

# Down Syndrome News

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NEWSLETTER OF THE



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As we celebrate fifty years, we reflect on the magnitude of our work and the critical role NDSC has played to yield a world where:

- New parents are no longer counseled to institutionalize their children with Down syndrome but instead are educated on the importance of saving for them to attend an institute of postsecondary education
- The narrative has changed from a list of things that children with Down syndrome may never do to one of inclusion in education, sports, employment opportunities, and even marriage
- The life expectancy of those with Down syndrome is no longer a mere 20 years, but today well over 60

Our success has been driven primarily by private donations. The generosity of personal donors has allowed us to share priceless information with thousands of families, increase awareness to bring about policies that protect and provide opportunities, and create a more inclusive community that better understands and supports those with Down syndrome.

**In line with the Celebration of 50 Years of NDSC, a private donor will be matching all end-of-year contributions made before December 31, up to \$50,000!** The contribution of this very generous donor will double the difference your 2021 end-of-year contribution will make, allowing us to have a more significant impact on the Down syndrome community.

**Now, your end-of-year contribution will allow us to touch more lives!**

**DOUBLE YOUR DONATION NOW**



NATIONAL  
DOWN SYNDROME  
CONGRESS

Fifty years ago, the National Down Syndrome Congress set out to reshape the way people understand and experience Down syndrome and create a world that provides equal rights and opportunities.

***What we did was create a better world.***

## Letter From the President

Dear NDSC Families,

It is hard to believe that we are already preparing to wrap up 2021. As we approach the end of the year, I think that we can all agree that this year has been one of resiliency. I remain proud to be a part of an organization that does so much for the people who count on us. This year, we built upon what last year taught us and held a second successful virtual convention complete with speakers and digital learning. Again, our staff, volunteer board members, and community volunteers pulled together to address our families' needs. Our impact in Washington, D.C., continued to ensure that the rights of people with Down syndrome and other disabilities were protected and that they were cared for properly. Like last year, this year brought challenges to so many families, but these challenges allowed us to step up for our members like never before. Now, more than ever, we understand that our work is important and essential. The NDSC staff and Convention Planning Committee are hard at work planning and preparing with excitement as we take the 50th Annual Convention & Celebration "in person" to New Orleans, LA next June 23-26.

This convention also means a changing of the guard. Each year at the annual convention, we elect new members to the Board of Directors who serve a three-year term. My term as NDSC President will end with the 2022 election. I am honored to have served as your NDSC Board of Directors President. I will remain on the board serving in the capacity of Immediate Past President.

Although we are best known as the "Greatest Family Reunion" and see most of you once a year, please know that we are here for you 365 days a year to provide resources and support. No matter what lies ahead, know that the NDSC will continue to work with and for you to promote the interests of people with Down syndrome.

I wish you and your family a very Happy Holiday season and a healthy New Year! It is my pleasure and privilege to serve you and your family.

With Gratitude,



Shauntel Neal-Howe



## We Welcome the New Executive Director of the National Down Syndrome Congress

With great pride and excitement, the NDSC Board of Directors is pleased to announce that Jordan Kough will be the new NDSC Executive Director, effective January 3, 2022. After a thorough and intense search process that yielded highly qualified candidates from across the country, Jordan rose to the top with a robust portfolio of executive and development experience and the innovative vision to lead NDSC into this next chapter.

Jordan is an accomplished leader with a deep level of connection to, and affinity for, the broader disability community. Since 2017, he has served as the Executive Director of the Disability Rights Legal Center (DRLC) in California, a non-profit, public interest advocacy organization that champions the civil rights of people with disabilities through education, advocacy, and litigation. Jordan also has a wealth of fundraising and development experience, founding Your Mission Possible, Inc. an organization that focuses on fundraising for nonprofits where he helped a diverse portfolio of nonprofit organizations significantly grow their funding streams from individual donors, corporate sponsorships, and grants.

"I am honored to be joining the National Down Syndrome Congress, a wonderful organization that has had an immense impact on the Down syndrome community over the past 50 years," Jordan Kough said. "I look forward to working with a stellar staff and an engaged Board of Directors to successfully lead the NDSC into the future. I believe the potential future impact of the NDSC to be significant and can only hope to lead the organization to success similar to a storied history."

Shauntel Neal-Howe, NDSC's Board President, explained, "Jordan Kough was chosen for his strong leadership experience, his zeal to engage all stakeholder groups, and his innovative approaches to fundraising." She continued, "We are confident that Jordan is the right person to set up the NDSC for another 50 years, and we are excited for this next chapter in the NDSC's history to begin."

