Down Syndrome News

VOLUME 42, NUMBER 3

NEWSLETTER OF THE

THIRD QUARTER 2019



People Joined us in Pittsburgh for #NDSC2019

They came from all over the globe to be a part of the greatest family reunion in the world! We saw friends from 47 states, the District of Columbia, and 14 countries, including Bermuda, Brazil, Canada, Chile, Colombia, Dominican Republic, El Salvador, Guatemala, Kenya, Mexico, Nigeria, Puerto Rico, Switzerland, and United Arab Emirates.



NATIONAL DOWN SYNDROME CONGRESS

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Letter From the President

Dear Families,

As you know, the 47th annual NDSC convention was held in Pittsburgh, PA. What you may not know is that Pittsburgh is my hometown. Although I grew up in Chicago, I have rooted my career and family in Pittsburgh. I want to thank everyone who was part of the amazing NDSC team that did an outstanding job bringing the NDSC, one-of-a-kind, convention to Pittsburgh. Thank you to all of the presenters and speakers, each and every sponsor and vendor, to the NDSC staff and the volunteers, and thank you to the families who attended and were a part of the "greatest family reunion" in the world.

It was an amazing weekend for me and my family. For the first time, they were convention attendees. They left the weekend feeling educated, prepared to advocate, empowered and inspired, and my brother Das, who is the inspiration behind my life's work, felt like a celebrity. I have to say, having him on stage with me during the opening Main Event was a highlight for both of us and a cherished time that neither of us will forget.

Work is underway for next year's convention and we can already feel the excitement building around being in New Orleans. Of course, we are working on a lot of projects outside of the convention. Currently, we are preparing for two Rural Outreach Programs, one in Central Nebraska on September 21st and one in Central Wisconsin on November 2nd, and soon we will release the lineup of Parent Webinars for the remainder of the year. We are constantly updating the website (ndsccenter.org) so that you have resources available day or night. The staff at the National Center is available to assist, so don't hesitate to reach out if we can help you in any way.

Take care,

Kishore

2

Kolme Vello

lolunteers

gave their time and energy to make the 47th Annual NDSC Convention run seamlessly. We are so grateful to our new and returning friends who helped ensure the weekend ran smoothly.





at the Research and Medical Care Roundtable hosted by Global Down Syndrome Foundation and at the LuMind IDSC Research Rally









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attended the "Heart and Soul" of the weekend; the Youth & Adult Conference! Everyone had a great time with friends, old and new; enjoyed fun activities; and experienced an empowering and inspiring few days celebrating all self-advocates!











attended the Brothers & Sisters Conference. They went on a field trip to Heinz Field and rode the Gateway Clipper.







People Took a 339 "Deep Dive" Into Pre-Conference Sessions.





SELF-ADVOCATE SPOTLIGHT Tony Piontek

Tony Piontek is the youngest of the seven children in his family. He was born in Guayama, Puerto Rico. Tony's first years were rough as he underwent pancreas surgery at birth and at age 3 Tony was diagnosed with Acute Myelomonocytic Leukemia (an adult form of leukemia). After four years of aggressive chemotherapy and radiation, he was finally declared in remission and given a clean bill of health.

At the age of seven, Tony and his family moved to New Iberia, Louisiana, where Tony fully entrenched in the "Cajun" culture. It was at this time that Tony was diagnosed with Mosaic Down Syndrome. Tony went on to attend New Iberia High School where he was a Combination (Regular/Special Ed) Student. He was a peer tutor, active in the Library Club, and was involved in many activities including Scouts where he earned his Eagle Scout badge. Tony also competed in Special Olympics internationally where he earned multiple medals, including gold in Aquatics. Tony graduated from New Iberia Senior High in 1994.

Scouting has been a major part of Tony's life. Tony has enjoyed being a Troop Assistant Scoutmaster where he can use his leadership skills to be an example and to inspire young boys to live the Scout values. He taught at the University of Scouting while developing a program for adults wanting to charter troops for boys with special needs. Tony has received many awards for his work with the Scouts. They include the Catholic Committee on Scouting Religious Award (2011), the William J. McGoffen Award (2011), the 2010 St. George Award, the 2009 Bronze Pelican Award, and the 2008 Scouting Scroll of Honor.

