Down Syndrome News

VOLUME 43, NUMBER 1 FIRST QUARTER 2020

NEWSLETTER OF THE NATIONAL DOWN SYNDROME CONGRESS

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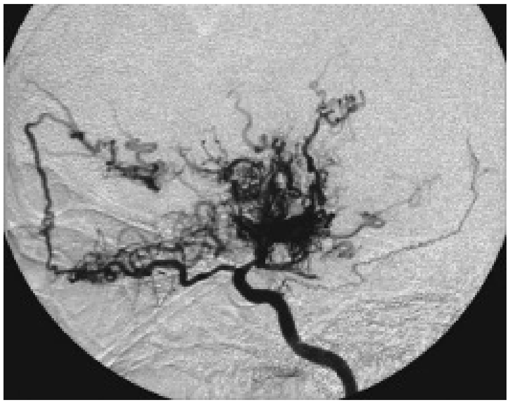
EN ESPAÑOL

Moyamoya Disease and Down Syndrome

Over the past decade, we've heard about more and more cases of moyamoya disease in the Down syndrome community.

Moyamoya is a rare, progressive, cerebrovascular disease caused by blocked arteries at the base of the brain, or narrowing of the internal carotid arteries. Moyamoya is a Japanese term for "puff of smoke", from the wispy tangles of new blood vessels that form when the body attempts to compensate for lower blood supply.



MRI showing the network of abnormal collateral vessels

Inadequate blood supply then leads to reduced oxygen delivery to the brain, and it is this oxygen deprivation that causes the signs of moyamoya. Symptoms are similar to those of a stroke, such as:

- weakness on one side of the body
- blurry or otherwise affected vision
- slurred speech
- headaches
- seizures

The standard tests for both diagnosing moyamoya and planning for surgery is an MRI or cerebral angiography. A delayed diagnosis can allow moyamoya disease to progress to a more advanced stage. While anyone can have moyamoya, research shows that individuals with Down syndrome are 2-3% more likely to develop the disease, which can be fatal if left undiagnosed. Because moyamoya is so rare, its causes are not fully understood. Moyamoya disease is slightly more common in girls than in boys, and somewhat more common in children of Asian descent than in other ethnic backgrounds.

There are several types of revascularization surgeries that can restore blood flow to the brain by opening narrowed blood vessels, or by bypassing blocked arteries. While children usually respond better to revascularization surgery than adults, the majority of individuals have no further strokes or related problems after surgery.

Continued on page 3...

Letter From the President

Dear Families,

Over the first weekend of the new year, our board and staff met in New Orleans to plan our course for 2020. One of the recurring themes was how do we make NDSC's resources and services more accessible? How do we reduce or remove barriers for families to participate? Out of our discussions came a couple of decisions with immediate financial benefit to you. First, we have eliminated standard membership dues. From now on, if you want to be a member of the NDSC, all you have to do is let us know. Once you're in, you'll stay in unless you tell us otherwise.

Another notable decision was to lower the individual registration fee for this year's NDSC Convention in New Orleans. Our annual "family reunion" is the world's largest gathering of individuals with Down syndrome, their families, and the professionals who work with them. Thousands come from around the globe to learn, laugh, and love at this one-of-a-kind event. Demand for both the conference and the destination (after all, who doesn't want to spend time in "The Big Easy"?) is high, so I encourage you to sign up as soon as registration opens on April 6th.

After 48 years, the Convention has grown to be better than ever, with programming expanding in breadth and depth. Of course, the best parts of our time together are the friendships developed and memories made throughout the weekend!

While highly visible and very enjoyable, the Convention is just a fraction of what we do throughout the year. We have continued to expand our outreach through one-day seminars in underserved areas. We are also taking our well-received Educators Conference on the road, impacting teachers and changing schools throughout the country. Of course, with this being an election year, the work of our Washington, DC-based Policy Team is more important than ever.

We continue to provide governance support for a variety of partner organizations. Our Policy and Advocacy Director, Heather Sachs, serves as Vice President for the Collaboration to Promote Self-Determination, an organization that focuses on employment, supports, and self-determination. She also serves as Co-Chair of the Consortium for Citizens with Disabilities Financial Security Task Force, which focuses on laws and policies to break the cycle of poverty for people with disabilities, and to help them become financially empowered and independent. NDSC Senior Policy Advisor Stephanie Smith Lee chairs the national Coordinating Center Accreditation Workgroup that is developing model program accreditation standards for postsecondary programs for students with intellectual disabilities and co-chairs the Inclusive Higher Education Committee that promotes improved policies and appropriations for programs for students with intellectual disabilities. Ricki Sabia, NDSC Senior Education Policy Advisor, serves as Parent Liaison to the technical assistance (TIES) national technical assistance center on inclusive practices and policies. And, Executive Director David Tolleson serves on the governance board of the National Institutes of Health Down Syndrome Consortium.

Throughout the year and through everything we do, the NDSC is focused on making the world a better place for you and your family. Thank you for your advocacy, as well as your ongoing financial support. We couldn't do it without you!

Gratefully,

Kishore Vellody

Kishore

Lagniappe: /lan'yap/ Noun: a bonus or extra gift

Convention Registration Opens April 6th—Are You Ready?

The NDSC Convention is a 4-day event designed to educate parents, family members, and caregivers, as well as medical and educational professionals. With the General Conference; Brothers & Sisters Conference; and the heart and soul of the weekend, Youth & Adult Conference as well as the Educators Conference there is something for everyone.

Make your plans to join us this June 25th – 28th in New Orleans, LA.

