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NEWSLETTER OF THE

NATIONAL DOWN SYNDROME CONGRESS

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Dental Care for Today

By: LaQuia A. Vinson, DDS, MPH

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The world is slowly opening up, and we are starting to see the light at the end of the pandemic tunnel. However, as we come out of the fog of what has been the last 12 months plus of all our lives, did we somehow overlook our dentist's appointments? According to a study published in the Journal of the American Dental Association recently, dental care for children was the greatest unmet health care need during the pandemic. Prior to the pandemic, dental decay was the number was chronic disease of childhood. However dental decay is completely preventable.

Many believe, oh it's just a baby tooth, it will fall out eventually. Yes, that is true, yet so much happens and can happen before then. Teeth serve so many purposes. Not only are they important for eating and proper nutrition, but also for proper speech and oral-motor development as well. Untreated tooth decay can not only result in pain,

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Letter From the President

Dear NDSC Families,

As we put a bow on the 49th Annual NDSC Convention, I would like to thank the staff, Board of Directors, sponsors, partners, presenters, and volunteers for all of the effort that went into convention planning and execution. I have always known that it took countless hours to undertake such a huge event, but in this first year as NDSC President, my eyes were opened to the reality of the complexity and the magnitude of detail required to bring our families this one of a kind event. I am beyond impressed with the energy, creativity, and commitment of all involved and thank you just does not seem to be enough to express my gratitude.

On May 21, an email was sent to all NDSC members announcing that the Board of Directors had initiated a search process to find the next Executive Director for the NDSC. We have hired the Executive Search Firm of Spencer Stuart to coordinate and find our new Executive Director.

For nearly 20 years, David Tolleson has served honorably and unwaveringly as the Executive Director of the National Down Syndrome Congress. David will be missed at the NDSC and we extend our very best wishes to him. David's last day of service with the organization will be October 31, 2021. We want to thank David for the gifts of his time, talent, and passion to NDSC and the disability community.

More information, including a complete position description, can be found on the NDSC website. The board of directors' goal is to have our new Executive Director in place by late fall. In the interim, the board and staff remain committed to mission excellence and increasing our impacts on the communities, organizations, and individuals we serve.

The NDSC staff is already at work planning and preparing for our milestone 50th Annual NDSC Convention Celebration, to be held June 23 – 26, 2022, in the amazing city of New Orleans. We are counting down the days until we get to bring everyone together again. Although we are known for our "Giant Family Reunion" and all the learning, networking, and memories those four days of Convention provide, please remember that we are here for you 365 days a year.

Sincerely,

Shauntel Neal-Howe

Mark your calendar! You are invited to join us at the second annual NDSC Soiree of Stars Gala on Thursday, October 21, 2021. This event will honor and celebrate stars in the Down syndrome community. Proceeds from the Soiree of Stars will fund programs that address the Down syndrome community's needs in the areas of inclusion, education, and employment.

but also lost days of school and work as well. In the worst scenario, tooth decay can cause infections and for children with Down Syndrome, this could be deadly if the infection spread to the heart since many are born with congenital heart defects.

So, what can you do? The most important thing we you do is schedule that dental check up! The American Academy of Pediatric Dentistry recommends that children have their first dental visit within 6 months of the eruption of their first tooth or by their first birthday. While this may seem early, especially if the child does not have many teeth, what you learn in this first visit is invaluable. I know anticipatory guidance, injury prevention, and caries risk assessment don't sound like fun, but the information you'll receive in that visit can insure a lifetime of cavity free smiles.

Dentistry now is not dentistry of the past. Your child's visit to the dentists looks nothing like how dentistry was for you as a kid. The pediatric dentist office is made to be a warm, inviting, and fun, yes F-U-N experience. You should anticipate a colorful, creative, and very child focused environment. Pediatric dentists understand the need to be flexible when it comes to working with children with special healthcare needs. Whether it is the need to take things very slow or to provide families with additional opportunities just to visit the office to get more comfortable, your pediatric dentist will work extremely hard to make your child's experience as positive as they possibly can.