Please join us in welcoming Jordan to the NDSC family!





The NDSC 50th Annual Convention & Celebration will be LIVE in New Orleans, LA, in 2022! We look forward to seeing everyone at the [Hyatt Regency New Orleans](#) from June 23-26, 2022.

The staff and Convention Planning Committee are already busy coordinating for the event. They are working closely with the Hyatt staff to follow CDC and local guidance around COVID-19 protocols to keep all of our families, vendors, speakers, volunteers, and staff safe. We understand that a lot can change in 6 months and will keep you updated on what we are doing to provide a safe event.



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CONGRESS

## BOARD OF DIRECTORS

**NOMINATIONS NOW BEING ACCEPTED**



**NOMINATIONS OPEN THROUGH  
APRIL 15, 2022**

The NDSC Board of Directors is a collegial group with a family feel. Like any Board of Directors, ours directs policy and has fiduciary oversight. To learn more about the responsibilities, terms of service, and commitments of board members, [please visit our website.](#)



**The awards nomination portal is open now!** Each year we honor the individuals and organizations whose achievements, service, and contributions to the Down syndrome community are exemplary. If you know of an individual or organization that you feel is deserving of consideration for one of the 2022 NDSC awards, please complete a nomination form and supply supporting materials via USPS mail, email, or fax to the NDSC Center **by Friday, January 7, 2022.**

The Board of Directors will review all nominations. The Awards Committee will make final selections. All awards will be presented at the NDSC 50th Annual Convention & Celebration, June 23-26, in New Orleans, LA.

More information, including descriptions of each award category, NDSC awards history, and previous years' winners, [can be found on our website.](#)

**SUBMIT A NOMINATION**

# David-Michael McDonnell-Forney – My friends call me Mack!

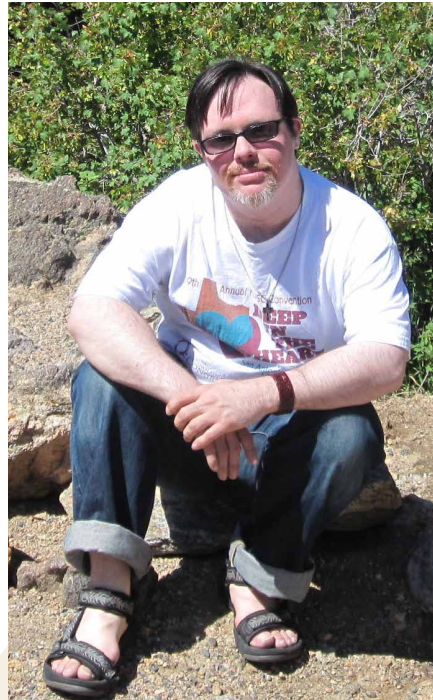
David-Michael McDonnell-Forney, the son of Kathleen and David, was born in the fall of 1978 in Minneapolis, Minnesota. He was named for his father and uncle and proudly carries the family names of both of his parents. According to David, he came home one day when David-Michael was a wee one and found his wife rocking their son when he heard her say “David Michael McDonnell-Forney sure is a long name; we’ll call you David Mack.... no...maybe we will call you Mack”. And so, the name Mack stuck. As a child, if Mack heard “David Michael,” he knew he was in a bit of trouble.

If asked, Mack’s friends would probably tell you that one of his greatest attributes is that he is a great and loyal friend. He loves his friends and has many that he has known for decades. One of his oldest friends is JT, who he met in pre-school! Mack’s first friend, though, was his sister Catherine. Mack loves his friends, but family is what is most important to him. He was thrilled when Catherine gave him a brother when she married Nick and even more excited when they blessed the family with Mack’s two nieces, Madeline and Amelia.

Growing up Mack attended Kenny Elementary School, where his favorite teacher was Kathy Nord. She was his teacher from first through third grade. He loved being in her class, and nearly 40 years later, she is still a great friend. Mack attended Anthony Middle School and then Washburn High. He thrived in high school due to his love of learning new things. He developed a love of history thanks to his high school history teacher. During his high school years, at the age of 16, he attended his first NDSC convention, where he met some lifelong friends with whom he still keeps in touch and even vacations with.

At 23, Mack moved from his parents’ house to his first apartment with his buddy Tom. Although Mack and Tom ultimately decided to get their own apartments, they have remained close. Tom lives in the apartment across the hall from Mack, so they still see each other every day! Mack has a lot of great friends that he also spends time with.