Important Registration Dates

Registration Opens: April 6th

Early Bird Deadline: May 8th

Registration Closes: June 5th

We Have Eliminated Membership Fees

Since our founding nearly 50 years ago, the NDSC has fought for inclusion and promoted easier access to needed services. In that spirit, our Board of Directors recently decided that we will no longer charge for membership. It's important to us that no one feels excluded from our family because they can't afford the annual membership fee. Supporting that decision was the fact that the NDSC Annual Convention has truly become a gathering place for the world Down syndrome community – an opportunity for our fellow organizations and the families and professionals we all support to come together. The more we can do to remove barriers to participation, the more it helps our community. After all, we're better all together!

NDSC is Going Green!

This will be the last edition of the *Down Syndrome News* that you will receive in your mailbox - The next edition will be in your inbox! If you would like to continue to receive a hard copy of the *Down Syndrome News* delivered to your home or business please visit our website at ndsccenter.org to sign up for your subscription.

Won't You Go Green With Us? When you've finished reading your Down Syndrome News, don't throw it away; please share it with another family, your doctor's office, or a school!

Moyamoya Disease and Down Syndrome (continued from page 1)

Without surgery, the majority of affected people experience recurrent strokes and gradual deterioration of cognitive function. No medication can stop the narrowing of the brain's blood vessels, or the development of the thin, fragile vessels that characterize the disease. However, medications are used to treat many of the symptoms of the disease and are often an important part of the management. Medications may include aspirin (to prevent or reduce the development of small blood clots); calcium channel blockers (which may improve symptoms of headaches and reduce symptoms related to transient ischemic attacks); and anti-seizure medications (when needed for a seizure disorder).

Greater awareness about moyamoya in patients with Down syndrome who are experiencing strokes, seizures and other related symptoms is needed amongst health care providers. The need for screening individuals with Down syndrome for moyamoya should be considered.

Sources:

- *GARD - Genetic and Rare Diseases Information Center*
- *NORD – National Organization of Rare Disorders*
- *Boston Children's Hospital*
- *Stanford School of Medicine – The Steinberg Lab*
- *ClinicalTrials.gov lists trials that are related to Moyamoya disease*

> ***"Everyone says 'in HINDSIGHT' or 'if I had known then what I do now'. My daughter was first diagnosed with Moyamoya in March 2016. The disease was in an advanced state. Many individuals can have success with the surgery to help if found early enough. I believe in individuals with Down syndrome some of the signs and symptoms are overlooked, as many doctors are not aware that of all Moyamoya patients, 24% of them have Down syndrome. My daughter Erin passed away July 19th, 2019 from complications from the disease mainly because it was detected too late. We need to educate the community that Moyamoya is not as "rare" as stated, so that others are diagnosed quickly to save more lives."***
>
> ***Maria Dellapina, Specs4Us***

SELF-ADVOCATE SPOTLIGHT

Jessica Leigh Smart

Jessica Leigh Smart, or as her friends call her, Jessie, is a dynamic young woman with an infectious smile, a heart of gold, and a passion for life. Jessie lives in Olive Branch, MS with her parents and her grandmother. Jessie will turn 31 this year and has lived in Olive Branch since moving there when she was just 16 months old. Jessie loves her community and the people of her community love her.

Jessie attended Olive Branch public schools and graduated from Lewisburg High School in 2009 with an occupational diploma. Although Jessie was very focused on her education, she did not miss out on the fun while in high school. She was voted Most School Spirited her senior year and Miss Congeniality in the Miss Lewisburg pageant. Jessie also took dance classes for 12 years and voice lessons for 5 years.

Jessie has an older brother named Justin, who lives in Jonesboro, AR with his wife, Christi, and Jessie's 2 nieces, Kaylee and Madison. She and her family are big love Ole Miss Football fans and have traveled to many games all over the country.

As a requirement of her diploma, Jessie worked in the Pre-K classroom in high and continued to work there even after graduation. When the Down Syndrome Association Memphis & Mid-South (DSAM) received a grant that was to be used to employ someone with Down syndrome to work in the office, they knew that Jessie would be the perfect fit, and she has been for the past 4 years. Jessie answers the phone, makes copies, puts packets together, opens the mail, and does just about anything that needs to be done.

> ***"Jessie works for us; so I get to see her strong work ethic. She is so devoted to her job. And, of course, she's so smart (but aren't all of our kids). It is a joy to have the opportunity to work with Jessie Smart. She has a strong work ethic and it shows in the job that she does for the Down Syndrome Association of Memphis and the Mid-South."***
>
> ***– Martine Hobson, Executive Director, Down Syndrome Association of Memphis and the Mid-South, and former NDSC Board Member.***

Jessie accompanies DSAM Executive Director, Martine Hobson, when speaking to businesses and schools in the area to educate them on the work of DSAM. Jessie also volunteers, serving as the chairperson for the wine pull at DSA Memphis & Mid-South's annual Get Down and Derby fundraiser.

Jessie also has a passion for advocacy. She was involved with the passing of the ABLE Act bill in MS and was with the Governor of MS when he signed it. She has served on the boards of local organizations such as DSAM for 6 years and national organizations such as the National Down Syndrome Congress.

Jessie attended her first NDSC Convention 7 years ago. At her second convention, she decided to run for the board.

She didn't win the election but in true "Jessie fashion" she didn't give up. She ran again the next year and won. After her term on the NDSC Board, Jessie really blossomed as a panelist for the second annual Self Advocate Bootcamp training session and looks forward to being involved again this summer in New Orleans.

Most people would describe Jessie as kind and compassionate, but also strong and independent. Last month Jessie and her grandmother's house, as well as her parent's home next door to theirs, were destroyed by a tornado. No one was hurt but it was very scary. They are working to rebuild one house that they will all live in, and it will have a pool!

Although it has been a rough start to the New Year, Jessie and her family are excited to buld their new home and as long, as everyone is safe and together it's all good. Jessie is looking forward to the NDSC Convention in New Orleans, seeing all of her friends, and of course, dancing!!!

