

Down Syndrome News

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FIRST QUARTER 2021

NEWSLETTER OF THE



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In this issue:

FEATURES

- 3** NDSC 49TH ANNUAL CONVENTION
- 5** NATIONAL ORGANIZATIONS WORK TOGETHER TO PROVIDE RESOURCES FOR THE DOWN SYNDROME COMMUNITY
- 7** AGES AND STAGES

EVERY ISSUE

- 2** LETTER FROM THE PRESIDENT
- 4** SELF-ADVOCATE SPOTLIGHT
Carrie Bergeron
- 6** ADVOCACY IN ACTION
- 8** MEET OUR LEADERS

EN ESPAÑOL

- 10** CONVENCIÓN DEL NDSC
- 12** NDSC AUTO DEFENSOR
Carrie Bergeron
- 13** DESTACADO LAS ORGANIZACIONES NACIONALES COLABORAN PARA OFRECER RECURSOS A LA COMUNIDAD DEL SÍNDROME DE DOWN
- 14** CONOZCA A NUESTROS LIDERES
- 15** CARTA DEL PRESIDENTE

NDSC 49TH ANNUAL CONVENTION



A Brand New Day

SAVE THE DATE
JUNE 21–26

The Benefits of Virtual

For decades, the NDSC Convention has been the largest gathering in the world of people with Down syndrome, their families, and the professionals that serve the community. This legacy continues as we have discovered a whole new way to bring information, resources, and networking opportunities to more families than ever before.

In 2020 we had to adapt to unprecedeted times created by the COVID-19 pandemic to provide those whom we serve a new type of learning experience. Our first virtual convention's success opened our eyes to the possibilities of what we could bring to more families than ever before. While the 2020 multi-week event, hosted on multiple platforms, provided an experience for many who had never attended an NDSC Convention, it also provided us with an understanding that our reach was no longer limited.

The NDSC 49th Annual Convention will feature NEW event software that will put the entire convention in the palm of your hand or on your laptop on one platform. This new platform will provide even more attendees access to workshops, Deep Dive sessions, Advocacy Training Boot Camp, the GLOBAL Research & Medical Care Roundtable, Virtual Visits, College Fair, the Virtual Exhibit Hall, Virtual Happy Hour, Plenary, and the 321 Zoom Dance!™ party.

Continued on page 3...



Letter From the President

Dear NDSC Families,

It looks like we've made it and a Brand New Day is on the horizon! But with this brand new day, we must continue to ask ourselves and each other, as a board and staff, how do we do better? How do we welcome in families, especially minority families, who may not have felt included in the past? How do we reduce or remove barriers for all families to participate? How do we fulfill our organization's mission to provide information, advocacy, and support concerning all aspects of life for individuals with Down syndrome and serve our purpose of promoting the interests of people with Down syndrome and their families through advocacy, public awareness, and information?

During a year when the world was very different from what we had ever seen before, many organizations struggled to serve their mission. We, to use the cliché, took the lemons that the pandemic handed us and made lemonade. At this time last year, we announced that our annual convention would be a virtual event. It was a difficult decision at the time, but the lemons had been given to us. We learned from the experience that there has never been a better time to carry out our work. Through the use of technology, we have advocated more broadly and provided more information for individuals with Down syndrome and their families than ever before.

Events that occurred in our nation last summer pushed us to host three Town Hall meetings addressing race relations in our community. While we had been mindful of being welcoming to all, to be honest, we had never had the difficult but necessary discussions needed to move our organization and community forward. These uncomfortable conversations are a first step to understanding one another better so that we may grow as

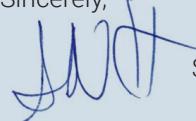
individuals and as an organization and to help ensure that we are welcoming to everyone in our community.

As we again pivoted and began planning the virtual NDSC 49th Annual Convention, it was only fitting to title the event "A Brand New Day!" We are preparing to bring the families that rely on us for resources, information and support a bigger, brighter virtual event than we ever dreamed possible. We have invested in a robust platform that will allow attendees to have the entire convention in the palm of their hand. Everything from schedules, workshop details, files, and handouts, the Virtual Exhibitor Hall, and so much more are all in one place! I sincerely hope that you and your family will join us June 21 – 26.

Serving on the Board of Directors for the NDSC has been a great honor. Seeing the changes that we are making through the resources we provide to families and the impact of the advocacy work we do to support those with Down syndrome and the disability community as a whole has been beyond gratifying. If you are interested in making more of an impact in the Down syndrome community, we would like to hear from you. We are always on the lookout for our future leaders!

It is indeed an honor and pleasure to serve you and your family. Thank you for your continued support of the NDSC!

Sincerely,



Shauntel Neal-Howe



NDSC CONVENTION PLENARY
SATURDAY,
JUNE 26, 2021
6 PM

KEYNOTE SPEAKER
Chris Frelic



IRONMAN®

1%
Better

The NDSC Convention: Serving More Families Than Ever Before

Unlimited Attendee Access with Limited Attendee Expense

Each year, our live event hosts approximately 3,800 attendees. The virtual event has no limit to the number of attendees. Lower cost to attendees allows more families to join us.

PRESENTING SPONSOR



GLOBAL
DOWN SYNDROME FOUNDATION®

More Workshops

When attending a live event, attendees can choose to participate in 1 workshop per cycle, but virtual attendees will receive access to all 50 workshop recordings. Please see our website to see the growing [list of workshops](#).

More Deep Dive Sessions

When attending a live event, attendees can choose to participate in 1 Deep Dive session, but virtual attendees can participate in multiple 3-hour intensive Deep Dive sessions. You can find a [complete list of Deep Dive sessions](#) on our website.

More College Fair

The 3rd Annual College Fair on Friday, June 25, 2021, from 4:00 to 7:00 PM EST

We are proud to partner again with the Think College National Coordinating Center (NCC) to host the 3rd Annual College Fair. Think College NCC is a national organization dedicated to developing, expanding, and improving inclusive higher education options for people with intellectual disability with a commitment to equity and excellence.