Mack is an office assistant at the law firm of Brown & Carlson, where he has been employed for 18 years. Due to COVID, he is currently working part-time but hopes to go back to a 5-day work week next year. Mack loves his job



and the people he works with. He says, “It is a great place to work.” The people he works with have become more than just co-workers; they are also Mack’s friends. He enjoys working with them and really enjoys their bowling and Christmas parties.

Mack knows that it is important to take care of himself and make healthy choices. He works out twice a week with a personal trainer and walks regularly. He uses his Fitbit to track his steps. Mack loves bowling, going to movies, drawing, traveling, photography, and studying genealogy. He has spent a great deal of time researching both his dad’s and mom’s families. Learning his family history and tracing his lineage has led Mack to travel to Ireland five times. He loves to travel, and Ireland is one of his favorite places that he has visited. It has also been the subject of many of his photography projects.

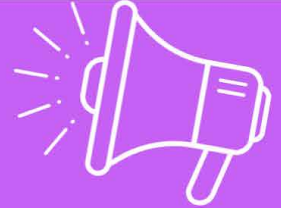
Mack has been attending NDSC Conventions for nearly three decades. Since the age of 16, Mack has only missed one conference! Unfortunately, an unplanned surgery kept Mack from attending the 2003 Convention in Philadelphia. Mack says, “I love the conferences. The workshops are great, and I always love seeing all my friends from around the country. I love the dance too! Also, I have a lot of friends that I have met at NDSC conferences. I have missed them a lot this past 2 years.” We have missed everyone too and can’t wait to see Mack in New Orleans next year!



# YOUTH & ADULTS CONFERENCE

June 24 - 26 | New Orleans, LA

## SPEAKER PROPOSAL DEADLINE EXTENDED TO JANUARY 4, 2022



We are looking for dynamic speakers to present during the 2022 NDSC Youth & Adults Conference in New Orleans! Do you have a special skill or craft that you would like to share? Can you lead a fun activity or game? If so, let's talk about YOU presenting at the NDSC 50th Annual Convention and Celebration!

If you need more information, [visit our website](#) or email NDSC Convention Coordinator Emily Carswell at [emily@ndsccenter.org](mailto:emily@ndsccenter.org). We look forward to seeing everyone in New Orleans.

**SUBMIT A  
PROPOSAL**

## COVID-19 & Down Syndrome Resource

Updated November 16, 2021



The spread of the coronavirus (COVID-19) has brought extraordinary challenges that continue to affect communities around the world. In our case, the pandemic called for a united response to better understand its impact on the Down syndrome community. NDSC has again joined forces with other national organizations to update our COVID-19 & Down Syndrome Resource for individuals with Down syndrome and their families. This Resource focuses on new and updated information specific to variants, boosters, and school safety. It also includes notes about testing, vaccines, mental health, ways to stay safe, and advocacy in hospital settings and for appropriate care. This resource can be found on the [NDSC COVID-19 Library](#) on our website. Copying or posting of this document is prohibited. However, providing a link or downloading [from the NDSC](#) or any of the collaborating organizations who published this document is permissible.



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# EDUCATORS CONFERENCE

2022



THURSDAY, JUNE 23 | 8:15 AM - 3:30 PM

HYATT REGENCY HOTEL | NEW ORLEANS, LA

## Calling all Educators!

The NDSC Educators Conference is Back! Make plans to join us at the NDSC 50th Annual Convention in New Orleans, LA, for a one-day conference designed for educators to enhance outcomes for their students with Down syndrome, autism, and intellectual and developmental disabilities.

**Save the Date! Thursday, June 23, 2022 • 8:15 AM – 3:30 PM • Registration is Open!**  
**\$150 - Will include materials, lunch, and certificate for CEU submission**

Practical in nature, the Educators Conference will engage participants in identifying and implementing strategies applicable to K-12 classrooms. Discussions will provide:

- strategies for educators to enhance instruction through effective reading interventions,
- differentiated and universally designed curriculum,
- technology solutions,
- and practical behavioral practices.

Attendees will leave equipped with ideas, tips, strategies, tools, and solutions to implement in the classroom. For [more information](#) or to [download the event brochure](#), visit our website.