> ***"I have had the pleasure of working alongside Jessie for many years on both local and national Down syndrome boards of directors. From the first time we met I have been impressed with her attentiveness to matters at hand and her desire to be a contributing member of not only the organization she is representing but also a contributor to the greater community. Jessie is kind and compassionate to others and passionate towards advocating for her herself and her peers. Whether she's attending a public event or mixing it up with national and state lawmakers, Jessie truly shines and I am proud to be able to call her my friend."***
>
> ***– Ray Jansco, former NDSC Board Member and DSAM President***

3rd Annual Advocacy Boot Camp

NATIONAL DOWN SYNDROME CONGRESS

2020

Thursday, June 25, 2020 | 8:00 AM–12:00 PM
FREE to all registered guests | RSVP required

Kick Off #NDSC2020

The 48th Annual NDSC Convention weekend kicks off Thursday, June 25th, with Advocacy Boot Camp. This intensive session will be led by NDSC Advocacy experts; staff, self-advocates, and community advocates who will give an overview of basic government processes of state and federal appropriations, define advocacy, and share their tips and experiences.

Advocacy Boot Camp is designed to be an Advocacy 101 mini-course with a focus on legislative advocacy, but even the most experienced advocate will walk away with something new and re-energized after joining the opens discussion on how to effectively engage with legislators.

NATIONAL DOWN SYNDROME CONGRESS
PARENT WEBINAR SERIES

Access recorded sessions at
www.NDSCCENTER.org
Convention
Webinars

Convention 101:

What is the NDSC Annual Convention and Why Should You Go?

2020 Educators Conference

NATIONAL
DOWN SYNDROME
CONGRESS

EFFECTIVE PRACTICES FOR STUDENTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: TOOLS FOR TODAY'S CLASSROOM

June 25, 2020 • 8:15 AM–4:00 PM
$129 per person • 6 CEU Credits
Hyatt Regency—New Orleans

Calling All Educators!

Join the National Down Syndrome Congress for a one-day conference designed just for educators working to enhance outcomes for their students with Down syndrome, autism, and other intellectual and developmental disabilities.

Practical in nature, this 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, and behavioral practices. Attendees will leave equipped with ideas, tips, strategies, tools, and solutions that they can implement in the classroom.

For more information including registration details, presentation abstracts, learning objectives, and presenter information visit ndsccenter.org – Annual Convention – Educator Conference, June 25, 2020

FUNDraise for NDSC

Text "BEADS" to 44321 to get started

Become our PARTNER for the 48th Annual Convention by making a donation or creating your own personal fundraising page.

Your efforts will help NDSC enhance our services and offerings, extend our outreach to rural and urban communities, and continue to support the families who need it the most.

TOGETHER let's bring our LAGNIAPPE to the BIG EASY!

The TOP fundraiser will be acknowledged at the convention during our Saturday night Masquerade Ball. Let the FUNDraising and FRIENDraising begin!

2020 COLLEGE FAIR

NATIONAL
DOWN SYNDROME
CONGRESS
48th ANNUAL CONVENTION

NEW ORLEANS, LA

3:00 PM – 5:30 PM
June 26

FREE to all NDSC Convention attendees
No RSVP required

A collaboration with THINK COLLEGE! College Options for People with Intellectual Disabilities

NDSC will hold our second College Fair on June 26, at the 48th Annual NDSC Convention in New Orleans. This event is a collaboration with Think College and will be a great opportunity for self-advocates and families to meet college representatives to learn more about postsecondary programs for students with intellectual disability.

Nominations Are Now Being Accepted Through April 15th For The NDSC Board of Directors

Are you interested in making a bigger impact in the Down syndrome community? We are looking for the right individuals to fill upcoming open seats on the NDSC Board of Directors. The National Down Syndrome Congress Board of Directors is composed of twenty-one parents, family members of individuals with Down syndrome, self-advocates, and professionals who work with the Down syndrome community. The Board of Directors is responsible for carrying out and shaping NDSC policy as well as overseeing the fiduciary responsibility of the organization. The Board Director elections will be held at the NDSC's General Membership Meeting at 4:00 PM, Friday, June 26, 2020, during the 48th Annual NDSC Convention in New Orleans, LA.

Nominations Deadlines

- **Nominations for Directors to be elected by the NDSC General Membership will be accepted through April 15, 2020.**
- **Nominations for Self-Advocate Directors must be submitted before May 1, 2020.**
- **Nomination forms can be found on the NDSC website at ndsccenter.org - About NDSC - Board of Directors**

- **NDSC Board Directors are elected by the membership of the NDSC to a three-year term.**
- **Any NDSC member in good standing is eligible for nomination to the Board of Directors.**
- **Individuals may self nominate or may be nominated by a third party individual or organization also in good standing.**
- **Elected members are expected to attend bi-annual Board/Staff meetings. Meetings are generally held in the Convention host city. One of the two meetings has historically been held the week of the Convention, and a mid-year meeting is held in January.**
- **Board members comprise the committees and strategic teams who carry out the work of the NDSC.**
- **Members will sit on one or more of these working groups and are expected to attend the work group's meetings usually conducted via conference call or webinar**
- **Each year one self-advocate is elected to the Board of Directors by their peers during the Youth and Adult Conference during the annual convention. All individuals with Down syndrome, age 22 and older, are eligible to run for the NDSC Board of Directors.**
- **Executive Officers are elected by the other Board members to serve one-year terms.**

NDSC Members are invited to attend the Annual General Membership Meeting to meet our newest self-advocate board member, who will be elected by his/her peers at the Youth & Adults Conference kick-off, at the 48th Annual Convention. Attendees will also hear reports from the NDSC Treasurer, NDSC Foundation Trustees, and an overview of activities by our Executive Director. The Nominating Committee will present its slate of candidates and the election of new NDSC board members will take place. Other business will be conducted as warranted.