Tony has also been very active in his local Down syndrome organization since its inception in 2004. In 2007 Tony was named to the Down Syndrome Association of Acadiana (DSAA), Board of Directors and DSAA Advisory Board. He has been involved with DSAA participating in events such as the DSAA Buddy Walk and Santa at Christmas parties. He also sends birthday greetings to DSAA members and has served as their activities photographer.

In 2008 Tony attended his first NDSC Convention. Just three years later Tony was elected to the NDSC Board of Directors as a selfadvocate representative. Tony has served on many panels, presented workshops at NDSC Conventions, and has been an integral member of the NDSC Self-Advocate Council where he has been involved in



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the Greeters Program, the Speakers' Bureau, the Book Project, and has been a part of the Development Committee.

Because his siblings are now spread out across the globe, Tony has become quite a world traveler, visiting places such as Italy, France, Corsica, Poland, Germany, Austria, Mexico, as well as Las Vegas, the Florida Keys and many other cities in the U.S. over the years.

Tony keeps himself very busy and is always an advocate and voice for the Down syndrome community. He feels that his most important job is to be a VOICE for all families who have children with Down syndrome.



Kids' Campers

enjoyed magicians, games, and meeting new friends.





105 (2/,605' Car













134 Medical Experts & Researchers Attended the DSMIG Conference

The Down Syndrome Medical Interest Group (DSMIG) – USA met in conjunction with the NDSC annual convention. DSMIG-USA® members and other professionals working in the field of Down syndrome research and healthcare, including physicians, research scientists, nurses, Down syndrome clinic coordinators, psychologists, dietitians, occupational and physical therapists, speech-language pathologists, and social workers came together to share knowledge and experiences related to the care of children and adults with Down syndrome. Many of the professionals in attendance also served as workshop presenters and shared their expertise with convention attendees.

125 Advocates Attended the 2nd Advocacy Boot Camp



gave their time and expertise to give NDSC 2019 attendees a world-class experience and to arm them with knowledge.

Educators Attended the Educator Conference

First Responders

received training that they will carry with them throughout their careers to better serve their communities.





Talent Show Contestants Put on a Show!

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During the NDSC Convention workshops, there were many questions about The Learning Program and LP Online. Below are some of the most common inquiries:

What Is The Learning Program?

The Learning Program is a platform developed in collaboration with researchers for sharing strategies, resources, and activities to improve academic outcomes for students with Down syndrome. Parent/Teacher sessions equip participants with the knowledge and tools to work effectively with students with Down syndrome in home and school settings. Student sessions focus on building literacy, math and social skills, with speech and occupational therapy components. Instructional content is delivered through face-to-face sessions with parents, teachers, and students. Most program resources are printed and distributed onsite.

What Is LP Online?

DSF works with NDSC's Center for Outreach & Education to deliver LP Online. LP Online is an online learning community based on The Learning Program. It also serves as a vehicle for sharing strategies, resources, and activities, but because the classroom is virtual, participants can progress at their own pace, as convenient. Instructional content is delivered through webinars in live and on-demand formats. Resources are provided through video demonstrations, online links, and printable PDFs.

How Are Sessions Structured?

Both programs consist of ten sessions created to support the development of literacy and math skill and address general topics related to education, such as accessing the curriculum, fostering independence and memory. Parents and teachers work through program levels depending on the age and skill level of each student with whom they work.

For most students, the levels break down as follows:

- **Pre-K & Level 1** support students in preschool through 1st grade
- Level 2 supports students in 2nd or 3rd grade
- Levels 3 & 4 support students in 4th through 6th grade

Can I Still Register And What Is The Cost?

Registration for The Learning Program usually opens in August (but may differ depending on your location). Feel free to contact us at info@dsfoc.org if you have questions about registering and we can direct you to the appropriate contact person and organization. Tuition varies based on partner and location, ranging from \$35 -\$60 per month (\$350-\$600 per year). Tuition includes both participation in sessions and take-home materials. Most partners offer partial to full



scholarships for those who demonstrate financial need.