NATIONAL  
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5th ANNUAL  
ALL KINDS OF HEROES  
**GOLF CLASSIC**

**WORLD DOWN  
SYNDROME DAY**  
MARCH 21, 2022



Bear's Best  
Atlanta

For more information visit  
[NDSCCenter.org](http://NDSCCenter.org)



David Saville  
GRAND MARSHAL



## Understanding the Role of Paraprofessionals in Your

## Child's Education in Inclusive Classrooms



Ricki Sabia and Martha L. Thurlow

Paraprofessionals should be available to students with significant cognitive disabilities in the inclusive classroom if needed for a Free Appropriate Public Education (FAPE). Depending on each student's needs, paraprofessionals may provide supports, including supports for instruction, communication, or movement. Individualized Education Program (IEP) teams may push back on a request for a paraprofessional. They may point to limited resources or claim that a paraprofessional makes the general education classroom a more restrictive environment. These arguments are not valid. The paraprofessional decision must be based what an individual student needs to have a satisfactory education in the general education classroom. The Least Restrictive Environment (LRE) provisions in the Individuals with Disabilities Education Act (IDEA) focus on the amount of time a student spends in general education settings with peers without disabilities. They do not address the type of supports a student needs in the classroom.

Paraprofessionals may not be required to have specific credentials. However, they should be trained to meet the needs of the students with whom they work. It is important for parents to know what paraprofessionals should be expected to do in inclusive classrooms. Parents should also know what qualities paraprofessionals should have, and what supports and training they need to be successful in their role.

### Including the "Paraprofessional" in a Student's IEP

Paraprofessional support can be noted in several parts of an IEP, depending on the student's needs and the format of the IEP. It may be listed in:

- Supplementary Aids and Services
- Transportation
- Addendum

The IEP statement of Present Level of Academic Achievement and Functional Performance (PLAAFP) should document the student's needs that would justify paraprofessional support.

Paraprofessionals should be expected to fulfill several basic functions in the inclusive classroom, including collaborating with members of the instructional team and directing supports and using modifications and adapted materials in a way that maximizes student independence, social relationships, and learning.

The student's assigned paraprofessional can serve many different purposes related to IEP goals. It is important not to use a paraprofessional when the student can be independent. To build greater independence, it is important to identify the specific purpose for paraprofessional support. Also, it is helpful to determine what support will look like and to plan for fading that support.

*To see the complete TIES Center Parent Brief by Sabia, R., & Thurlow, M. L. (2021, October).*

*Understanding the role of paraprofessionals in your child's education in inclusive classrooms (Brief #7) visit <https://files.tiescenter.org/files/kH3Xm-6Tj6/understanding-the-role-of-paraprofessionals-in-your-childs-education-in-inclusive-classrooms>.*

### Other Terms for "Paraprofessional"

Paraprofessionals may be called by other terms in your state, district, or school. Some of these names are:

- Paraeducator
- Parapro
- Aide
- Teaching assistant
- Independent assistant



## Prenatal Testing & Information ABOUT DOWN SYNDROME

## Acknowledgments

The Global Down Syndrome Foundation, the National Down Syndrome Congress, and the National Down Syndrome Society would like to thank the following contributors for their valuable time and expert advice.

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Karen Gaffney	Patricia C. Winders, PT



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## #StrongerTogether

In 2012 National Down Syndrome Congress and GLOBAL Down Syndrome Foundation teamed up to publish the groundbreaking *Prenatal Testing & Information About Down syndrome* pamphlet (PTP), available in [English](#), [Spanish](#) and [Icelandic](#). We later collaborated again to bring the second edition, created from the first national survey of pregnant women and medical professionals, including information about the accuracy of different prenatal tests, what parents and families can expect, early milestones, and other available resources. The PTP is easily accessible electronically in the [NDSC Ages & Stages Library \(Birth-2\)](#), or printed copies are provided by request to NDSC members at no cost.

We are pleased to announce that we have entered into a strategic collaboration to co-publish the third edition of this important free resource bringing the National Down Syndrome Society into the fold. This collaboration yields the first resource for expectant parents supported by all three national Down syndrome advocacy organizations.

## NDSC Bringing Families Together!

The Tomkins and the Underdown families live on opposite ends of the country. One just west of Portland, OR, and the other in Hickory, NC. The parents are roughly 15 years apart in age and the children are separated by 7 years, but the love of sports and the NDSC has made them life-long friends.

In the summer of 2017, Barb and Ted Tomkins traveled south from Oregon to attend the NDSC Annual Convention in Sacramento, CA. As they waited at the airport for the shuttle to take them to their hotel, their son Deric struck up a conversation with Matthew Underdown, a young man who shared a love of sports, particularly baseball and basketball, and who, like Deric, had an extra 21st chromosome.

