NATIONAL DOWN SYNDROME CONGRESS

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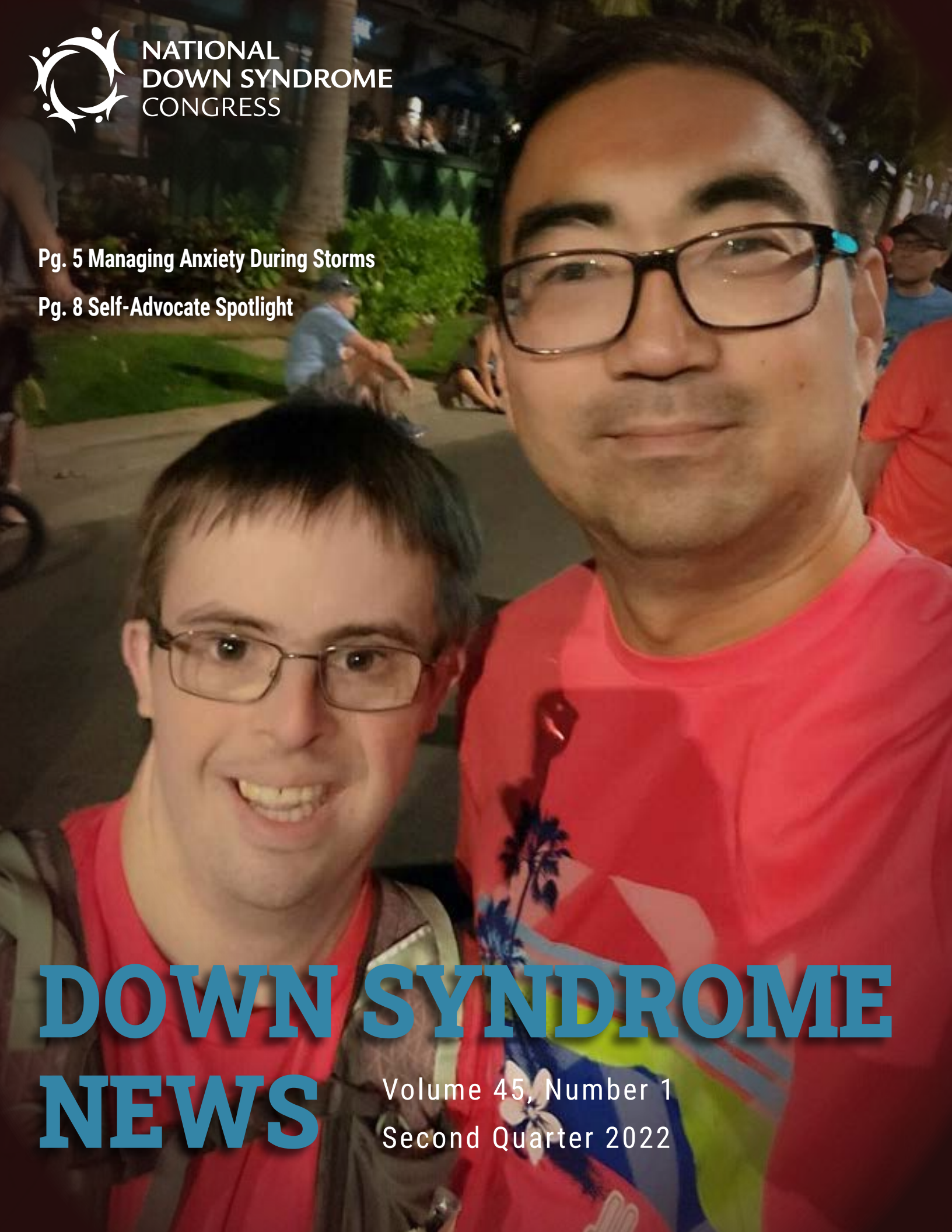

DOWN SYNDROME NEWS

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BEHIND THE PICTURE

with Daniel Chaplin

Refer to the cover image (pg.1) taken at the Hapalua Half-Marathon in Honolulu this April with NDSC Executive Director, Jordan Kough.

I first got interested in running in 2012, when I took a health class at Samford, where the final exam was to complete a 5k. This was really hard for me since I have Down syndrome. But after that, I did many more 5ks, one 10k, one 5-mile. Then I heard from several friends of mine about the Talladega half marathon, So, I entered the race. This was my very first half marathon. I ended up sleeping for more than 18 hours afterward since I had never run that long of a distance before.