This event offers attendees an opportunity to virtually visit colleges and universities as they showcase their post-secondary programs for students with intellectual disabilities.

No additional registration required for Convention attendees. The registration deadline for college and university programs to participate is June 14. For more [information about the College Fair](#) visit our website. For more information or questions, contact NDSC Programs Coordinator Alexis Glaubitz at Alexis@NDSCcenter.org.

A Bigger, Better NDSC Advocacy Training Boot Camp Monday, June 21, from 6:00 to 9:00 PM EST

This year we kick off the NDSC Convention with the NDSC 3rd Annual Advocacy Training Boot Camp. This 3-hour session designed for both beginner and seasoned advocates is a great opportunity to get the advocacy training you need to take your advocacy efforts to the next level. This virtual NDSC Advocacy Training Boot Camp is included with all General Conference and Youth & Adults Conference registrations with no additional registration or RSVP required. This session will feature information from self-advocates who are making a difference through their personal advocacy efforts, parent advocates, and the expert NDSC Policy & Advocacy Team. From the comfort of your own device, learn what advocacy is, the basics of the legislative process, how to engage

and build relationships with your elected officials, and how to utilize social media in your advocacy efforts. Those in attendance will also have access to download other important resources to refer to.

Advocacy Training Boot Camp is designed to be an Advocacy mini-course with a focus on legislative advocacy. Whether you are new to advocacy or are an experienced advocate, you will walk away with something new and be energized after this session. This NDSC Advocacy Training Boot Camp is appropriate for parents, professionals, and of course, self-advocates!

No additional registration required. For more information NDSC Advocacy Training Boot Camp [visit our website](#) or contact NDSC Policy Coordinator Lauren Gates at lauren@ndsccenter.org.

More Networking

It wouldn't be an NDSC Convention without a 321 Dance!™, but this year we are also adding a Happy Hour, Virtual Visits, and more networking opportunities.

All From the Comfort of Your Device

We can't wait until next year when we are all together for the NDSC 50th Annual Convention in New Orleans, LA. This year, though, we will all enjoy the benefits of digital. Attendees who register for either the General Conference, the Youth & Adults Conference, or the Siblings Conference will have access to all workshops, whether attending the live sessions or listening to the recordings; the GLOBAL Research & Medical Care Roundtable; the NDSC Advocacy Training Boot Camp; the Virtual Exhibit Hall including College Fair Exhibitors; the 321 Dance; Happy Hour and other social events all from their personal device and on one platform!

REGISTRATION OPENS

April 26 at 1 AM

SELF-ADVOCATE SPOTLIGHT

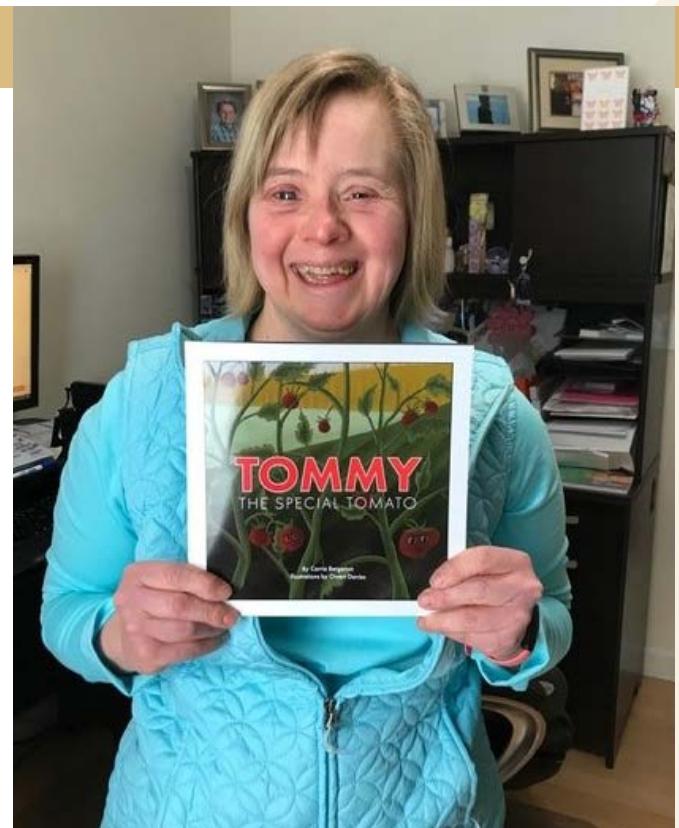
Carrie Bergeron

Carrie Bergeron is what most would consider a 'people' person with many friends. She grew up in Dolgeville, NY, in a loving and supportive family. At the age of 23, Carrie moved from Dolgeville to Rome, NY. Two years ago, she decided to move to Fairport, NY, to be near her sister, Katie, who will one day be her legal guardian. Carrie loves being near Katie and her family. The move to Fairport was challenging initially, but it didn't take long for Carrie to conquer the challenge. She was pleased to live closer to her other sister, Wendy, and her family, who live about forty-five minutes away. Carrie enjoys her life in Fairport and is involved in her community. Carrie takes classes at ~ 2 'Y's, a Karate school, loves the fitness center and pool in her complex, spends time at the local library, and is involved with the Gigi's Playhouse/Rochester. Living two and a half hours from her parents and brother is one drawback to moving to Fairport, but Carrie visits them as often as she can.

Carrie and her parents have always set high goals for her. She was the first baby to participate in her county's Early Intervention program and continued to receive these services when attending preschool. Her mother and the Early Intervention Director also ensured that she was enrolled in a general education Kindergarten class. Her school days were a combination of general education and special education classes. Carrie's parents were happy that Carrie attended the local school with her siblings and were proud when at 21 years old, Carrie graduated with an I.E.P. diploma. When Carrie moved to Rome, NY, she received an N.Y.S. Self-Determination plan, which provided Carrie 45 hours per week of support staff.