Friday, June 26th, at 4:00 PM
Hyatt Regency Hotel New Orleans
601 Loyola Avenue
New Orleans, LA 70113

48th Annual Convention Souvenir Journal Messages

Included with every NDSC Convention registration is a copy of the 2020 NDSC Souvenir Journal. a Souvenir Journal message is a great way to show your support of the work of the NDSC or an individual who will certainly be honored to be featured in the book.

Exhibitors, speakers, vendors, families, and other members of the community are invited to place a message in the NDSC Convention Souvenir Journal.

Messages may provide information, recognition, well wishes, or may memorialize or honor an individual. Business logos and photos may be included. All funds received will be used to offset the cost to produce the Souvenir Journal for the 2020 convention. All orders for ads need to be placed by May 1, 2020.

For more information regarding ad specifications, requirements, pricing, and how to order please email sarah@ndsccenter.org.

2020 Census—What You Will Be Asked and Why

The 2020 Census is easy. The questions are simple. Responses to census questions provide a snapshot of the nation. Census results affect your voice in government, how much funding your community receives, and how your community plans for the future. When you fill out the census, you help:

- **Determine how many seats your state gets in Congress.**
- **Inform how more than $675 billion in federal funding is distributed to states and communities each year.**
- **Create jobs, provide housing, prepare for emergencies, and build schools, roads and hospitals.**

The 2020 Census will ask for the following information:

Number of people at address - We ask this question to collect an accurate count of the number of people at each address on Census Day, April 1, 2020. Each decade, census results determine how many seats your state gets in Congress. State and local officials use census counts to draw boundaries for congressional districts, state legislative districts, and school districts.

Any additional people living or staying there - Our goal is to count people once, only once, and in the right place according to where they live on Census Day. Keeping this goal in mind, we ask this question to ensure that everyone living at an address is counted.

Owner/Renter - We ask about whether a home is owned or rented to create statistics about homeownership and renters. Homeownership rates serve as an indicator of the nation's economy and help in administering housing programs and informing planning decisions.

Phone number - We ask for a phone number in case we need to contact you. We will never share your number and will only contact you if needed for official Census Bureau business.

Name - We ask for names to ensure everyone in the household is counted. This also helps us to keep ancestry records. Listing the name of each person in the household helps respondents include all members, particularly in large households where a respondent may forget who was counted and who was not.

Sex - We ask about the sex of each person to create statistics about males and females. Census data about sex is used in planning and funding government programs, and in evaluating other government programs and policies to ensure they fairly and equitably serve the needs of males and females. These statistics are also used to enforce laws, regulations, and policies against discrimination in government programs and in society.

Age and date of birth - We ask about age and date of birth to understand the size and characteristics of different age groups and to present other data by age. Local, state, tribal, and federal agencies use age data to plan and fund government programs that provide assistance or services for specific age groups, such as children, working-age adults, women of childbearing age, or the older population. These statistics also help enforce laws, regulations, and policies against age discrimination in government programs and in society.

Hispanic, Latino, or Spanish origin - We ask about whether a person is of Hispanic, Latino, or Spanish origin to create statistics about this ethnic group. The data collected in this question is needed by federal agencies to monitor compliance with anti-discrimination provisions, such as the Voting Rights Act and the Civil Rights Act.

Race - We ask about a person's race to create statistics about race and to present other statistics by race groups. The data collected in this question is needed by federal agencies to monitor compliance with antidiscrimination provisions, such as the Voting Rights Act and the Civil Rights Act.

Whether a person lives or stays somewhere else - Our goal is to count people once, only once, and in the right place according to where they live on Census Day. Keeping this goal in mind, we ask this question to ensure individuals are not included at multiple addresses.

Relationship - We ask about the relationship of each person in a household to one central person to create estimates about families, households, and other groups. Relationship data is used in planning and funding government programs that provide funds or services for families, people living or raising children alone, grandparents living with grandchildren, or other households that qualify for additional assistance.

For more information, visit: 2020CENSUS.GOV.

NDSC is thrilled to announce the launch of NDSC merchandise on Amazon.

Visit our website at NDSCCenter.org
Support & Get Involved
Shop NDSC
to shop for products.