I had read and heard some people talking about a great club, the 50 States Half marathon club, which I joined. That is when I started my journey to complete a half marathon in all 50 states. I hope to become the first person with Down syndrome to accomplish this.

All of this training and running has changed me in a significant way. Whether it is just standing at the start line of one of my half marathons, standing at the start line of my first ever marathon, or standing at the start line of any race I break down in tears. I find myself having to fight the tears because I never thought I'd be able to run a half marathon, marathon, or any race since I have had to overcome so many odds and obstacles associated with Down syndrome.

My friends and family have supported me throughout this journey. I would like to encourage people to realize that they have a lot of potential to be successful and that they can do whatever they put their mind to. Everyone who has Down syndrome is very special and can make an impact on this world to show everyone that individuals with Down syndrome are able to participate in more physical activities. It also shows that individuals with Down syndrome really are **More Alike Than Different.**

Letter From the President

To all the supporters of the NDSC,

I want to recognize all of you as you have withstood the difficulty of these nearly two and a half years, during what has been a uniquely challenging, and even scary, time for so many of us. The NDSC has postponed our last two in-person Conventions — an event that represents one of the most important, rejuvenating, and connective times for NDSC families.

Today, though, I am delighted to write to you as we embark on what we hope is our "new normal." Below are some of the exciting NDSC events in the past quarter, and a list of more to come.

This year we hosted an amazing golf tournament in Atlanta with over 150 supporters. The event was led by Grand Marshall David Saville, who brought one of his multiple championship rings, flashing it for all our attendees to see. We raised nearly $50,000 to support the NDSC's critical work, but perhaps the highlight of the day was a player hitting a hole-in-one and winning $50,000 himself. Join us for next year's tournament for your own chance to win $50,000!

In April, we joined national leaders in the Down syndrome community for a policy symposium (Image directly left). Among guests like Judy Heumann, author of Being Heumann, and Kayla McKeon, the first registered lobbyist with Down syndrome, I felt lucky to partner with esteemed leaders to discuss the future of our joint efforts, including how organizations can support one another and how the community can grow together toward inclusion. As we take these steps to work symbiotically, we have the opportunity to "10x" the return on our efforts — a theme shared consistently at the event — and I believe that this rejuvenating weekend led to important steps forward for our entire community.

I would be remiss if I didn't conclude by mentioning **NDSC's 50th Annual Convention in New Orleans**. I couldn't be more proud as the President of the Board to present this event that has touched the lives of so many people with Down syndrome. This year's Convention will bring together the history of who we are and all that we have learned, and many of the lessons left to learn that lie ahead of us.

But Convention is special not only because of the event's lineup of tremendous speakers and activities, but also because of the families there with us. Because travel is more expensive than ever, due to escalating gas prices and limited flights, we have **extended Early Bird pricing** through the entire pre-registration process, to make it possible for families like yours to attend this special event. I know I'll be there, and I hope you'll be able to join us for the excitement at the Hyatt Regency New Orleans, June 23-26, 2022.

Shauntel Neal Howe
Board President
National Down Syndrome Congress

Managing Anxiety During Storms

We received a question from a family member of an individual with Down syndrome who is anxious and fearful of bad weather, particularly thunderstorms. Thunder, lightning, strong winds, heavy rain, hail, and other weather phenomena can be a source of anxiety and fear for some individuals with Down syndrome. We have shared a list of tips for managing anxiety during storms below.

- It can be helpful for some individuals to make a plan for the next time there is a storm.
  - Questions to answer in the plan could include: Where will I go during the storm? What will I do during the storm? What will I do if the storm happens during the middle of the night? Who can I ask for help?
- When a storm starts, reassure the individual. Remind them that the storm will pass.
- If seeing the storm is distressing, close the window blinds or move into a room without windows.
- If hearing the storm is distressing, try wearing ear plugs to reduce the noise. You can also try listening to music or watching a TV show or movie (with or without headphones) to reduce the noise.
- Consider using sensory strategies to help the individual calm down. These strategies could include using a weighted product such as a blanket, doing joint compression, or squeezing a stress ball, among many others. For more information on sensory strategies, please see our sensory resources at this link.
- Encourage the individual to do calming activities such as taking deep breaths, counting to ten, or stretching/doing yoga. We have a visual handout with several calming activities at this link.
- Ask the individual what would make them feel better. Encourage the individual to do an activity such as coloring, watching TV or a movie, listening to music, reading, doing an exercise video or other indoor exercise, working on a puzzle, or performing household chores. A list of additional activities you can do at home can be found at this link.
- Avoid watching weather reports on TV or following weather updates on phones, tablets, or computers.