After graduation, Carrie went on to a community college where she studied Early Childhood Education. College was a challenge, but being the achiever that Carrie is, after four years of working hard, she completed the course! She has volunteered over the years at various childhood centers and loves the time she spends with children.

A turning point in Carrie's life was at age eighteen. Her mother was concerned when Carrie was not following the same course as many of her friends and classmates and felt that Carrie needed something new to keep her involved with her peers. She researched and found the Youth & Adults program at NDSC. In 1995 the Bergerons attended their first NDSC Convention in Washington, D.C. Although Carrie was nervous at first, she was warmly welcomed by Carlene Mattson, who has become a lifelong friend. Carrie was hooked and became a regular NDSC Convention attendee. In natural Carrie fashion, she set her goals high, and in 2000, Carrie was elected by



her peers to the NDSC Board of Directors, where she served through 2002. She worked on the Self-Advocate Book Project as Carrie has a particular love for books and continues to serve on the NDSC Self-Advocate Council today. When asked to tell us her thoughts on being a representative of NDSC, Carrie says, "NDSC rocks!"

So far, 2021 has been a great year for Carrie! She has accepted her first job. After volunteering for a year, she has joined the staff at Gigi's Playhouse in Rochester, NY! It is a dream job. She loves preschoolers and young children and is so thrilled to now be a paid employee. 2021 has also been a year that Carrie has made a lifetime dream come true! She published her first book, "Tommy, the Special Tomato." Carrie has always wanted to write a children's book based on the "My Special Tomato" story that she wrote in high school. With the help of her first staff in Fairport, an English teacher, and a family friend who provided illustrations, Carrie's dream has come to life! She wrote the book with the hope of spreading positive awareness about Down syndrome and other disabilities.

Carrie exercises daily and tries to make healthy choices when eating. She loves to create scrapbooks for her family and friends as gifts. Signing and interpreting music makes her happy, and she loves to dance. She is taking a line dancing class and teaches Zumba classes. One of her favorite things to do, though, is to keep up daily with her friends. Many she stays in touch with on Facebook and several she talks to on FaceTime.

National Organizations Work Together to Provide Resources for the Down Syndrome Community



Over the past year, the world has seen some of its greatest challenges due to COVID-19. But one positive result of the pandemic has been a united effort by national Down syndrome organizations to respond quickly to the needs of the community and better understand the impact of the virus on those with Down syndrome.

Last year, NDSC worked together with Global Down Syndrome Foundation, Down Syndrome Medical Interest Group-USA, LuMind IDSC Down Syndrome Foundation, National Down Syndrome Society, and National Task Group on Intellectual Disabilities and Dementia Practices to develop and update [the Q&A on COVID-19 and Down Syndrome](#).

In March, we came together again to create a [new COVID-19 and Down Syndrome Resource](#) that emphasizes important updates and contains important new information about COVID-19 vaccinations. The document focuses on new and updated information about COVID-19 testing, mental health, ways to stay safe, advocating in hospital settings, visitation rights, and appropriate care.

These resources can also be found in Spanish.

[P&R sobre COVID-19 y síndrome de Down](#)

[Recurso sobre COVID-19 y Síndrome de Down](#)

This resource is intended to be used as a guide and for general information only. Although the Down Syndrome Medical Interest Group was a collaborator and a valuable source of information, COVID-19 & Down Syndrome Resource is not intended to provide medical advice and is not a substitute for the advice of medical or other professionals who care for you or a family member regularly. For medical advice, consult with your doctor or other healthcare professional(s).



NDSC COVID-19 Resources

Many of you have called the NDSC Center with questions about the COVID-19 vaccines, particularly whether or not they are recommended for individuals with Down syndrome. In response, the NDSC staff, with input from medical professionals, has created a [COVID-19 Vaccine FAQ Sheet](#) (released 01/25/2021) and a [COVID-19 Vaccine Information simple language sheet](#).

These resources can be found in Spanish on the NDSC website - COVID-19 Vaccine FAQ Sheet and COVID-19 Vaccine simple language sheet. https://www.ndsccenter.org/wp-content/uploads/COVID-19-Vaccine-Infographic_SPA.pdf.



NDSC Policy Priority: Medicaid Home and Community-Based Services

Medicaid HCBS: A Game-Changing New Bill is On the Horizon

By Heather Sachs, NDSC Policy & Advocacy Director



Medicaid Home and Community-Based Services (HCBS)

are vital to helping people with disabilities live at home and participate in their communities instead of living in institutional settings. HCBS are long-term services and supports (LTSS) funded by Medicaid, which is a partnership between states and the federal government to support low-income people with disabilities and the elderly. These services can meet medical needs (such as nursing care, case management, and durable medical equipment) and support daily living (such as personal care like dressing and bathing, managing their health care or finances, and employment support like job coaching). Services provided under HCBS waiver programs have been widely shown to be more cost-effective for the state than institutions. There is also an overwhelming preference by people with disabilities overwhelmingly to live in the community rather than nursing homes.

Despite their cost-effectiveness and demonstrated enhancements to the quality of life for people with disabilities and their families, there are many weaknesses in the current structure of HCBS. First, HCBS are optional and are not required to be funded by the states. This has resulted in HCBS programs having extremely long waiting lists, forcing people with disabilities to often wait years or even decades to access these services. There are over 850,000 people on HCBS waitlists around the country, and access to services depends on the state in which you live, resulting in huge disparities and equity issues. By contrast, states ARE required to provide institutional services, so if people are waiting for HCBS services and have no other means of assistance, they are forced to go into institutions or nursing homes to receive care. This is known as the "institutional bias" in Medicaid, and NDSC, along with the rest of the disability community, has been advocating to change this for decades.

A second major problem with the HCBS system is that once people get on a waiting list or even get access to services, they are trapped in their state due to the lack of portability. These state-based waitlists preclude people with disabilities and their families from moving from one state to another because they would have to go to the bottom of the waiting list in the new state. This often prevents people with disabilities from moving closer to their siblings or other family members and is particularly difficult for military families that move frequently.