Sadly, the pandemic has wreaked havoc on oral health. We have seen increases in dental decay, tooth grinding and tmj pain. Some of the reasons behind all of these changes have been everything from the stress we have all endured when our daily lives were turned upside down, but also the changes that our new day to day activities brought. We were snacking more because we had full access to our home pantries, and we were grazing more because we didn't have the set schedules that we had been used to having since we were working and learning out of our homes and doing things at unusual times.

Now, if you had put regular dental care on the back burner because of the pandemic, it is time you catch up! Maintaining optimal oral health is vitally important for children with Down Syndrome since many are born with congenital heart defects. Neglect of our teeth can result in a proliferation of bacteria in the mouth. This excessive growth of oral bacteria could travel in the bloodstream and put the child at risk for endocarditis which is an infection of the inner lining of the heart. So to protect your child from this possibility, it is important to make sure that dental decay, oral infections, and gum disease are always treated.

Dental offices are and have been very safe healthcare facilities. Practices have always been on the forefront of using personal protective equipment (PPE), and the only change that many made was just enhancing the level of PPE they used with patients. To date, there have been no known COVID-19 infections traced back to a dental office. More importantly, dentists were some of the first people to be eligible to receive COVID-19 vaccinations since they work in the mouth, and many have been vaccinated. So, as you plan the rest of your summer, make sure it is filled with plenty of activities that promote good oral health: brushing twice daily, flossing, avoiding sugary snacks, and drinking lots of water. Most importantly though, call and schedule those checkups to make sure your days are filled with cavity free smiles as well.

References:

- **https://doi.org/10.1016/j.adaj.2021.02.001**
- **https://www.cdc.gov/healthywater/hygiene/disease/dental_caries.html**

"The Man" John T Farley

John T Farley is one of those people you meet and immediately know you've found a friend. He is the guy who will always make you smile and keep you on the go. John T has a love for life and makes the most of every day.

Born in Memphis, TN, in 1986, John T is the only child of Brenda and Jerry Farley. John T loves Memphis and still lives there today with his mom and dad. He is well known by many because of his extensive involvement in his community. John T went to school in the Memphis area and was educated in a general education classroom. Thirty-five years ago, it was not common to have a student with Down syndrome in a general ed classroom, but his parents insisted. As a result, John T was the first child with Down syndrome to attend his elementary school. John T didn't know then of the barriers he was breaking down; he was just thrilled that he got to ride the big yellow bus and attend school with his best buddy, Wells.

It was shortly after beginning school that John T found a life-long passion when he started dancing. At the age of six, he was enrolled in his first dance class. By his early teens, John T's love for dance inspired his mother to help start a dance company, Company D, where John T became a member of the Night Fever Dancers. A fun fact: John T has taught dance workshops and the Night Fever Dancers once performed at the NDSC Convention!

At age twelve, he found a new interest in gymnastics but continued to dance. However, it was in high school that John T really blossomed and began to explore new interests. He made new friends and tried new sports and activities any chance he had. Through high school, John T wrestled, began powerlifting, and was a cheerleader. A highlight of high school came when John T entered his high school talent show, where he was discovered by a member of a talent agency who extended an invitation to perform at the Mid-South Fair. One of John T's most memorable moments was when he danced to "Night Fever" on the same stage that Elvis once performed. Today, John T still attends 8 hours of dance classes each week at Fred Astaire.

After high school, John T attended the University of Memphis. Not long after enrolling as a student, John T's love for sports and his experience paid off when he interviewed with the University's Baseball Head Coach Daron Schoenrock, who invited him to be a Managers Assistant. John T also held a position under Football Coach Tommy West as a Tee Retriever. John T still works with the University of Memphis Baseball

team and is always there to pump up and encourage the players. John T was a driving force in the energy that led the Tigers to the 2021 Conference Tournament. He was proud to travel with his team to Clearwater for the tournament this past May.

John T is looking forward to the fall when he will go back to work at Farmington Elementary as a Teaching Assistant. This year marks his 7th year as a Teachers' Assistant. He began teaching as a volunteer but was recommended after his first year for a paid position. He has taught children in kindergarten, 1st, 2nd, and 4th grades but always as the right hand to Ms. Caryne Sheets-Daugherty, who insists that John T be placed in her classroom each year. John T is willing to work with any teacher when needed and spends time helping in kindergarten classes and as a P.E. Assistant, but in Sheets-Daugherty's classroom is where he calls home.