Dive In to the NDSC Convention and Take Learning to a New Level

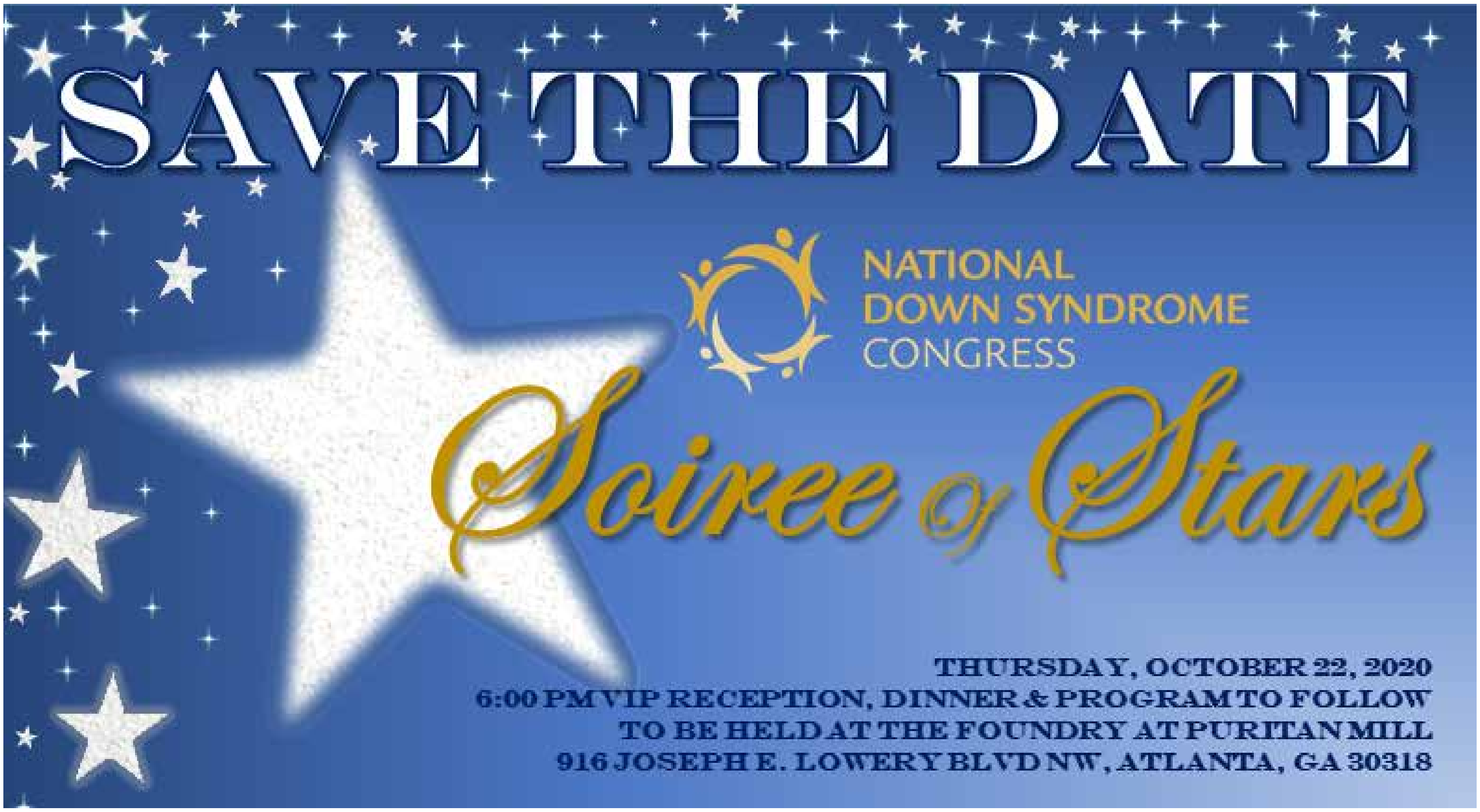
Deep Dive sessions allow attendees the chance to spend four hours with a nationally known presenter engaging in in-depth learning and discussion on one specific topic. Content presented in these Deep Dive sessions is research-based, and presented with best practices and provide proven "how-to" strategies. All sessions will include session handouts for each attendee but are only available to those in attendance. Each session will also include time for Q & A.

Deep Dives sessions are an Add-On to General Conference registration and require a separate registration and additional fees. Attendees may register for only one Deep Dive session as all sessions will be held simultaneously Friday, June 26th from 8:00 AM – 12:00 PM. Space is limited in most sessions, so register early. On-site registration will be available but cannot be guaranteed.

A Glimpse at Some 2020 Deep Dive Sessions and Speakers

Stacy Taylor	**Behavior News You Can Use!**
Libby Kumin	**The Goal Is Understandable Speech**
Kathy Everett	**IEP Bootcamp**
Sean Smith and Mitch Rothholz	**Practical Tips & Strategies to Enhance Inclusion in the General Education Classroom**
Charlotte Gray and Jeanne Doherty	**DS-ASD 101 Understanding the Basics of Co-Occurring Down Syndrome and Autism Spectrum Disorder**
Terri Couwenhoven	**There's No Place Like Home…For Sexuality Education: Supporting Healthy Sexuality Throughout the Lifespan**
Rob Snow	**The Improvaneer Method: The missing Link to Increasing Social and Workplace Opportunities**

For more detailed information about all Deep Dive sessions and speaker information visit ndsccenter.org – Annual Convention – Deep Dives.



SAVE THE DATE

NATIONAL DOWN SYNDROME CONGRESS

Soiree of Stars

THURSDAY, OCTOBER 22, 2020
6:00 PM VIP RECEPTION, DINNER & PROGRAM TO FOLLOW
TO BE HELD AT THE FOUNDRY AT PURITAN MILL
916 JOSEPH E. LOWERY BLVD NW, ATLANTA, GA 30318

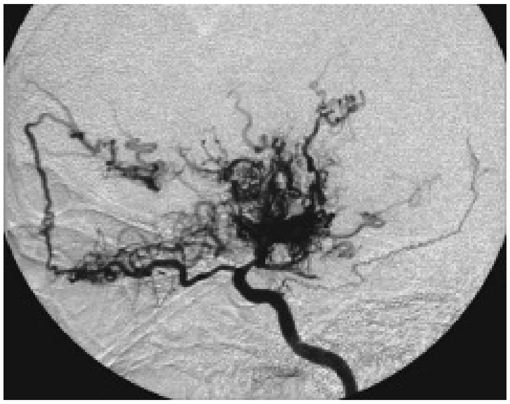
The FIRST NDSC Soiree of Stars

The National Down Syndrome Congress is thrilled to announce the date of our first ever Soiree of Stars Gala to be held October 22, 2020. Look for more details in the coming weeks. For more information or to learn about sponsor opportunities email NDSC Development Director, Christine Milano, at Christine@NDSCCenter.org.

Enfermedad Moyamoya y Síndrome de Down

En la ultima década hemos escuchado mas y mas sobre casos que involucran la enfermedad moyamoya en la comunidad de síndrome de Down.

Moyamoya es enfermedad infrecuente, progresiva, cerebrovascular causada por arterias bloqueadas en la base del cerebro o por la contracción de las arterias carótidas interiores. Moyamoya es un termino Japones que describe "bocanada de humo" por los enredos finos de los nuevos vasos sanguíneos que forman cuando el cuerpo trata de compensar por suministro de sangre bajos.