A third problem with the current Medicaid HCBS system is that direct support professionals (DSPs), the people who provide the services to people with disabilities to help them with critical tasks (who are mostly women of color), are vastly



underpaid resulting in large industry turnover and disruption in continuity and quality of care. DSPs play a critical role in supporting people with disabilities to help them participate in their community and the DSP workforce needs to be strengthened.

These three major problems have plagued the Medicaid HCBS system for decades, and we finally may have the opportunity to address them. Recently, Congresswoman Dingell (D-MI), Senator Hassan (D-NH), Senator Casey (D-PA), and Senator Brown (D-OH) released a discussion draft of the HCBS Access Act, which would mandate HCBS in Medicaid to provide services, create national minimum requirements for HCBS, and make it possible to improve upon those services and the DSP workforce. The bill's lead sponsors are currently seeking stakeholder feedback on various technical issues, and an actual bill is expected to be introduced in Congress in the near future. This bill could be an absolute game-changer for people with disabilities and their families.

NDSC has designated Medicaid LTSS as one of its **top priority issues**, and we have already started working with our allies, coalition partners, and others to develop the best possible bill; we will then work diligently with our grassroots advocates to obtain bipartisan support for it. This is not going to be easy, and it is not going to be quick. One way you can help is to join NDSC's grassroots advocacy program, the **National Down Syndrome Advocacy Coalition (NDAC)**. We also encourage you to sign up for **NDSC's Action Alerts**, so that you will be notified when action on this issue or other policy issues impacting people with Down syndrome is needed. When NDSC puts out the call for actions like calling on your Members of Congress to support this bill and sharing your personal stories about the importance of HCBS, please step up and heed the call. Together, as a community, we can improve opportunities for people with Down syndrome and other disabilities as we completely re-vamp the Medicaid HCBS system. Advocacy is a marathon and not a sprint, and we will need your help to make real systems change.

NATIONAL DOWN SYNDROME CONGRESS

Ages & Stages

Premium
Access
\$21



The National Down Syndrome Congress supports individuals with Down syndrome, their families & caregivers, and the medical & educational professionals who serve them – **across the lifespan**. For new and expectant parents through aging and Alzheimer's, we have arranged our accurate and up-to-date information to suit your needs.

The Ages & Stages Resource Library is arranged with documents and articles for each age or stage you are navigating through or toward. We have collaborated with experts from across the country to bring you content relevant to each age or stage. Each age and stage includes one free webinar and access to the Resource Library. **Ages & Stages Premium Access** includes two additional top-notch webinars and the opportunity to join sharing sessions to ask questions and share experiences with others who are navigating each stage **for just \$21**.

It is not too late to register. When you join an Ages & Stages Premium Access age or group, you will receive recording links to all three recorded webinars produced especially for the age or group and will be invited to future sharing sessions.

Visit Ages
& Stages

Become an
ally for
advocacy

NATIONAL
DOWN SYNDROME
CONGRESS



Your support is critical, and today your participation can make an even bigger impact. When you join the NDSC ally for advocacy campaign, a monthly giving program, you will support NDSC's policy and advocacy efforts. Your ongoing monthly contribution will support the NDSC Advocacy & Policy team to engage with policymakers on a bipartisan basis and to educate and empower stakeholders to speak up for policies that will improve the lives of individuals with Down syndrome and their families.

Meet Our Leaders



Board Member Spotlight!

Meet **Barb Helm, NDSC Board Member** elected in 2020. Barb is from Overland Park, KS, where she has been the Executive Director of Arcare, a social service agency that provides services to individuals with disabilities for the past 30 years. Barb has a heart for giving and is involved in other non-profit organizations whose purpose is to serve families of those with disabilities. She is the chairperson of Nation Plan Alliance, a non-profit organization dedicated solely to meeting families' planning needs with adult children with disabilities and also a board member for the Association for Aging with Developmental Disabilities Organization. Barb also gives her time as a member of Christ Lutheran Church. She is on the leadership team of re/engage, a marriage enrichment program at her church.

Barb says that some of the things she loves most to do when not volunteering are spending time with her granddaughters and being outdoors! She enjoys biking, walking, and hiking whenever she gets the opportunity and recently got a kayak so that she could spend time on the water. Barb also loves to combine her love for the outdoors and her passion for doing good in the world. Until last year she had ridden the MS bike ride for 27 consecutive years! Unfortunately, due to the pandemic, the ride was canceled in 2020, so her streak will be broken.

We are proud to have Barb on our team. She brings much knowledge and experience to our organization, and having her is such an asset.



Staff Member Spotlight!

Our Staff Member Spotlight is **Tamara Pursley!** Tamara is currently the NDSC Programs & Partnerships Director (and Chief Web Developer) - but during her tenure, she has worn many hats. Tamara began her career with NDSC in 2013 as a Resource Specialist and has since held the titles of Communications Director, Program Director, and Affiliate Relations Director.

Tamara, her husband, and three tween/teen boys live in Georgia near the NDSC National Center. She is one busy mama bear!

Tamara and her husband were introduced to the Down syndrome community in 2005 when their middle son, Jackson, was born. They did not have a prenatal diagnosis but were told upon Jackson's arrival that Jackson had Down syndrome. The news of Jackson's diagnosis was handled in a way that, well - has driven Tamara to educate those delivering this news in a joyous and celebratory manner.

Tamara loves to cook. She says that it is her outlet. It is how she shows love and where she looks to learn new things, but most of all, it makes Tamara happy to make people happy with her food. Her boys are not complaining about her favorite hobby either! She even loves to watch cooking shows, especially competitions like "Chopped" or "Top Chef," and likes crime dramas/documentaries. A little fun fact about Tamara - she loves to sing Karaoke!

Hot off the Presses: A Great New Resource!

**Mental Wellness in Adults with Down Syndrome:
A Guide to Emotional and Behavioral Strengths
and Challenges**

Second Edition, March 2021

Written by Dennis McGuire, Ph.D. & Brian Chicoine, M.D.