Teaching is one of John T's greatest joys. He considers working with children an honor, so he has no trouble setting his alarm, getting himself ready, and going to work. John T loves kids and one day hopes to have a family of his own.

John T has been a part of the NDSC family since a very young age. He attended his first NDSC Convention at age two, when the annual convention was held in Memphis. John T's mother was the President of the then Downs Parents of Memphis (now the DSA of Memphis), so his family was an intricate part of planning the convention that year. John T was elected to the NDSC Board of Directors in 2012 and served as a self-

Search for the New NDSC Executive Director

The National Down Syndrome Congress Board of Directors is embarking on a search for a talented and qualified leader to serve as the organization's next Executive Director. The Executive Director will report to the Board of Directors and will be responsible for providing strategic vision/leadership and executing/advancing objectives and programs based on this vision.

The next Executive Director of NDSC will be a strong, visionary leader who has non-profit experience and a record of strengthening organizations, delivering breakthrough results, and setting the direction for sustainable growth and impact in the future. Candidates with varied backgrounds will be considered, although ideal candidates will have demonstrated experience and success in the following areas:

- **Ten to fifteen years of increasing professional experience in a leadership role with demonstrated success and achievement.**
- **Preferred candidates will have experience managing an equal or larger organization or possess a professional background in successfully leading large teams.**
- **Management experience in the not-for-profit sector with particular interest in those coming from human services, the disability community or the Down syndrome community is preferred but not required for the right candidate.**
- **Experience, understanding of and connection to the disability community.**

The National Down Syndrome Congress has retained Spencer Stuart to assist in this recruitment. To nominate an individual, express personal interest in the position, or communicate comments, questions, or suggestions to the search committee, please feel free to use the confidential search mailbox ndsced@spencerstuart.com.

A complete position description will be sent on request or can be found **online**.

advocate member until 2015. He has been a member of the Self-Advocate Council since 2015. Assisting with the Self-Advocate Book Project has been one of the things that John T enjoys most about being a SAC member. His love for books has been a lengthy affair. He has participated in a book club through his local library for the past 16 years, and although he enjoys reading many genres, he says that his favorite books are those by Dr. Seuss because he loves reading them to his students.

Though most of his family calls him John T, he has many other nicknames. Some close friends and family simply call him J.T., and many football teammates still call him Teeman. He thinks that having different nicknames is pretty cool but is most fond of the nickname "Tizzle," which means the epitome of COOL, and was given to him by a buddy on the University of Memphis Tigers Baseball Team!

Besides spending his time at work and the University of Memphis Baseball Team, John T likes to canoe, write and read in his spare time. He loves watching football and baseball, and family time spent boating, riding the wave runner and "Big Mable" behind the Pontoon boat at Pickwick Lake.

The Think College National Coordinating Center (NCC) Accreditation Workgroup, chaired by NDSC Senior Policy Advisor Stephanie Smith Lee, recently sent the Secretary of Education and relevant Congressional committees the Report on Model Accreditation Standards for Higher Education Programs for Students with Intellectual Disability: Progress on the Path to Education, Employment, and Community Living that includes final model standards for these programs and policy recommendations. Implementation of the standards and recommendations will improve the quality of, and accountability for, inclusive higher education programs. The Higher Education Act required the NCC to convene the workgroup to develop the standards and issue the report. To learn more about **the report on the Think College website.**

TIES Center and the Pivot to In-Person Instruction Series

The TIES Center is the National Technical Assistance Center on inclusive practices and policies to benefit students with significant cognitive disabilities. TIES stands for **Increasing (T)ime, (I)nstructional Effectiveness, (E)ngagement, and State and District (S)upport for Inclusive Practices.** TIES supports multiple groups and voices at all levels of the system to build inclusive education, including families, educators and administrators. TIES develops many resources for families to share with their district and school teams, as well, they provide technical assistance to state, district, and school-level teams to meet the needs of each and every student within their general education standards-based curriculum and classrooms, side by side with their age-grade peers. Ricki Sabia, NDSC Senior Education Policy Advisor, is the parent liaison to the TIES Center. To learn more about the TIES Center, please watch the Introduction to the TIES Center video, or visit the **TIES Center website**.