Registration for LP Online is available year-round through DSF's website at https://www.dsfoc.org. Tuition is \$20 per month (\$200 per year). Tuition includes access to DSF's LP Online Classroom Level 1, 2 or 3. DSF offers partial to full scholarships for those who demonstrate financial need.

Do I Need To Enroll In These Programs To Access Resources?

Not at all. There is a very large inventory of free resources available through the DSF website. To access these resources, you simply register as a "user" on the website (for free) and use the menu to navigate to the literacy or math resources you need.

Have Questions?

Even if you do not enroll in one of our programs, please feel free to reach out with educational questions or to find resources that may be supportive to you in your educational journey.

For those with whom we already work, whether in California, across the nation or through the NDSC Convention, thank you! Together, we are making great progress towards effective education and community inclusion for all learners with Down syndrome.



Playback <mark>Now</mark>i

Access to all recorded sessions was included in the 2019 Convention Attendee Registration. All registered attendees should have received an email with instructions to access their free account. If you could not attend #NDSC2019 or would like to upgrade to a downloadable or flash drive subscription visit www.playbackndsc.com. Packages start at just \$129.



were on display with free information and items for sale. This included 14 sponsors and 65 general exhibitors. Exhibitors traveled from 25 states and included 18 self-advocate entrepreneurs, 35 nonprofit organizations, and 26 for-profit entities.





SPONSORS

We depend on the generosity of our convention sponsors to support our convention each year. Their donations allow us to keep the cost of registration at a minimum, help us offer a limited number of scholarships, and provide simultaneous interpretation for our Spanish-speaking attendees. Many sponsors also serve as workshop presenters and partner hosts for events such as the Research and Medical Care Roundtable, Research Rally, Kids' Camp, Advocacy Boot Camp, and the 321 Dance![™].

SpecialCare

Gateway Health.

Specs Aus

ABLEnow



Monongahela Level

UPMC CHILDREN'S

28

Kids' Camp



Three Rivers Level



Ohio Level

Clipper Level



DSDN

Down Syndrome Association of Minnesota

DOWN SYNDROME

AFFILIATES IN ACTION





UPMC HEALTH PLAN

Majestic Level



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2019 NDSC Exceptional Meritorious Service Award - Sheila Cannon – Pittsburgh, PA



2019 Pueschel-Tjossem Memorial Research Award - LuMind IDSC Foundation -Burlington, MA



NDSC Board Service Awards were presented to – Kathleen Forney, Minneapolis, MN; Chandra Torry – Ocala, FL (pictured); and self-advocate, Katie Kremer, Las Vegas, NV. Also receiving recognition for their service but not in attendance were Julie Harmon, Andy Bean, and Jeannie Visootsak.

2019 NDSC President's Award

- Global Down Syndrome

Foundation - Denver, CO.



2019 Outstanding Affiliate Organization -Down Syndrome Connection of the Bay Area - Danville, CA

D NDSC Awards Were Presented

as we recognized the following organizations and individuals who have made extraordinary contributions to research, advocacy, and awareness of the Down syndrome community.

- 2019 NDSC Convention Support Award
 The 2019 Pittsburgh Host Committee Pittsburgh, PA.
- 2019 Sig Pueschel Service Award -Madeleine Will – Washington, D.C.
- 2019 NDSC Award for Media "Intelligent Lives" – Dan Habib, Film Maker
- 2019 NDSC Education Award Endrew F. and Parents



2019 NDSC Employer of the Year Award -Giant Eagle – Pittsburgh, PA



Colleges Exhibited at the 1st EVER NDSC College Fair.

Thanks to a collaboration with Think College, colleges from around the country joined us in Pittsburgh to discus



in Pittsburgh to discuss options for students with intellectual disabilities to attend postsecondary education programs.

6 Films Were Highlighted at the 2019 NDSC Film Festival

Pittsburah. PA

2019 NDSC President's Award

- Down Svndrome Center

of Western Pennsvlvania at

UPMC Children's Hospital -

A <mark>special</mark> thanks to Gail Williamson of Kazarian/Measures/Ruskin & Associates Talent Agency, Studio City, CA for once again coordinating the NDSC Film Festival. The 2019 Film Festival brought a wonderful mix of fiction and documentary pieces.