Mental Wellness emphasizes that understanding and appreciating both the strengths and challenges of people with Down syndrome is the key to promoting good mental health. It shows readers how to distinguish between bona fide mental health issues and common characteristics of Down syndrome—quirks or coping strategies. For example, although talking to oneself *can* be a sign of psychosis, many adults with Down syndrome use self-talk as an effective problem-solving strategy.

What Is Normal?

Self-Esteem & Self-Image

Self-Talk

Grooves & Flexibility

Life-Span Issues

Social Skills

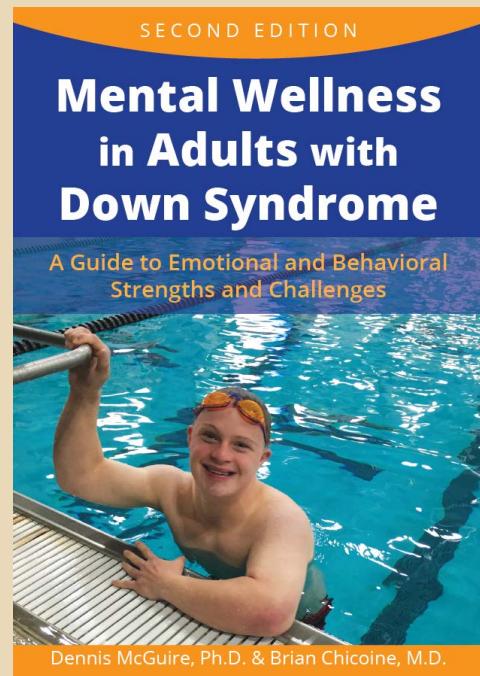
Mood & Anxiety Disorders

And more

The second edition includes new chapters on sensory issues (written by Dr. Katie Frank) and regression, expanded and now separate chapters on communication, concrete thinking, and visual memory, and an extensively updated chapter on Alzheimer's disease citing abundant new research. Other chapters cover a range of conditions and assessment and treatment options:

Available for pre-orders on www.woodbinehouse.com

Link to order: <https://www.woodbinehouse.com/product/mental-wellness-in-adults-with-down-syndrome-a-guide-to-emotional-and-behavioral-strengths-and-challenges/>



State of the Art Conference on Inclusive Postsecondary Education and Individuals with Intellectual Disability

This popular conference of 300+ participants provides opportunities for colleges of all sizes, universities, researchers, program staff, parents and self-advocates to learn about the current state of research and practice in the field, and to network with each other. Panels that include faculty and staff from postsecondary education initiatives, parents, self-advocates, and other experts, share effective practices during break-out sessions with opportunities for group discussion. The Student Leadership Conference is a new, parallel conference which brings more high school and college students into the conversation.

While we wish we could gather in person, we have decided to present, we have decided to present a virtual event this year to ensure broader access. We are working diligently to make sure the conference offers opportunities to connect with your peers and engage in meaningful conversations. Keep an eye out for:

- Call for Proposals (Deadline May 11)
- Registration (Opening this Summer)
- College Fair
- Sponsorship Opportunities

Learn more at www.sotaconference.com.

**SAVE
THE
DATE!**

**Virtual Event
November 8-9,
2021**

NDSC 49^a CONVENCION ANUAL



Un Día nuevo

APARTA LA FECHA
JUNIO 21 - 26

Las Ventajas De Lo Virtual

Durante décadas, la Convención del NDSC ha sido la reunión más grande del mundo de personas con síndrome de Down, sus familias y los profesionales que sirven a la comunidad. Este legado continúa, ya que hemos descubierto una forma totalmente nueva de llevar información, recursos y oportunidades de establecer contactos a más familias que nunca.

En 2020 tuvimos que adaptarnos a los tiempos sin precedentes creados por la pandemia del COVID-19 para proporcionar a aquellos a quienes servimos un nuevo tipo de experiencia de aprendizaje. El éxito de nuestra primera convención virtual nos abrió los ojos a las posibilidades que podíamos ofrecer a más familias que nunca. Si bien el evento de varias semanas de duración de 2020, organizado en múltiples plataformas, proporcionó una experiencia a muchos que nunca habían asistido a una Convención de la NDSC, también nos hizo comprender que nuestro alcance ya no era limitado.

La 49^a Convención Anual de la NDSC contará con un NUEVO software de eventos que pondrá toda la convención en la palma de su mano o en su ordenador portátil. Esta nueva plataforma proporcionará a los asistentes un acceso aún mayor a los talleres, las sesiones de Deep Dive, el Advocacy Training Boot Camp, la Mesa Redonda de Investigación y Atención Médica GLOBAL, las Visitas Virtuales, la Feria Universitaria, el Salón de Exposiciones Virtual, la Happy Hour Virtual, la Plenaria y la fiesta 321 Zoom Dance.

Al servicio de más familias que nunca

**Acceso ilimitado
de asistentes con
gastos limitados de
asistencia**

Cada año, nuestro evento presencial acoge a unos 3.800 asistentes. El evento virtual no tiene límite de asistentes. El menor coste para los asistentes permite que más familias se unan a nosotros.

Más talleres

Al asistir a un evento en vivo, los asistentes pueden elegir participar en 1 taller por ciclo, pero los asistentes virtuales recibirán acceso a las grabaciones de los 50 talleres. Calendario de talleres: www.ndsccenter.org/annual-convention.

**Más sesiones
de inmersión
profunda**

Cuando asisten a un evento en vivo, los asistentes pueden elegir participar en 1 sesión de inmersión profunda, pero los asistentes virtuales pueden participar en múltiples sesiones de inmersión profunda intensivas de 3 horas. Horario de las sesiones de Deep Dive: www.ndsccenter.org/annual-convention.

PRESENTING SPONSOR



Mas Ferias Universitarias

**La 3^a Feria Universitaria Anual
Viernes, 25 de junio de 2021, de 4:00 a 7:00 PM EST**

Estamos orgullosos de asociarnos de nuevo con el Think College National Coordinating Center (NCC) para organizar la 3^a Feria Universitaria Anual. Think College NCC es una organización nacional dedicada a desarrollar, ampliar y mejorar las opciones de educación superior inclusiva para las personas con discapacidad intelectual con un compromiso de equidad y excelencia.