TIES Center

PIVOT TO IN-PERSON INSTRUCTION

Ready for launch: "Pivot To In-Person Instruction," a new program from the TIES Center

To better support families during the pandemic, the TIES Center created the **Distance Learning (DL) Series**. Now, with students returning to schools, we want to pause and reflect on the strategies, processes, and tools that have been successful for students, families, and educators - as well as offer even more ideas as to how to build and support engagement and collaboration once students return to the school buildings.

The TIES Center will launch the new Pivot to In-Person Instruction (PI) Series in early August. The PI Series will offer eleven articles that will focus on what we learned, what worked well and we need to continue to expand, and what we need to consider changing at this unique time when students return to in-person instruction. The past year has taught us a great deal. The PI series hopes to capture that learning, add even more practical examples for teams to try, and ensure students are welcomed and successfully supported as they go back to their school communities.

Be looking for the details about the launch of the PI Series in our **TIES Center Newsletter** or on the **TIES Center Facebook** page!

ARE YOU A PARENT OF A ADOLESCENT WITH DOWN SYNDROME?

AKRON CHILDREN'S HOSPITAL & KENT STATE UNIVERSITY ARE RECRUITING PARTICIPANTS FOR VOLUNTARY RESEARCH VIA A 20 MINUTE ONLINE SURVEY

Akron Children's Hospital and the Kent State University Department of Psychological Sciences is conducting a research study entitled "Parental Vaccine Hesitancy for Adolescents with Down Syndrome" and is seeking parents/guardians 18 years of age with a child of at least 10 years old and not more than 21 years old with Down Syndrome to participate in a brief voluntary online research study.

The purpose of this study is to learn the beliefs parents of children with Down Syndrome have about vaccines. This study is approved by the Institutional Review Board. There is no compensation for participating in this study.

For more information about the study, please contact the principal investigators, Dr. Diane Langkamp at **dlangkamp@akronchildrens.org** or Dr. Beth Wildman at **bwildman@kent.edu**.

If you are ready and willing to participate, please click **this survey link** to review the consent and begin your participation in the study.

Meet Our Leaders

Board Member Spotlight!

Meet **Megan Smulski!** Megan serves as the NDSC Executive Committee Secretary. She was elected to the NDSC Board of Directors in 2018 and was appointed to the Executive Committee in 2019. Megan lives in Pittsburgh, Pennsylvania where she also serves on the Board of Directors of the Down Syndrome Association of Pittsburgh and also volunteers her time and talents at St. Anthony School Programs, a Catholic-based inclusive educational environment for children ages 5-21 with Down Syndrome, Autism Spectrum Disorder, and/or other Intellectual Disabilities. Megan is dedicated to serving her community in both her personal and professional life. She is a Senior Major Gifts Officer for the Children's Hospital Foundation of Pittsburgh.

Juggling her many roles, including wife, and mom of two (her youngest who has Down syndrome) keeps Megan busy, but she says that she does everything "to help make an impact in families like ours." One of Megan's favorite wasy to spend her free time include enjoying cooking with friends and family. Megan leads a very active life and much of her family time is spent attending her children's sporting events, skiing, running, and cycling. A fun fact about Megan is that she made a field goal at Heinz Field during the halftime of a Steeler game, in a field goal kicking contest!

Staff Member Spotlight!

Stephanie Smith Lee is the National Down Syndrome Congress Senior Policy Advisor. The NDSC is fortunate to have such a dynamic advisor with such vast experience. Stephanie has over thirty-five years of public policy experience, including serving in senior staff positions in the US Senate and House of Representatives. Since her daughter, Laura, was born with Down syndrome in 1982, she has led many successful disability advocacy efforts at the local, state, and federal levels. As the Director of the Office of Special Education Programs (OSEP) for the US Department of Education, Stephanie has directed the policy development, program planning, monitoring, evaluation, research, and implementation of IDEA, the federal special education law. In addition, she developed and trained an effective grassroots campaign, advocated with Congress, and directed a postsecondary project that developed inclusive postsecondary programs in various states and she led the successful effort to amend the Higher Education Act (HEA) to obtain federal financial aid and model programs for students with intellectual disabilities (ID), and most recently chaired the Accreditation Workgroup on Model Accreditation Standards for Higher Education Programs for Students with Intellectual Disability: Progress on the Path to Education, Employment, and Community Living from 2011 to 2020.