Akron. OH

Just released in theaters on August 9th was "The Peanut Butter Falcon". Although not a featured film at the Film Festival, several NDSC staff members were invited to a prerelease preview of the movie. All who have viewed it have given it a "thumbs up" and would recommend it to viewers over the age of 13 (rated PG-13) as there is some strong language.

Christian Pueschel Memorial

Citizen Award - Todd Eisinger -

A review from Rotten Tomatoes calls it a modern Mark Twain style adventure story, THE

PEANUTBUTTER

PEANUT BUTTER FALCON tells the story of Zak (Zack Gottsagen), a young man with Down syndrome, who runs away from a residential nursing home to follow his dream of attending the professional wrestling school of his idol, The Salt Water Redneck (Thomas Haden Church). A strange turn of events pairs him on the road with Tyler (Shia LaBeouf), a small-time outlaw on the run, who becomes Zak's unlikely coach and ally. Together they wind through deltas, elude capture, drink whiskey, find God, catch fish, and convince Eleanor (Dakota Johnson), a kind nursing home employee charged with Zak's return, to join them on their journey.

ndsccenter.org

AMAZING DAYS IN PITTSBURGH





were elected at the Annual General Membership Meeting. Maggie Erickson from Apple Valley, MN, who was nominated by her self-advocate peers; Dr. Nicole Baumer, a sibling and Director of the Boston Children's Hospital Down Syndrome Program; and, Daniel Chaplin, a member of NDSC's Self-Advocate Council, from Homewood, AL will serve on the NDSC Board of Directors for a 3-year term.



Maggie Erickson is a past board member of the Down Syndrome Association of MN. She enjoys speaking for DSAMN and volunteering with Jack's Basket and Gigi's Playhouse in Minnesota where she lives. Maggie is a graduate of the BUILD program at Bethel University. She is currently employed by the MN Twins and MN Vikings and holds a volunteer data entry position. She lives in her own apartment and is part of a dance troupe with friends with Down syndrome.



Nicole Baumer, MD, MEd, of Chestnut Hill, MA, is a boardcertified pediatrician, child neurologist, and neurodevelopmental disabilities specialist, and Director of the Boston Children's Hospital Down Syndrome Program. She received both her medical and master's degrees from Harvard University. Dr. Baumer, who has a sister, Heather, who has Down syndrome, serves on the Board of Directors of both the Federation for Children with Special Needs and the Down Syndrome Medical Interest Group - USA.







Daniel Chaplin lives in Homewood, AL, is a member of NDSC's Self-Advocate Council, having previously been elected to the organization's Board of Directors by his peers. Daniel has worked at a law firm for 8 years, is a competitive ballroom dancer, and is actively pursuing his goal of completing a half-marathon in each of the 50 states.













Looking Ahead to #NDSC2020 The Excitement is Already Building in New Orleans!

The plans are in the works and we are well on our way to an amazing convention in New Orleans. Local affiliate organizations are calling, sponsors are reaching out, and the New Orleans Convention & Visitors Bureau is preparing for our arrival. Here is a glimpse of what is already in store for our attendees!

- A special "New Orleans Second-Line Parade"
- Complimentary admission to New Orleans City Park Amusement Park and Storyland Theme Park
- Complimentary admission for children ages 2-12 to the Aquarium of the Americas, the Audubon Zoo, and the Insectarium

2020 Sponsorship Opportunities

Does your company want to be a part of our 48th Annual Convention in the celebratory town of New Orleans? We are already working with sponsors for next year, as the requests are coming in early! No matter how small, or how large your company is, we will find the place for you. Come join us in NOLA- NDSC 2020 is going to be FABULOUS!

If you are interested or would like more information, contact Kathy Edwards (404) 242-3640 – Kathy@ndsccenter.org or Rhonda Rice (678) 770-6641 – Rhonda@ndsccenter.org.