Este evento ofrece a los asistentes la oportunidad de visitar virtualmente colegios y universidades mientras muestran sus programas postsecundarios para estudiantes con discapacidad intelectual.

No se requiere inscripción adicional para los asistentes a la Convención. El plazo de inscripción para que los programas de colegios y universidades participen es el 14 de junio. Para obtener más información sobre la Feria Universitaria, visite nuestro sitio web.

Para más información o preguntas por favor comunicarse con la Coordinadora de Programas Alexis Glaubitz at Alexis@NDSCcenter.org.

Un Campamento De Entrenamiento De Abogacía Mas Grande Y Mejor De NDSC

Lunes, 21 de junio, de 6:00 - 9:00 PM EST

Esta sesión de 3 horas está dirigida a los defensores principiantes y es una excelente oportunidad para obtener la formación de defensa que ha querido pero no tuvo tiempo de expresar durante la Convención Anual de NDSC. Esta sesión presenta información de autodefensores eficaces, padres defensores y el equipo experto en políticas y defensa de la NDSC. El Campamento de Entrenamiento de Abogacía está diseñado para ser un mini curso de Abogacía 101 enfocado en la abogacía legislativa, pero incluso el defensor más experimentado saldrá con algo nuevo y re-energizado después de unirse a la discusión abierta sobre cómo comprometerse con los legisladores efectivamente. Esta sesión es apropiada para padres, profesionales y, por supuesto, para los autodefensores.

No se requiere inscripción adicional.

Para más información comunicarse con lauren@ndsccenter.org.

MÁS REDES

DESDE LA COMODIDAD DE SU LUGAR DE RESIDENCIA
MÁS EXPOSICIÓN PARA LOS PATROCINADORES Y EXPOSITORES
GLOBAL- Patrocinador Expositor

SE ABRE EL REGISTRO

26 de Abril a las 1 AM EST

NDSC AUTO DEFENSOR DESTACADO

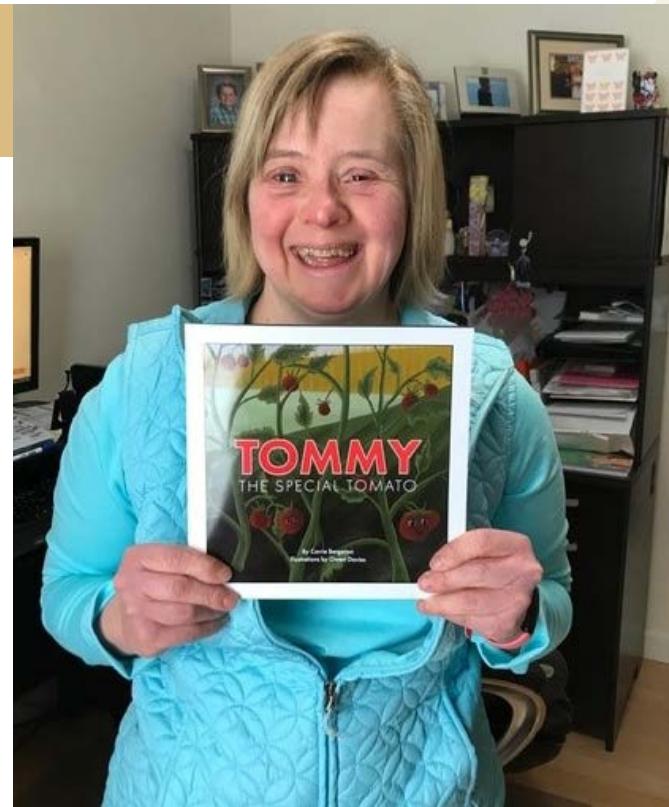
Carrie Bergeron

Carrie Bergeron es lo que la mayoría consideraría una persona "sociable" con muchos amigos. Creció en Dolgeville, Nueva York, en una familia cariñosa y solidaria. A los 23 años Carrie se mudó de Dolgeville a Rome, NY. Luego, hace dos años, decidió mudarse a Fairport, NY para estar cerca de su hermana, Katie, que algún día será su tutora legal. A Carrie le encanta estar cerca de Katie y su familia. La mudanza a Fairport fue un reto al principio, pero Carrie no tardó en superarlo. Estaba muy contenta de vivir también más cerca de su otra hermana, Wendy, y su familia, que viven a unos cuarenta y cinco minutos. Carrie disfruta de su vida en Fairport y participa en su comunidad. Carrie toma clases en ~ 2 'Y, una escuela de karate, le encanta el centro de fitness y la piscina en su complejo, pasa tiempo en la biblioteca local, y está involucrado con el Gigi's Playhouse / Rochester. Vivir a dos horas y media de sus padres y de su hermano es una de las desventajas de mudarse a Fairport, pero Carrie los visita tan a menudo como puede.

Carrie y sus padres siempre se han fijado metas altas para ella. Fue el primer bebé que participó en el programa de Intervención Temprana de su condado y siguió recibiendo estos servicios cuando asistía a la escuela infantil. Su madre y el Director de Intervención Temprana también se aseguraron de que estuviera inscrita en una clase de jardín de infancia de educación general. Sus días de escuela eran una combinación de clases de educación general y de educación especial. Los padres de Carrie estaban contentos de que Carrie asistiera a la escuela local con sus hermanos y se sintieron orgullosos cuando a los 21 años Carrie se graduó con un diploma de I.E.P. Cuando Carrie se trasladó a Roma, Nueva York, recibió un plan de autodeterminación del Estado de Nueva York que proporcionó a Carrie 45 horas semanales de personal de apoyo.

Después de la graduación, Carrie fue a un colegio comunitario donde estudió Educación Infantil. La universidad fue un reto, pero siendo la triunfadora que es Carrie, después de cuatro años de trabajo duro completó el curso. A lo largo de los años ha sido voluntaria en varios centros infantiles y le encanta el tiempo que pasa con los niños.