IRM enseñando la red anormal de vasos sanguíneos colaterales

Vaso sanguíneo no adecuado que causa suministro de oxigeno reducido al celebro, y es esta carencia de oxigeno que es lo que causa síntomas de moyamoya. Síntomas son similares a los de una embolia, como los siguientes:

- Debilidad en un lado del cuerpo
- visión borrosa o afectada
- habla arrastrada
- dolores de cabeza
- convulsiones

Las pruebas estándar para diagnosticar moyamoya y planificar la cirugía son una resonancia magnética o una angiografía cerebral. Un diagnostico demorado puede permitir que la enfermedad moyamoya progrese a una etapa avanzada. Si bien cualquiera puede tener moyamoya, la investigación muestra que las personas con síndrome de Down tienen un 2-3% más de probabilidades de desarrollar la enfermedad, que puede ser fatal si no se diagnostica. Debido a que moyamoya es tan raro, sus causas no son entendidas completamente. La enfermedad moyamoya es un poco mas común en niñas que en niños, y algo más común en niños de ascendencia asiática que en otros orígenes étnicos.

Hay varios tipos de cirugías de revascularización que pueden restablecer el flujo sanguíneo al cerebro abriendo los vasos sanguíneos estrechos o desviando las arterias bloqueadas. Aunque los niños suelen responder mejor a la cirugía de revascularización que los adultos, la mayoría de los individuos no tienen más accidentes cerebrovasculares o problemas relacionados después de la cirugía. Sin cirugía, la mayoría de las personas afectadas experimentan apoplejías recurrentes y un deterioro gradual de la función cognitiva. Ningún medicamento puede detener el estrechamiento de los vasos sanguíneos del cerebro o el desarrollo de los delgados y frágiles vasos que caracterizan a la enfermedad. Sin embargo, los medicamentos se utilizan para tratar muchos de los síntomas de la enfermedad y suelen ser una parte importante del tratamiento. Los medicamentos pueden incluir la aspirina (para prevenir o reducir el desarrollo de pequeños coágulos de sangre); bloqueadores de los canales de calcio (que pueden mejorar los síntomas de los dolores de cabeza y reducir los síntomas relacionados con los ataques isquémicos transitorios); y medicamentos anticonvulsivos (cuando se necesitan para un trastorno convulsivo).

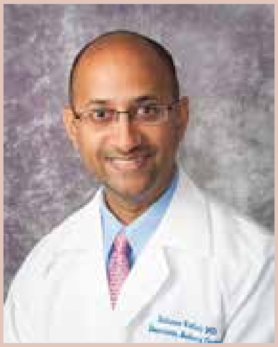
Se necesita una mayor conciencia sobre la moyamoya en pacientes con síndrome de Down que están experimentando derrames cerebrales, convulsiones y otros síntomas relacionados entre los proveedores de atención médica. Se debe considerar la necesidad de examinar a los individuos con síndrome de Down para detectar moyamoya.

Fuentes:

- *GARD (por sus siglas en ingles) - Centro Informático de Enfermedades Genéticas y Extraños*
- *NORD (por sus siglas en ingles) – Organización Nacional Organization de Enfermedades Raras*
- *Hospital Infantil de Boston*
- *Escuela de Medicina Stanford – Laboratorio Steinberg*
- *ClinicalTrials.gov lista de estudios relacionados con la enfermedad Moyamoya*

> ***"Todos dicen, 'en RETROSPECTIVA' o 'si supiera lo que se ahora'. Mi hija fue diagnosticada por primera vez con Moyamoya en marzo del 2016. La enfermedad estaba en una etapa avanzada. Mucho individuos pueden tener éxito con la cirugía si es diagnosticado en una etapa temprana. Yo creo que con individuos con síndrome de Down ciertos signos y síntomas son sobrepasados, muchos doctores no saben que de todos los pacientes con Moyamoya, 24% de ellos tienen síndrome de Down. Mi hija Erin falleció el 19 de julio del 2019 de complicaciones de la enfermedad, y fue principalmente por que fue detectado muy tarde. Tenemos que educar a nuestra comunidad de que la enfermedad Moyamoya no tan "infrecuente" como muchas veces es dicho, para que otros puedan ser diagnosticados mas rápido y salvar mas vidas."***
>
> ***Maria Dellapina, Specs4Us***

Mensaje del Presidente



Queridos Amigos,

Durante el primer fin de semana de este año, nuestra mesa directiva se reunió en Nueva Orleans para planear nuestro camino del 2020. Uno de los temas recurrentes era, ¿como logramos hacer los recursos y servicios del NDSC mas accesibles? ¿Como reducimos o quitamos barreras para que familias puedan participar? De nuestras discusiones salieron varias decisiones que tendrán un beneficio inmediato financiero. Primero, hemos eliminado cuotas de membresía estándar. De ahora en adelante, si quieres ser miembro del NDSC, lo único que tienes que hacer es dejarnos saber que quieres ser miembro. En cuanto te conviertas miembro te mantendrás como miembro al menos que nos pidas que te quitemos.

Otra decisión notable fue que reducimos la cuota de inscripción individual para esta Convención en Nueva Orleans. Nuestra "reunión de familia" anual es la reunión mas grande del mundo de personas con síndrome de Down, sus familias y los profesionales que trabajan con ellos. Miles vienen de todo el mundo para aprender, reír, y amar en este evento único. La demanda tanto para la conferencia como del destino (después de todo, ¿quién no quiere pasar tiempo en "The Big Easy") es alta, así que les animo a que se inscriban tan pronto se abra la inscripción el 6 de abril.

Después de 48 años, la Convención ha crecido para ser mejor que nunca, con una programación que se expande en amplitud y profundidad. Por supuesto, lo mejor de nuestro tiempo juntos son las amistades desarrolladas y los recuerdos hechos durante el fin de semana!