Convención del NDSC

Divirtiéndose. Aprendiendo. Haciendo Amistades. Esto es lo que puede esperar cuando asiste a nuestra convención anual y es exactamente lo que sucedió. ¡Esperamos que nos acompañe en Nueva Orleans,del 25 al 28 de junio de 2020!







Alcance Hispano El NDSC ha estado viajando:

Viajamos a Colombia para ser parte del 7º Congreso Iberoamericano. Estuvimos en Tejas para una conferencia de un día (en español) para muchas familias latinas y maestros para aprender mas sobre el síndrome de down.





Guía para hermanos mayores" ndsccenter.org Nuestro Director del Programa Multicultural viajó a El Paso, Tejas, para presentar nuestra "Guía para hermanos mayores" en español. Los hermanos adultos que quieran estar presentes en la vida de su hermano o hermana pero no estén familiarizados con todos los datos relacionados pueden utilizar este manual para hablar con sus padres y saber cómo ser un buen defensor, amigo y, tal vez, cuidador de su hermano cuando sus padres ya no puedan. ¿Interesado en traer esta presentación a su área? Envíe un correo electrónico a Mateo Fernández a matthew@ndsccenter.org.

Novedades en el cuidado del síndrome de Down

El 8 de noviembre del 2018 De Down Syndrome World caso 3 2018

George T. Capone es uno de los autores principales de la Medical CareGuidelinesforAdultswith Down Syndrome (guía para el cuidado médico de adultos con síndrome de Down). Actualmente, Capone continúa con su trabajo sobre la mejora del cuidado médico probado para las personas con síndrome de Down.

El doctor en medicina George T. Capone ha pasado los últimos 30 años especializándose en el tratamiento e intervenciones documentados y de calidad para las personas con síndrome de Down. Como investigador científico, director del Instituto Kennedy Krieger de síndrome de Down y del centro de investigación (DSCRC por sus siglas en inglés), y profesor asociado de pediatría en la facultadde medicina de la Universidad de Johns Hopkins; ha visto más de 2500 pacientes cuyo rango de edad varía desde la infancia hasta la tercera edad. El Dr. Capone contribuye desde los años 1980 a la mejora del cuidado de los adultos con síndrome de Down.

Gracias a su amplio conocimiento, experiencia y pasión; Capone fue elegido para unirse al grupo de médicos e investigadores que se encargan de actualizar la guía para el cuidado médico de adultos con síndrome de Down, un proyecto que surge de la mano de la Global Down SyndromeFoundation.

Defensor de la investigación traslacional

La trayectoria de Capone en el tratamiento de la guía para el cuidado médico de adultos con síndrome de Down comienza en 1988 cuando crea un grupo de neurobiología en la facultadde medicina de la Universidad de Johns Hopkins. En ese momento los investigadores de la Johns Hopkins, incluyendo su mentor, Joseph T. Coyle (doctor en medicina), estaban llevando a cabo un estudio innovador en el campo de la genética que conectaba el síndrome de Down con el Alzheimer. Uno de los proyectos que presenció en el laboratorio del Dr. Coyle fue una investigación que utilizaba ratones con trisomía 16 para estudiar el impacto de las tres copias del cromosoma 21 (la característica específica del síndrome de Down) en los principios del Alzheimer. Este fueuno de los primeros estudios en la materia.

Su estancia en el laboratorio de Coyle incrementó el interés de Capone en la aplicación directa del estudio sobre la salud y el bienestar de los pacientes con síndrome de Down. Se unió al Instituto Kennedy Krieger a principios de los años 1990 donde descubrió que el DSCRC proporcionaba la oportunidad para desarrollar hipótesis y vías de investigación sobre la base neurobiológica y neuroconductual del deterioro cognitivo asociado al síndrome de Down. La diversidad clínica del grupo permite la «investigación clínica centrada en la persona y enfocada en las condiciones de salud médicas y mentales que vemos a diario». El estudio, además de beneficiar a pacientes con síndrome de Down, beneficia también a personas con enfermedades correlacionadas con este síndrome, como el Alzheimer, la apnea del sueño y algunas enfermedades cardíacas.