If these strategies do not provide relief, consider scheduling an assessment with a healthcare or mental health provider to explore other therapies to reduce anxiety. Recommendations on how to find a mental health provider are described in this resource.

This article is from Advocate Medical Group Adult Down Syndrome Center's online resource Library: adscresources.advocatehealth.com

Please note: The information on this site is for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health, or behavioral evaluation, diagnosis, or treatment plan by a qualified professional. We recommend you review the educational material with your health providers regarding the specifics of your health care needs.

Dr. Brian Chicoine

Dr. Brian Chicoine has provided medical care to individuals with Down syndrome for over 30 years. He graduated from Loyola University of Chicago Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital.

Plenary Keynote Speakers

Jake Pratt is a 23-year-old advocate for those with Down syndrome who regularly raises awareness and works to break down barriers for the community. In 2017, Jake went viral when he scored a touchdown for his high school football team, Vestavia Hills. This media attention enabled him to promote inclusion and advocate for individuals with Down syndrome, showing the world that you can achieve your dreams when you work hard. Jake proved this again when he achieved his dream of attending and graduating from college upon completing the ClemsonLIFE program at Clemson University.

Jake has achieved yet another milestone since his graduation just a few years ago. After working in a few different part-time positions, Jake landed his dream job. In 2020, Jake started working as a part-time seasonal employee with UPS over the holidays. His team quickly saw his commitment and capability during this time, and not long after, Jake was offered a full-time position with UPS. He gladly accepted the offer and continues to work there today.

Jake has been a vital advocate in the Down syndrome community. Not only has he been speaking out on social media and educating his followers, but he shows the world daily through his actions that people with Down syndrome have valuable contributions to the world.

Debbie Antonelli was a three-year starter on N.C. State's women's basketball team, playing for the legendary coach, the late Kay Yow, and is currently the leading broadcast analyst of women's basketball.

Debbie works for ESPN, Big Ten Network, CBS, FOX, and Westwood One. She also calls WNBA games for ESPN and NBATV and has been the play-by-play voice of the Indiana Fever since 1996. Debbie, a two-time Emmy-award winner, has also received the Gracie Award for her work in broadcasting basketball. She was also honored with the WBCA Mel Greenberg Award, which recognizes a media, marketing, or sports communications professional who has best displayed a commitment to women's basketball and advancing the media's role in promoting the women's game.

Debbie is the mother of three sons. Her middle son, Frankie, a student at ClemsonLIFE, has Down syndrome. Debbie has been an advocate, and when not broadcasting, she raises awareness and funds for those with Down syndrome. Frankie was the inspiration for her annual "24 Hours Nothing But Net" fundraiser benefitting Special Olympics. Each year Debbie raises thousands of dollars through the fundraiser by shooting 100 free throws every hour for 24 hours.

Learn more about our 2022 keynote speaker, Debbie Antonelli, at https://espnpressroom.com/us/bios/debbie-antonelli.

Debbie with her son, Frankie.

Research to Develop the Human Trisome Project Biobank

Research Opportunity

The purpose of this study is to provide qualified and approved researchers with access to biological samples and health information to answer specific research questions. This project will significantly increase the speed of Down syndrome research and the understanding of associated medical conditions such as leukemia and Alzheimer's disease.

Who can participate?

Anyone 6 months to 89 years old who: (1) has Down syndrome, or (2) has a family member with Down syndrome, or (3) does not have Down syndrome.

Email us at dsresearch@cuanschutz.edu to learn more and participate.
You can also call us at 303-724-0491.

Want more information? Check out our www.trisome.org website to learn more about the science enabled by the Biobank.

Congratulations to our Hole-in-One winner at this year's All Kinds of Heroes Golf Classic!

Self-Advocate Spotlight

Bradley Carlisle

Bradley Carlisle, 32 years old, lives in Jackson, GA, with his host parents Ms. Andrea and Chuck, step-brother Ryan, and best friend, Wesley. The boys call themselves the Wolfpack. Bradley has a large extended family and many friends he loves spending time with. His mom and stepdad live nearby and his dad lives in Florida. He also has what he calls his "Dunwoody family," the Arnos. Sheryl and Richard Arno and their children, welcome Bradley into their home regularly so he can be involved with activities at the Jewish Community Center like Habima theater.