Aunque nuestra Convención es muy visible y muy agradable, es solo una fracción de lo que hacemos a lo largo del año. Hemos seguido ampliando nuestro alcance a través de seminarios de un día en zonas desatendidas. También estamos llevando nuestra bien recibida Conferencia de Educadores por el a diferentes comunidades, impactando a los maestros y cambiando las escuelas en todo el país. Por supuesto, siendo este un año de elecciones, el trabajo de nuestro equipo de póliza con base en Washington, DC es importante mas que nunca.

Seguimos prestando apoyo en materia de gobernanza a diversas organizaciones asociadas. Nuestra Directora de Póliza y Defensa, Heather Sachs, es la Vicepresidenta de la Colaboración para la Promoción de la Autodeterminación, una organización que se centra en el empleo, el apoyo y la autodeterminación. También se desempeña como Co-presidenta del Grupo de Trabajo de Seguridad Financiera del Consorcio para Ciudadanos con Discapacidades, que se centra en leyes y políticas para romper el ciclo de pobreza de las personas con discapacidades, y para ayudarlas a ser económicamente autónomas e independientes. La Asesora Principal de Pólizas del NDSC, Stephanie Smith Lee, preside el Grupo de Trabajo de Acreditación del Centro de Coordinación Nacional que está desarrollando normas de acreditación de programas modelo para programas post secundarios para estudiantes con discapacidades intelectuales y co-preside el Comité de Educación Superior Inclusiva que promueve políticas y apropiaciones mejoradas para programas para estudiantes con discapacidades intelectuales. Ricki Sabia, Asesor Superior de Pólizas de Educación de NDSC, sirve como enlace de los padres con el centro nacional de asistencia técnica (TIES) sobre prácticas y políticas inclusivas. Y, el Director Ejecutivo David Tolleson es miembro de la junta de gobierno del Consorcio del Síndrome de Down de los Institutos Nacionales de Salud.

A lo largo del año y de todo lo que hacemos, la NDSC se centra en hacer del mundo un lugar mejor para ti y tu familia. Gracias por su defensa, así como por su continuo apoyo financiero. No podríamos hacerlo sin ustedes!

Con gratitud,

Kishore Vellody

Kishore

Jueves, 25 de junio 2020 8:00 AM - 12:00 PM
GRATIS para todos los asistentes a la Convención de NDSC
Se Requiere Reservación

Lanzamiento NDSC2020 en el Campamento de Entrenamiento Abogacía

La 48ª Convención Anual de la NDSC comienza el jueves 25 de junio con el campamento de entrenamiento de abogacía. Esta sesión intensiva será dirigida por expertos en defensa de NDSC; personal, autodefensores y defensores de la comunidad que darán una visión general de los procesos básicos de gobierno de los créditos estatales y federales, definir la defensa, y compartir sus consejos y experiencias.

El campamento de entrenamiento de abogacía está diseñado para ser un minicurso de Abogacía 101 (fundamentos) con un enfoque en la defensa legislativa, pero incluso el defensor más experimentado saldrá con algo nuevo y revitalizado después de unirse a la discusión abierta sobre cómo participar efectivamente con los legisladores.

Lagniappe in the Big Easy

NATIONAL DOWN SYNDROME CONGRESS

48TH ANNUAL CONVENTION

Lagniappe: /lan'yap/ Noun: a bonus or extra gift

Inscripción para la Convención se abre el 6 de abril, ?esta listo?

La Convención NDSC es un evento de 4 días diseñado para educar a los padres, familiares y cuidadores, así como a los profesionales médicos y educativos. Con la Conferencia General; la Conferencia de Hermanos y Hermanas; y el corazón y el alma del fin de semana, la Conferencia de Jóvenes y Adultos, así como la Conferencia de Educadores, hay algo para todos.

Haga sus planes para acompasarnos el 25-28 de Junio en Nueva Orleans, Louisiana.

Fechas de Inscripción Importantes

Se abre la inscripción: 6 de abril

Fecha limite anticipada : 8 de mayo

Se cierra el registroL 5 de junio

NATIONAL DOWN SYNDROME CONGRESS

SERIE DE WEBINARS PARA PADRES

Acceda a la sesión grabada en
www.NDSCCENTER.org
Convention
Webinars

Convención 101:

¿Qué es las Convención NDSC y por qué debería ir?

Este al tanto - Aprenda de los que saben

Webinar de la Convención en español

Aprenda todo lo que necesita saber sobre la 48ª Convención Anual de la NDSC y por qué debe asistir.

2020
COLLFERIA UNIVERSITARIA
EGE FAIR
NATIONAL DOWN SYNDROME CONGRESS
18th ANNUAL CONVENTION
NEW ORLEANS, LA
3:00 PM – 5:30 PM
de junio 26
GRATIS para todos los asistentes a la Convención de NDSC
No se requiere Reservación
Una colaboración con THINK COLLEGE! College Options for People with Intellectual Disabilities

Feria Universitaria

La NDSC celebrará su segunda Feria Universitaria el 26 de junio, en la 48ª Convención Anual de la NDSC en Nueva Orleans. Este evento es una colaboración con Think College y será una gran oportunidad para que los autodefensores y las familias se reúnan con los representantes de las universidades para aprender más sobre los programas postsecundarios para estudiantes con discapacidad intelectual.

INFORMACIÓN BÁSICA SOBRE EL CENSO: LO QUE USTED NECESITA SABER

¡El Censo del 2020 está más cerca de lo que usted cree! Esto es un repaso rápido de lo que es y de por qué es esencial que todos sean contados.

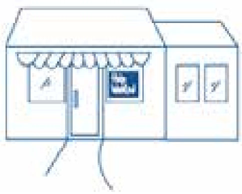
Todos cuentan

El censo cuenta a todas las personas que viven en los Estados Unidos una vez, solo una vez y en el lugar correcto.