El DSCRC, encabezado por Capone, ha realizado varias investigaciones de diferentes tipos que incluyen el espectro del autismo y la deficiencia de atención o hiperactividad. Estos estudios han ayudado a caracterizar el autismo en los niños con síndrome de Down, perfiles del desarrollo y neuroconductuales poco comunes en niños y adolescentes,así como el retraso en el desarrollo en personasde todos las edadesque poseen el síndrome.

Además, ha dirigido varios ensayos farmacológicos de medicamentos para la mejora de la memoria y la cognición tanto en niños como en adultos. En estos se incluyen la risperidona, guanfacina y rivastigmina.

La ciencia es fascinante y las condiciones médicas asociadas, complejas y sorprendentes. Las familias con las que trabajo son encantadoras. Siempre me quedo sorprendido con los niños y adultos con los que interactúo» afirma Capone.

En la creación de nuevas vías para el cuidado médico de los adultos

Capone está de acuerdo conque un mayor conocimiento e implicación por parte de los padres y los profesionales de la salud, el establecimiento de clínicas especializadas como EL DSCRC y los avances en el cuidado médico y quirúrgico de los niños, ha ayudado a progresar en cuanto al cuidado de las personas con síndrome de Down. Aun así, a pesar de las contribuciones, es necesario investigar más en este campo para poder mejorar la calidad de vida de estas personas.

Es necesario entender el origen patogenético y los factores de riesgo asociados a ciertas condiciones médicas, así

como qué tipo de tratamientos y estrategias de prevención son los más beneficiosos para los pacientes. También es necesaria una mejor organización de la información para mejorar la toma de decisiones clínica, el conocimiento del paciente y del cuidador, y la calidad de vida» explica Capone.

La guía para el cuidado médico de adultos con síndrome de Down permitirá mejorar la toma de decisiones clínicas v los resultados sanitarios. Las guías actuales disponibles para adultos con síndrome de Down datan del 2001 ya no se adaptan al hecho de que la esperanza de vida en estas personas ha sobrepasado el doble de edad desde los años 1980. A medida que aumenta la esperanza de vida de los adultos con síndrome de Down, estos requieren cuidados específicos para su edad y los factores de riesgo que conlleva.

Muchos médicos que se encargan de los adultos no tienen una formación adecuada para tratar las necesidades de las personas con condiciones genéticas y neuroconductuales especiales. Las condiciones médicas que experimentan los adultos pueden parecer sobrecogedoras y fuera del alcance para muchos médicos, pero con la formacióny los recursos adecuados podemos formar a los proveedores de atención primaria y otros cuidadores para que puedan realizar su trabajo cuidado para adultos con seguridad dice Capone.

La creación de nuevas guías pondrá de manifiesto lo poco que sabemos sobre las "mejores prácticas" cuando se trata de un adulto con

síndrome de Down que envejece y que sufre de condiciones médicas crónicas. Espero que esto genere mayor interés y más investigación enel, a menudo olvidado, campo de la investigación clínica.

Para saber más sobre el cuidado de adultos con síndrome de Down visita globaldownsyndrome.org/our-story/linda-crnic-institute.

Este artículo La importancia del sistema inmune en las personas con síndrome de Down, fue escrito y publicado por la galardonada revista Down Syndrome World ™, una publicación de la Fundación Mundial del síndrome de Down. Traducción al español dentro del proyecto para la traducción gratuita de páginas web y documentos para ONG y asociaciones sin ánimo de lucro. Proyecto dirigido por Mondo Agit. Traductora: Candela Gómez

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Executive Director: David Tolleson

Editor: Rhonda Rice

General Correspondence and Memberships: National Down Syndrome Congress 30 Mansell Court, Suite 108 Roswell, GA 30076

phone: 800.233.NDSC | 770.604.9500 fax: 770.604.9898 email: info@ndsccenter.org 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.

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

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Down Syndrome News

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30 MANSELL COURT, SUITE 108 ROSWELL, GA 30076 WWW.NDSCCENTER.ORG 800.232.NDSC (6372) 770.604.9500 INFO@NDSCCENTER.ORG

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