Bradley is involved with his community through activities at the Jewish Community Center and volunteering with several local organizations. Bradley loves to be around people and perform for them. He just finished playing the role of Skye in the Habima Theater's production of Mama Mia! Bradley loves anything to do with music and musical performances. His favorite musical is CATS which he has seen seven times! He has been a guest head usher at the Fox Theater in Atlanta and three years ago, he had the opportunity to be a Guest Cat for the evening. He wore full stage makeup like the performers, experienced the show backstage, and was even invited to go on stage!

Bradley attended Coralwood School, a public school in the suburbs of Atlanta dedicated to serving children with and without special needs between three and six years of age. He then attended Rock Chapel Elementary, Conyers Middle School, and Tucker High School. Bradley loved school and the routine his classes provided. He enjoyed the learning opportunities that were available and had fun.

Bradley advocated for and helped pass Gracie's Law. Gracie's Law is legislation in Georgia that aims to prevent organ transplant discrimination based on any ability. In the past, people with disabilities have been denied organ transplants based on misconceptions about the quality of life and bias in medicine. Gracie's Law was passed due to the hard work of self-advocates and our disability rights community.

Bradley continues to work hard at building better advocacy skills through the My Voice, My Board, My Participation program and now serves on the Down Syndrome Association of Atlanta Board. He was also chosen as the DSAA Self-Advocate of the Year in 2020.

Bradley and his family have been involved with NDSC since he was born. His mother, Debbie, was a valuable partner as the DSAA President when the annual Convention was in Atlanta. Bradley attended his first conference as an adult in 2019 at the Convention in Pittsburgh. He loved participating in the Youth & Adults conference and is planning to attend this year's Convention in New Orleans. His mother will also attend as an attendee and volunteer. We look forward to seeing them both there!

Sign up at www.signupgenius.com/go/10c0e4dafa82da3fcc16-ndsc

Lagniappe in the Big Easy

50th National Down Syndrome Congress Annual Convention

VOLUNTEERS NEEDED!

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Manejo De La Ansiedad Durante Las Tormentas

Recibimos una pregunta de un miembro de la familia de una persona con síndrome de Down que está ansiosa y temerosa del mal clima, particularmente de las tormentas eléctricas. Los truenos, relámpagos, vientos fuertes, lluvias torrenciales, granizo y otros fenómenos meteorológicos pueden ser una fuente de ansiedad y miedo para algunas personas con síndrome de Down. A continuación, compartimos una lista de consejos para controlar la ansiedad durante las tormentas.

- Puede ser útil para algunas personas hacer un plan para la próxima vez que haya una tormenta.
  - Las preguntas a responder en el plan podrían incluir: ¿Adónde iré durante la tormenta? ¿Qué haré durante la tormenta? ¿Qué haré si la tormenta ocurre durante la mitad de la noche? ¿A quién puedo pedir ayuda?
- Cuando comience una tormenta, tranquilice a la persona. Recuérdele que la tormenta pasará.
- Si ver la tormenta es angustioso, cierre las persianas de las ventanas o muévase a una habitación sin ventanas.
- Si escuchar la tormenta es angustioso, trate de usar tapones para los oídos para reducir el ruido. También puede intentar escuchar música o ver un programa de televisión o una película (con o sin auriculares) para reducir el ruido.
- Considere el uso de estrategias sensoriales para ayudar a la persona a calmarse. Estas estrategias podrían incluir el uso de un producto pesado como una manta, hacer presión en las articulaciones o apretar una pelota antiestrés, entre muchos otros. Para obtener más información sobre estrategias sensoriales, consulte nuestros recursos sensoriales en este enlace.
- Anime a la persona a realizar actividades relajantes, como respirar profundamente, contar hasta diez o estirarse/hacer yoga. Tenemos un folleto visual con varias actividades relajantes en este enlace.
- Pregúntele a la persona qué la haría sentir mejor. Anime a la persona a realizar una actividad como colorear, mirar televisión o una película, escuchar música, leer, hacer un video de ejercicios u otro ejercicio en el interior, armar un rompecabezas o realizar tareas domésticas. Puede encontrar una lista de actividades adicionales que puede hacer en casa en este enlace.
- Evite ver informes meteorológicos en la televisión o seguir las actualizaciones meteorológicas en teléfonos, tabletas o computadoras.

Si estas estrategias no brindan alivio, considere programar una evaluación con un profesional de la salud física y/o mental para explorar otras terapias para reducir la ansiedad. En este recurso se le hacen recomendaciones sobre cómo encontrar un proveedor de salud mental.

Este artículo es de la biblioteca de recursos en línea del 'Advocate Medical Group Adult Down Syndrome Center': adscresources.advocatehealth.com.