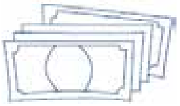
Se trata de una representación justa

Cada 10 años, los resultados del censo se usan para llevar a cabo la redistribución proporcional de la Cámara de Representantes, determinando cuántos representantes recibe cada estado.

Las empresas utilizan los datos del censo

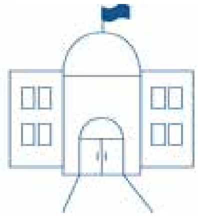


Las empresas usan los datos del censo para decidir dónde construir fábricas, oficinas y tiendas, lo cual crea empleos.



Distribución de Fondos

La distribución de más de $675 mil millones de fondos federales, subsidios y apoyo a los estados, condados y comunidades se basa en los datos del censo. Ese dinero se usa para escuelas, hospitales, carreteras, obras públicas y otros programas vitales.

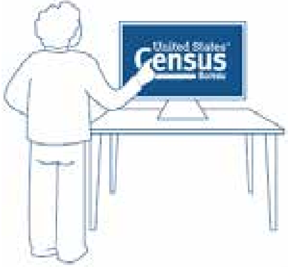


Los gobiernos locales utilizan el censo

Los gobiernos locales usan el censo para la seguridad pública y la preparación para emergencias..

El 2020 será más fácil que nunca

En el 2020, usted podrá responder al censo por internet.



Su privacidad está protegida

Es contra la ley que la Oficina del Censo divulgue públicamente sus respuestas de cualquier manera que pudiera identificarle a usted o a su hogar. Por ley, sus respuestas no pueden ser usadas en su contra y solo pueden ser usadas para producir estadísticas.

Para mas información visite 2020census.gov

United States Census Bureau
United States Census 2020

Ahora se están aceptando nominaciones para la Junta Directiva de la NDSC

¿Le interesa tener un mayor impacto en la comunidad del síndrome de Down? Estamos buscando a los individuos adecuados para llenar los próximos puestos vacantes en la Junta Directiva del NDSC. La Junta Directiva del Congreso Nacional del Síndrome de Down está compuesta por padres, familiares de personas con síndrome de Down, autodefensores y profesionales que trabajan con la comunidad del síndrome de Down. La Junta Directiva es responsable de llevar a cabo y dar forma a la política del NDSC, así como de supervisar la responsabilidad fiduciaria de la organización. Las elecciones de directores de la Junta se llevarán a cabo en la reunión general de miembros del NDSC a las 4:00 PM, el viernes 26 de junio de 2020, durante la 48ª Convención Anual del NDSC en Nueva Orleans, LA.

Fecha límite de las Nominaciones

- **Se aceptarán nominaciones para directores que serán elegidos por los miembros generales del NDSC hasta el 15 de abril de 2020.**
- **Las nominaciones para Directores Autodefensores deben ser presentadas antes del 1 de mayo de 2020.**
- **Las solicitudes de nominación se pueden encontrar en el sitio web del NDSC en ndsccenter.org - Acerca de NDSC - Junta Directiva**

Los miembros de la NDSC están invitados a asistir a la Reunión General Anual de Miembros para conocer a nuestro más reciente miembro de la junta de auto-defensa que será elegido por sus pares en la Conferencia de Jóvenes y Adultos que se llevará a cabo en la 48ª Convención Anual. Los asistentes también escucharán informes del tesorero del NDSC, de los fideicomisarios de la Fundación NDSC, y una visión general de las actividades de nuestro Director Ejecutivo. El Comité de Nominaciones presentará su lista de candidatos y se llevará a cabo la elección de los nuevos miembros de la junta del NDSC. Otros asuntos se llevarán a cabo según se justifique.

Viernes 26 de junio a las 4:00PM
Hyatt Regency Hotel Nueva Orleans
601 Loyola Avenue
New Orleans, LA 70113

- **Los directores de la Junta Directiva de la NDSC son elegidos por los miembros de la NDSC por un período de tres años.**
- **Cualquier miembro de la NDSC que esté al día con su membresía es elegible para ser nominado a la Junta Directiva.**
- **Los individuos pueden auto nominarse o pueden ser nominados por una tercera persona u or-ganización también en regla.**
- **Se espera que los miembros elegidos asistan a las reuniones bianuales de la Junta Directi-va/Personal. Las reuniones se celebran generalmente en la ciudad anfitriona de la Convención. Una de las dos reuniones se ha celebrado históricamente la semana de la Convención, y una reunión de mitad de año se celebra en enero.**
- **Los miembros de la Junta son los comités y equipos estratégicos que llevan a cabo el trabajo de la NDSC.**
- **Los miembros se sentarán en uno o más de estos grupos de trabajo y se espera que asistan a las reuniones del grupo de trabajo que normalmente se llevan a cabo a través de conferencia tele-fónica o webinar**
- **Cada año, un autogestor es elegido para la Junta Directiva por sus pares durante la Conferencia de Jóvenes y Adultos en la convención anual. Todos los individuos con síndrome de Down, de 22 años o más, son elegibles para presentarse a la Junta Directiva del NDSC.**
- **Los Oficiales Ejecutivos son elegidos por los otros miembros de la Junta para servir durante un año.**

Sesión de inmersión profunda de la Convención ¡Solo para hispanohablantes!

Acompáñenos el viernes 26 de junio de 8:00 AM a 12:00 PM para una conversación en profundidad con Hilda Torres mientras hablamos sobre Expectativas y Estrategias del Habla y Lenguaje en Personas con Síndrome de Down.

Down Syndrome News

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website: ndsccenter.org

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.

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Down Syndrome News

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To renew or join, visit ndsccenter.org.
To update your contact information, call 800-232-6372 or email 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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CONGRESS

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Down Syndrome News

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