Un punto de inflexión en la vida de Carrie fue a los dieciocho años. Su madre estaba preocupada cuando Carrie no seguía el mismo curso que muchos de sus amigos y compañeros de clase y sentía que Carrie necesitaba algo nuevo para mantener a Carrie involucrada con sus compañeros. Investigó y encontró el programa de Jóvenes y Adultos en NDSC. En 1995, los Bergerons asistieron a su primera Convención de la NDSC en Washington, D.C. Aunque Carrie estaba nerviosa al principio, fue recibida calurosamente por Carlene Mattson,



que se ha convertido en una amiga de toda la vida. Carrie se enganchó y se convirtió en una asistente habitual a la Convención de la NDSC. Como es natural en Carrie, se puso metas altas y en el año 2000 fue elegida por sus compañeros para la Junta Directiva de la NDSC, en la que estuvo hasta 2002. Carrie trabajó en el Proyecto de Libros para Autogestores, ya que a Carrie le gustan especialmente los libros y sigue formando parte del Consejo de Autogestores de la NDSC. Cuando le pedimos que nos diga lo que piensa de ser una representante de NDSC Carrie dice "¡NDSC mola!".

¡Hasta ahora 2021 ha sido un gran año para Carrie! Ella fue, y ha aceptado, su primer trabajo. Después de ser voluntaria durante un año, se ha unido al personal de Gigi's Playhouse en Rochester, NY. Es un trabajo de ensueño. Le encantan los niños de preescolar y los niños pequeños y está encantada de ser una empleada remunerada. 2021 también ha sido un año en el que Carrie ha hecho realidad el sueño de su vida. Ha publicado su primer libro, "Tommy, el tomate especial". Carrie siempre ha querido escribir un libro para niños basado en la historia "Mi tomate especial" que escribió en el instituto. Con la ayuda de su primer personal en Fairport, un profesor de inglés, y un amigo de la familia que le proporcionó las ilustraciones, ¡el sueño de Carrie ha cobrado vida! Escribió el libro con la esperanza de difundir una conciencia positiva sobre el síndrome de Down y otras discapacidades.

Hago ejercicio a diario y trato de tomar decisiones saludables a la hora de comer. Me encanta hacer álbumes de recortes para regalar a mi familia y amigos. Me hace feliz firmar e interpretar música, y me encanta bailar y dar clases de Zumba. También estoy tomando clases de baile en línea. Me mantengo al día con muchos de ellos en FB y en FaceTime.

Las organizaciones nacionales colaboran para ofrecer recursos a la comunidad del síndrome de Down



En el último año, el mundo ha visto algunos de sus mayores desafíos debido al COVID-19. Pero un resultado positivo de la pandemia ha sido el esfuerzo conjunto de las organizaciones nacionales de síndrome de Down para responder rápidamente a las necesidades de la comunidad y comprender mejor el impacto del virus en las personas con síndrome de Down.

El año pasado, el NDSC colaboró con la Global Down Syndrome Foundation, el Down Syndrome Medical Interest Group-USA, la LuMind IDSC Down Syndrome Foundation, la National Down Syndrome Society y el National Task Group on Intellectual Disabilities and Dementia Practices para desarrollar y actualizar **las preguntas y respuestas sobre COVID-19 y el síndrome de Down**.

En marzo, nos reunimos de nuevo para crear un nuevo recurso sobre la COVID-19 y el síndrome de Down que hace hincapié en importantes actualizaciones y contiene información nueva e importante sobre las vacunas de la COVID-19. El documento se centra en información nueva y actualizada sobre las pruebas de COVID-19, la salud mental, las formas de mantenerse a salvo, la defensa en entornos hospitalarios, los derechos de visita y la atención adecuada.

Estos recursos pueden ser encontrados en español en los siguientes enlaces:

P&R sobre COVID-19 y síndrome de Down

Recurso sobre COVID-19 y Síndrome de Down

Este Recurso está destinado a ser utilizado como una guía y para información general solamente. Aunque el Grupo de Interés Médico del Síndrome de Down fue un colaborador y una valiosa fuente de información, el Recurso COVID-19 y el Síndrome de

Down no pretende proporcionar asesoramiento médico y no sustituye el consejo de los profesionales médicos o de otro tipo que le atienden a usted o a un miembro de su familia con regularidad. Para obtener asesoramiento médico, consulte a su médico o a otro(s) profesional(es) de la salud.



Recursos NDSC COVID-19

Muchos de ustedes han llamado al Centro NDSC con preguntas sobre las vacunas COVID-19, en particular sobre si están o no recomendadas para personas con síndrome de Down. En respuesta, el personal del NDSC, con la aportación de profesionales médicos, ha creado una hoja de **preguntas frecuentes sobre la vacuna COVID-19** (publicada el 25/01/2021) y **una hoja de información sobre la vacuna COVID-19 en lenguaje sencillo**.

Estos recursos se pueden encontrar en español en el sitio web del NDSC - Hoja de preguntas frecuentes sobre la vacuna COVID-19 y Hoja de lenguaje sencillo sobre la vacuna COVID-19. https://www.ndsccenter.org/wp-content/uploads/COVID-19-Vaccine-Infographic_SPA.pdf.

Conozca a nuestros líderes



Miembro de la Junta Directiva destacado

Conozca a **Barb Helm**, **miembro de la Junta de NDSC** elegida en 2020. Barb es de Overland Park, KS, donde ha sido la Directora Ejecutiva de Arcare, una agencia de servicios sociales que proporciona servicios a personas con discapacidades durante los últimos 30 años. Barb tiene un corazón para dar y está involucrado en otras organizaciones sin fines de lucro cuyo propósito es servir a las familias de las personas con discapacidad. Es la presidenta de Nation Plan Alliance, una organización sin ánimo de lucro dedicada exclusivamente a satisfacer las necesidades de planificación de las familias con hijos adultos con discapacidades, y también es miembro de la junta de la organización Association for Aging with Developmental Disabilities. Barb también dedica su tiempo como miembro de la Iglesia Luterana de Cristo. Está en el equipo de liderazgo de re/engage, un programa de enriquecimiento matrimonial en su iglesia.