Tenga en cuenta: La información en este sitio es solo para fines educativos y no pretende servir como sustituto de una evaluación, diagnóstico o plan de tratamiento médico, psiquiátrico, de salud mental o conductual realizado por un profesional calificado. Le recomendamos que revise el material educativo con sus proveedores de salud con respecto a los detalles de sus necesidades de atención médica.

Dr. Brian Chicoine
El Dr. Brian Chicoine ha brindado atención médica a personas con síndrome de Down durante más de 30 años. Se graduó de la Facultad de Medicina de la Universidad Loyola de Chicago y completó su residencia en Medicina Familiar en el Lutheran General Hospital.

Autodefensor Destacado

Bradley Carlisle

Bradley Carlisle, de 32 años, vive en Jackson, GA, con sus padres anfitriones, la Sra. Andrea y Chuck, su hermanastro Ryan y su mejor amigo, Wesley. Los chicos se hacen llamar 'La manada de lobos'. Bradley tiene una gran familia extendida y muchos amigos con los que le encanta pasar tiempo. Su mamá y su padrastro viven cerca y su papá vive en Florida. También tiene lo que él llama su "familia Dunwoody", los Arno. Sheryl y Richard Arno y sus hijos dan la bienvenida a Bradley a su casa con regularidad para que pueda participar en actividades en el Centro Comunitario Judío como el teatro Habima.

Bradley está involucrado con su comunidad a través de actividades en el Centro Comunitario Judío y como voluntario en varias organizaciones locales. A Bradley le encanta estar rodeado de gente y actuar para ellos. ¡Acaba de terminar de interpretar el papel de Skye en la producción de 'Mama Mia' del Teatro Habima! A Bradley le encanta todo lo relacionado con la música y las actuaciones musicales. ¡Su musical favorito es CATS, que ha visto siete veces! Ha sido el principal invitado en el Fox Theatre de Atlanta y hace tres años tuvo la oportunidad de ser un invitado CAT por una noche. ¡Usó maquillaje de escenario completo como los artistas, experimentó el espectáculo detrás del escenario e incluso fue invitado a subir al escenario!

Bradley asistió a Coralwood School, una escuela pública en los suburbios de Atlanta dedicada a atender a niños con y sin necesidades especiales de entre tres y seis años de edad. Luego asistió a la escuela primaria Rock Chapel, la escuela secundaria Conyers y la escuela secundaria Tucker. Bradley amaba la escuela y la rutina que brindaban sus clases. Disfrutó de las oportunidades de aprendizaje que estaban disponibles y se divirtió.

Bradley abogó y ayudó a aprobar la 'Ley de Gracie'. La Ley de Gracie es una legislación en Georgia que tiene como objetivo prevenir la discriminación por trasplante de órganos basada en cualquier capacidad. En el pasado, a las personas con discapacidades se les han negado trasplantes de órganos en base a conceptos erróneos sobre la calidad de vida y prejuicios en la medicina. La Ley de Gracie fue aprobada gracias al arduo trabajo de los autogestores y nuestra comunidad de derechos de las personas con discapacidad.

Bradley continúa trabajando arduamente para desarrollar mejores habilidades de defensa a través del programa Mi Voz, Mi Junta, Mi Participación y ahora es miembro de la Junta de la Asociación de Síndrome de Down de Atlanta. También fue elegido Autodefensor del año de la DSAA en 2020.

Bradley y su familia han estado involucrados con NDSC desde que nació. Su madre, Debbie, fue una valiosa socia como presidenta de la DSAA cuando la convención anual se llevó a cabo en Atlanta. Bradley asistió a su primera conferencia como adulto en 2019 en la Convención de Pittsburgh. Le encantó participar en la conferencia de Jóvenes y Adultos y planea asistir a la Convención de este año en Nueva Orleans. Su madre también asistirá como asistente y voluntaria. ¡Esperamos verlos a ambos allí!

Carta de la Presidenta

A todos los colaboradores del NDSC

Quiero reconocerles a todos ustedes por haber resistido la dificultad de estos casi dos años y medio, durante lo que ha sido un momento excepcionalmente desafiante, e incluso aterrador, para muchos de nosotros. El NDSC tuvo que posponer nuestras últimas dos convenciones en persona, un evento que representa uno de los momentos más importantes, rejuvenecedores y de conexión para las familias del NDSC.