The weekend spent together was the beginning of a friendship that now includes regular calls to talk about sports, trips across the country, holidays and vacations together, and friends who cannot wait to meet up in New Orleans for the 50th Annual NDSC Convention!



# Soiree of Stars

On Thursday, October 21, we held the 2nd Soiree of Stars Virtual Gala. The event celebrated and honored those making a difference in the Down syndrome community.

**Congratulations to our 2021 Everyday Heroes.** These three individuals are shining examples of individuals who speak up, make their own decisions, and through self-determination, have made positive impacts as they have continued their education through postsecondary or vocational trade programs.



*Christopher Bennett has been an exemplary employee at the Meritage Resort and Spa for three years, where he was awarded the Team Member Employee of the Month.*



*Marina Martinez is a graduate of the University of Georgia's Destination Dawgs Inclusive Postsecondary Education Program, where she majored in marketing with concentrations in public relations, journalism, and advocacy.*



*Taylor Freeman is a 2021 graduate of Hart County High School in Hartwell, GA. She is a current freshman at Clemson University enrolled in the ClemsonLIFE™ program.*

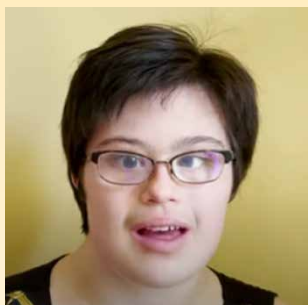
We want to send a special thank you to the self-advocates who introduced the evening's honorees:



*Jake Pratt introducing UPS -Corporate Honoree*



*David Saville introducing Dabo Swinney- Individual honoree*



*Martha Haythorn introducing the GA Inclusive-Organization honoree*



*Julianna Cabollero and her sweet son Diego - introducing Jack's Basket – Non-profit Honoree.*



2021 SPONSORS

A special thank you to  
**Steve & Christine Morse**  
for their generous contribution

★ Celestial Circle ★

The family and friends of Will Yates  
Mitch & Julie Rothholz

Thank you to the more than 1000 families who have tuned in and supported us through the Soiree of Stars Virtual Gala. If you missed the event, you can watch the recording on the [NDSC YouTube channel](#).

As we celebrate five decades of serving the Down syndrome community, we have never needed your support more to continue our mission to provide information and advocate for the rights of individuals and families touched by Down syndrome as they pertain to all aspects of life. If you would like to show your support, donating is easy; text NDSC to 26989 or [visit the website](#). Thank you to all who supported the Soiree of Stars Virtual Gala. Your personal contributions and sponsorships are greatly appreciated.



**El portal de nominaciones a los premios ya está abierto.** Cada año honramos a las personas y organizaciones cuyos logros, servicios y contribuciones a la comunidad del síndrome de Down son ejemplares. Si conoce a una persona u organización que cree que merece ser considerada para uno de los premios NDSC 2022, por favor, llene un formulario de nominación y proporcione los materiales de apoyo a través del correo USPS, correo electrónico o fax al Centro NDSC antes del viernes **7 de enero de 2022**.

El Consejo de Administración examinará todas las candidaturas. El Comité de Premios hará la selección final. Todos los premios se entregarán en la 50ª Convención y Celebración Anual de la NDSC, del 23 al 26 de junio, en Nueva Orleans, LA.

Puede encontrar más información, incluida la descripción de cada categoría de premios, la historia de los premios NDSC y los ganadores de años anteriores, [en nuestro sitio web](#).

**ENVÍE UNA NOMINACIÓN**



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## JUNTA DIRECTIVA

### SE ACEPTAN NOMINACIONES



**CANDIDATURAS ABIERTAS HASTA  
EL 15 DE ABRIL DE 2022**

La Junta Directiva de NDSC es un grupo colegiado con un sentimiento familiar. Como cualquier Junta Directiva, la nuestra dirige la política y tiene supervisión fiduciaria. Para obtener más información sobre las responsabilidades, los términos de servicio y los compromisos de los miembros de la junta, [visite nuestro sitio web](#).

Convención del Congreso Nacional del Síndrome de Down 2022

# ¡RESERVE LA FECHA!

**50th**  
NATIONAL DOWN SYNDROME CONGRESS  
ANNUAL CONVENTION

**23-26 de junio 2022 | Nueva Orleans, LA**

La 50ª Convención y Celebración Anual de la NDSC se celebrará en vivo en Nueva Orleans, LA, en 2022. Esperamos ver a todos en el [Hyatt Regency New Orleans](#) del 23 al 26 de junio.