Barb dice que algunas de las cosas que más le gusta hacer cuando no es voluntaria son pasar tiempo con sus nietas y estar al aire libre. Le gusta montar en bicicleta, caminar y hacer senderismo siempre que tiene la oportunidad y recientemente ha comprado un kayak para poder pasar tiempo en el agua. A Barb también le gusta combinar su amor por el aire libre y su pasión por hacer el bien en el mundo. Hasta el año pasado, había participado en la marcha ciclista de la esclerosis múltiple durante 27 años consecutivos. Lamentablemente, debido a la pandemia, la carrera se canceló en 2020, por lo que su racha se romperá.

Estamos orgullosos de tener a Barb en nuestro equipo. Aporta muchos conocimientos y experiencia a nuestra organización, y contar con ella es una gran ventaja..



Miembro del personal destacado

Nuestro miembro del personal es **Tamara Pursley**. Tamara es actualmente la Directora de Programas y Asociaciones de NDSC (y Jefa de Desarrollo Web) - pero durante su mandato, ha llevado muchos sombreros. Tamara comenzó su carrera con NDSC en 2013 como especialista en recursos y desde entonces ha ocupado los títulos de Directora de Comunicaciones, Directora de Programas y Directora de Relaciones con Afiliados.

Tamara, su marido y sus tres hijos adolescentes viven en Georgia, cerca del Centro Nacional de NDSC. Es una mamá oso muy ocupada.

Tamara y su marido conocieron la comunidad del síndrome de Down en 2005, cuando nació su hijo mediano, Jackson. No tenían un diagnóstico prenatal, pero a la llegada de Jackson les dijeron que tenía síndrome de Down. La noticia del diagnóstico de Jackson se manejó de una manera que, bueno, ha llevado a Tamara a educar a los que dan esta noticia de una manera alegre y festiva.

A Tamara le encanta cocinar. Dice que es su válvula de escape. Es la forma en que demuestra su amor y donde busca aprender cosas nuevas, pero, sobre todo, a Tamara le hace feliz hacer feliz a la gente con su comida. Sus hijos tampoco se quejan de su afición favorita. Incluso le encanta ver programas de cocina, especialmente concursos como "Chopped" o "Top Chef", y le gustan los dramas/documentales de crímenes. Un dato curioso sobre Tamara: ¡le encanta cantar en el karaoke!

Carta del Presidente

Queridas familias del NDSC,

Parece que lo hemos conseguido y que se avecina un nuevo día. Pero con este nuevo día, debemos seguir preguntándonos a nosotros mismos y a los demás, como junta directiva y personal, ¿cómo lo hacemos mejor? ¿Cómo podemos acoger a las familias, especialmente a las de las minorías, que no se han sentido incluidas en el pasado? ¿Cómo reducimos o eliminamos las barreras para que todas las familias puedan participar? ¿Cómo cumplimos la misión de nuestra organización de proporcionar información, defensa y apoyo en relación con todos los aspectos de la vida de las personas con síndrome de Down y cumplir nuestro propósito de promover los intereses de las personas con síndrome de Down y sus familias mediante la defensa, la concienciación pública y la información?



Durante un año en el que el mundo era muy diferente de lo que habíamos visto antes, muchas organizaciones se esforzaron por cumplir su misión. Nosotros, utilizando el tópico, cogimos los limones que nos dio la pandemia e hicimos limonada. El año pasado por estas fechas, anunciamos que nuestra convención anual sería un evento virtual. Fue una decisión difícil en ese momento, pero los limones se nos habían dado. Aprendimos de la experiencia que nunca ha habido un mejor momento para llevar a cabo nuestro trabajo. Gracias al uso de la tecnología, hemos defendido más ampliamente y proporcionado más información a las personas con síndrome de Down y a sus familias que nunca antes.

Los acontecimientos que se produjeron en nuestra nación el verano pasado nos empujaron a organizar tres reuniones del Ayuntamiento en las que se abordaron las relaciones raciales en nuestra comunidad. Aunque habíamos sido conscientes de que debíamos acoger a todos, para ser sinceros, nunca habíamos mantenido las difíciles pero necesarias conversaciones que se necesitan para que nuestra organización y nuestra comunidad avancen. Estas conversaciones incómodas son un primer paso para entendernos mejor, de modo que podamos crecer como individuos y como organización, y para ayudar a garantizar que seamos acogedores para todos en nuestra comunidad.

Cuando volvimos a girar y empezamos a planificar la 49^a Convención Anual virtual de la NDSC, era lógico titular el evento "¡Un nuevo día!" Nos estamos preparando para ofrecer a las familias que confían en nosotros para obtener recursos, información y apoyo un evento virtual más grande y brillante de lo que jamás habíamos soñado. Hemos invertido en una sólida plataforma que permitirá a los asistentes tener toda la convención en la palma de su mano. Todo, desde los horarios, los detalles de los talleres, los archivos y los folletos, el Salón Virtual de Expositores y mucho más, está en un solo lugar. Espero sinceramente que usted y su familia se unan a nosotros del 21 al 26 de junio.

Ser miembro de la Junta Directiva de la NDSC ha sido un gran honor. Ver los cambios que estamos haciendo a través de los recursos que proporcionamos a las familias, y el impacto del trabajo de defensa que hacemos para apoyar a las personas con síndrome de Down y la comunidad de la discapacidad en su conjunto ha sido más que gratificante. Si está interesado en tener un mayor impacto en la comunidad del síndrome de Down, nos gustaría saber de usted. Siempre estamos buscando a nuestros futuros líderes.

Es un honor y un placer servirle a usted y a su familia. Gracias por su continuo apoyo al NDSC.

Sinceramente,

Shauntel Neal-Howe

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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:

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