable de brindar los programas y recursos de NDSC entre numerosas poblaciones minoritarias y, en general, de promover la inclusión y la diversidad en la comunidad del síndrome de Down. Además, trabaja, desarrolla y apoya la diversa red de afiliados y líderes de NDSC, tanto a nivel nacional como internacional. Matt supervisa el Programa de Alcance Rural de NDSC, asociándose con organizaciones locales de Síndrome de Down a lo largo de los EE. UU. Para organizar una conferencia de un día, proporcionando una gama completa de recursos y servicios a poblaciones que de otra

manera no recibirían el apoyo adecuado.

Antes de unirse al NDSC, Matt estuvo involucrado con Best Buddies, una organización dedicada a establecer amistades uno a uno, empleo integrado y desarrollo de liderazgo para personas con discapacidades intelectuales y de desarrollo. Durante su tiempo trabajando como interno de Best Buddies, Matt ayudó con sus conferencias, eventos especiales, consejos y desarrollo de la organización. Más importante, Matt conoció a sus dos mejores amigos John y Howard, ambos tienen síndrome de Down.

Matt continúa siendo voluntario de Best Buddies y recientemente fue nominado como el Campeón del Año para Georgia mientras intenta ayudar a Best Buddies a expandir su misión allí. Matt también pasó tiempo con The Arc, donde ayudó a numerosas personas con discapacidades intelectuales y de desarrollo a conseguir un empleo; y con las Olimpiadas Especiales como voluntario, y participante de su movimiento Play Unified.

En su tiempo libre, Matt disfruta de pasar tiempo con su familia y amigos, ver deportes y ir al gimnasio. Un graduado de la Universidad de Florida, Matt recibió su título de Educación. Corrientemente vive en Atlanta, GA y espera algún día adoptar un niño con síndrome de Down.

## Instrucciones Para Participantes Del Programa Kroger Community Rewards:

El Congreso Nacional de Síndrome de Down se complace en anunciar nuestra asociación con más de 900+ Kroger y tiendas de la familia Kroger para permitir a nuestros miembros, así como a sus familiares y amigos, apoyar a la NDSC cuando comprando en sus tiendas Kroger locales, simplemente usando sus Tarjetas Kroger Plus. Usando su tarjeta Kroger Plus para soporte NDSC no afecta sus otros programas Kroger como Kroger Fuel Points. Para apoyar el NDSC a través de los partidarios del programa Kroger Community Rewards debe tener una tarjeta Kroger Plus registrada cuenta en línea para poder vincular su tarjeta al NDSC. A continuación encontrará las instrucciones para registrar su tarjeta Kroger Plus y asociarse con el NDSC.

### Si no tiene una tarjeta Kroger Plus:

- Puede obtener una cuenta de Kroger.com creando una en línea en [www.KrogerCommunityRewards.com](http://www.KrogerCommunityRewards.com) y haciendo clic en "crear una cuenta" o en cualquier tienda de Kroger.

### Si tienes una tarjeta Kroger Plus, pero no tienes una cuenta de Kroger.com que desea vincular al Programa de Recompensas Comunitarias de NDSC/ Kroger:

- Visita [www.KrogerCommunityRewards.com](http://www.KrogerCommunityRewards.com)
- Clic a "Sign In", si no, sigue las instrucciones para crear una cuenta
- Cuando termine de poner su información verá un mensaje que le pedirá que revise su buzón de correo



electrónico para después dar clic al enlace que estará en el mensaje que se le envió. Esto activará su cuenta de Kroger.

### ¿Ya tiene una cuenta en Kroger.com?

- Visita [www.KrogerCommunityRewards.com](http://www.KrogerCommunityRewards.com)
- Clic en "I'm a Customer"
- Escriba a máquina su dirección de correo electrónico y haga clic en "Sign In"
- Donde dice "Find an Organization", escriba a máquina "National Down Syndrome Congress"

## Down Syndrome News

is a benefit of your annual membership in the NDSC.

To renew or join, visit [ndsccenter.org](http://ndsccenter.org).

To update your contact information, call 800-232-6372 or email [info@ndsccenter.org](mailto:info@ndsccenter.org).

When we **empower** individuals and families from all demographic backgrounds, we **reshape** the way people understand and experience Down syndrome.



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## Down Syndrome News

A newsletter published throughout the year  
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## Thank You to our 2019 Early Bird Sponsors