El personal y el Comité de Planificación de la Convención ya están ocupados con la planificación del evento. Están trabajando estrechamente con el personal del Hyatt para seguir las orientaciones de los CDC y de las autoridades locales sobre los protocolos de la COVID-19 para mantener la seguridad de todas nuestras familias, vendedores, oradores, voluntarios y personal. Entendemos que muchas cosas pueden cambiar en 6 meses y les mantendremos informados de lo que estamos haciendo para ofrecer un evento seguro.

PERSONAS DE APOYO O CUIDADORES DE  
ADULTOS CON DISCAPACIDADES  
INTELECTUALES QUE HABLEN ESPAÑOL

# Comparte con nosotros

[materialeseducativosCOVID19.thehennegroup.com](http://materialeseducativosCOVID19.thehennegroup.com)

Su opinión sobre la apariencia, estilo y sensación  
sobre materiales educativos de COVID-19

El CDC y RTI International están interesados en hablar con adultos que viven con una discapacidad intelectual, así como con sus familiares o personas de apoyo. El propósito de la entrevista es obtener comentarios sobre los materiales educativos de COVID-19 para adultos con discapacidad intelectual. En este momento, solo estamos entrevistando a adultos con una discapacidad intelectual (IDD) y familiares o cuidadores que hablan español.

Cualquier persona interesada puede seguir el enlace a continuación para completar un cuestionario. Usaremos esta información para determinar quién es elegible para participar en una entrevista de 45 minutos en Zoom.

Las entrevistas se llevarán a cabo a partir del 08 de Diciembre y los participantes elegibles recibirán una tarjeta de regalo de \$50 en agradecimiento por su tiempo. La entrevista se realizará en español.

**Spanish:** <http://www.covid19educationalmaterials.thehennegroup.com/>

## Carta del Presidente

Estimadas familias de NDSC,

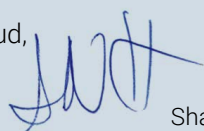
Es difícil de creer que ya nos estemos preparando para concluir el año 2021. A medida que nos acercamos al final del año, creo que todos podemos estar de acuerdo en que este año ha sido uno de resistencia. Sigo estando orgullosa de formar parte de una organización que hace tanto por las personas que cuentan con nosotros. Este año, nos basamos en lo que nos enseñó el año pasado y celebramos una segunda convención virtual de gran éxito, con ponentes y aprendizaje digital. Una vez más, nuestro personal, los miembros de la junta directiva y los voluntarios de la comunidad se unieron para atender las necesidades de nuestras familias. Nuestro impacto en Washington, D.C., continuó asegurando la protección de los derechos de las personas con síndrome de Down y otras discapacidades y su adecuada atención. Al igual que el año pasado, este año trajo desafíos a muchas familias, pero estos desafíos nos permitieron dar un paso adelante para nuestros miembros como nunca antes. Ahora, más que nunca, entendemos que nuestro trabajo es importante y esencial. El personal de la NDSC y el Comité de Planificación de la Convención están trabajando duro para planificar y preparar con entusiasmo la 50ª Convención y Celebración Anual "en persona" en Nueva Orleans, LA, el próximo 23-26 de junio.

Esta convención también significa un cambio de guardia. Cada año, en la convención anual, elegimos a los nuevos miembros de la Junta Directiva que cumplen un mandato de tres años. Mi mandato como Presidente de la NDSC terminará con las elecciones de 2022. Me siento honrada de haber servido como su Presidente de la Junta Directiva de NDSC. Seguiré formando parte de la junta en calidad de ex presidente inmediato.

Aunque se nos conoce como la "Reunión Familiar Mas Grande" y vemos a la mayoría de ustedes una vez al año, sepan que estamos aquí para ustedes los 365 días del año para proporcionarles recursos y apoyo. Independientemente de lo que nos depara el futuro, sepan que el NDSC seguirá trabajando con y para ustedes para promover los intereses de las personas con síndrome de Down.

Le deseo a usted y a su familia unas muy felices fiestas y un saludable año nuevo. Es un placer y un privilegio servirle a usted y a su familia.

Con gratitud,



Shauntel Neal-Howe



# 2022 NDSC

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## THANK YOU FOR YOUR SUPPORT

## 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.

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