Hoy, sin embargo, me complace escribirles mientras nos embarcamos en lo que esperamos sea nuestra "nueva normalidad". A continuación se presentan algunos de los emocionantes eventos de NDSC en el último trimestre y una lista de otros por venir.

Este año organizamos un increíble torneo de golf en Atlanta con más de 150 seguidores. El evento fue dirigido por el Gran Mariscal David Saville, quien trajo uno de sus múltiples anillos de campeonato y lo mostró a todos nuestros asistentes para que lo vieran. Recaudamos casi $50,000 para apoyar el trabajo fundamental de la NDSC, pero quizás lo más destacado del día fue un jugador que logró un hoyo en uno y ganó $50,000. ¡Únase a nosotros en el torneo del próximo año para tener la oportunidad de ganar $50,000!

En abril, nos unimos a los líderes nacionales de la comunidad con síndrome de Down en un simposio sobre políticas. Entre invitados como Judy Heumann, autora de Being Heumann, y Kayla McKeon, la primera cabildera registrada con síndrome de Down, me sentí afortunada de asociarme con estimados líderes para discutir el futuro de nuestros esfuerzos conjuntos, incluso cómo las organizaciones pueden apoyarse entre sí y cómo la comunidad puede crecer junta hacia la inclusión. A medida que tomamos estos pasos para trabajar simbióticamente, tenemos la oportunidad de multiplicar por 10 el rendimiento de nuestros esfuerzos, un tema compartido constantemente en el evento, y creo que este fin de semana rejuvenecedor condujo a importantes avances para toda nuestra comunidad.

Sería negligente de mi parte si no concluyera mencionando la **50ª Convención Anual de NDSC** en Nueva Orleans. No podría estar más orgullosa como Presidenta de la Junta de presentar este evento que ha tocado la vida de tantas personas con síndrome de Down. La Convención de este año reunirá la historia de quiénes somos y todo lo que hemos aprendido, y muchas de las lecciones que nos quedan por aprender y que nos esperan.

Pero la Convención es especial no solo por la alineación del evento de tremendos oradores y actividades, sino también por las familias que están allí con nosotros. Debido a que los viajes son más caros que nunca, debido al aumento de los precios de la gasolina y los vuelos limitados, **hemos ampliado los precios de preventa** durante todo el proceso de preinscripción para que familias como la suya puedan asistir a este evento especial. Sé que estaré allí y así mismo espero que pueda unirse a nosotros para este emocionante reencuentro en el Hyatt Regency New Orleans, del 23 al 26 de junio de 2022.

Shauntel Neal Howe
Presidente de la Junta
Congreso Nacional de Síndrome de Down

Detrás de la Imagen

con Daniel Chaplin

Consulte la imagen de portada (pág. 1) tomada en el medio maratón de Hapalua en Honolulu este abril con el director ejecutivo de NDSC, Jordan

Me interesé por primera vez en correr en 2012, cuando tomé una clase de salud en Samford, donde el examen final era completar una carrera de 5 km. Esto fue muy difícil para mí ya que tengo síndrome de Down. Pero después de eso, hice muchos más 5 km, uno de 10 km, uno de 5 millas. Luego escuché de varios amigos míos sobre el medio maratón de Talladega, así que entré en la carrera. Esta fue mi primera media maratón. Terminé durmiendo durante más de 18 horas después, ya que nunca antes había corrido una distancia tan larga.

Había leído y escuchado a algunas personas hablar sobre un gran club, el '50 States Half Marathon Club', al que me uní. Fue entonces cuando comencé mi viaje para completar una media maratón en los 50 estados. Espero convertirme en la primera persona con síndrome de Down en lograrlo.

Todo este entrenamiento y el correr me han cambiado de manera significativa. Ya sea parado en la línea de salida de una de mis medias maratones, parado en la línea de salida de mi primer maratón o parado en la línea de salida de cualquier carrera, rompo en llanto. Me encuentro luchando contra las lágrimas porque nunca pensé que sería capaz de correr una media maratón, una maratón o cualquier carrera, ya que tuve que superar tantas probabilidades y obstáculos asociados con el síndrome de Down.

Mis amigos y mi familia me han apoyado a lo largo de este camino. Me gustaría alentar a las personas a que se den cuenta de que tienen mucho potencial para tener éxito y que pueden hacer lo que se propongan. Todos los que tienen síndrome de Down son muy especiales y pueden tener un impacto en este mundo, y mostrarles a todos que las personas con síndrome de Down pueden participar en más actividades físicas. También muestra que las personas con síndrome de Down son realmente **más parecidas que diferentes.**

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

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

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