Stephanie has received many awards and honors, such as the "IDEA Hero Award" from The Arc of the US for the key role she played in the successful reauthorization of IDEA in 1997 and the "Distinguished Service to Education Award" from George Mason University in 2007.

For more about Stephanie and her most recent work with the Accreditation Workgroup on Model Accreditation Standards for Higher Education Programs for Students with Intellectual Disability: Progress on the Path to Education, Employment, and Community Living, read a blog written by Stephanie entitled **"Looking Back and Looking Forward: A Personal Perspective on How Accreditation Standards will Improve Inclusive Higher Education."**

Cuidado dental para hoy

By: LaQuia A. Vinson, DDS, MPH
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La escuela virtual ha terminado, el mundo se está abriendo poco a poco, y estamos empezando a ver la luz al final del túnel de la pandemia. Sin embargo, mientras salimos de la niebla de lo que han sido los últimos 12 meses (y más) de nuestras vidas, ¿pasamos por alto las citas con el dentista? Según un estudio publicado recientemente en el Journal of the American Dental Association, la atención dental de los niños fue la mayor necesidad de atención sanitaria no cubierta durante la pandemia. Antes de la pandemia, la caries dental era la enfermedad crónica número uno de la infancia. Sin embargo, la caries dental es completamente prevenible.

Muchos creen que es sólo un diente de leche, que ya se caerá. Sí, eso es cierto, pero hay muchas cosas que suceden y pueden suceder antes de eso. Los dientes sirven para muchas cosas. No sólo son importantes para la alimentación y la nutrición adecuada, sino también para el desarrollo del habla y la motricidad oral. Las caries no tratadas no sólo pueden provocar dolor, sino también la pérdida de días de escuela y trabajo. En el peor de los casos, las caries pueden causar infecciones y, en el caso de los niños con síndrome de Down, esto podría ser mortal si la infección se extendiera al corazón, ya que muchos nacen con defectos cardíacos congénitos.

Entonces, ¿qué puede hacer? Lo más importante que podemos hacer es programar esa revisión dental. La Academia Americana de Odontología Pediátrica recomienda que los niños tengan su primera visita al dentista a los 6 meses de la erupción de su primer diente o antes de su primer cumpleaños. Aunque esto puede parecer temprano, especialmente si el niño no tiene muchos dientes, lo que se aprende en esta primera visita es invaluable. Sé que la orientación anticipada, la prevención de lesiones y la evaluación del riesgo de caries no parecen divertidas, pero la información que recibirá en esa visita puede asegurarle una vida de sonrisas sin caries.

La odontología actual no es la del pasado. La visita de su hijo al dentista no se parece en nada a cómo era la odontología para usted cuando era niño. La oficina del dentista pediátrico está hecha para ser una experiencia cálida, acogedora y divertida, sí F-U-N (divertido). Usted debe anticipar un ambiente colorido, creativo y muy centrado en los niños. Los dentistas pediátricos comprenden la necesidad de ser flexibles cuando se trata de trabajar con niños con necesidades sanitarias especiales. Ya sea la necesidad de tomar las cosas muy despacio o de proporcionar a las familias oportunidades adicionales sólo para visitar la oficina para sentirse más cómodo, su dentista pediátrico trabajará muy duro para hacer la experiencia de su hijo tan positiva como sea posible.

Lamentablemente, la pandemia ha causado estragos en la salud bucodental. Hemos observado un aumento de las caries, del rechinar de dientes y del dolor. Algunas de las razones detrás de todos estos cambios han sido desde el estrés que todos hemos soportado cuando nuestra vida diaria se puso patas arriba, pero también los cambios que trajeron nuestras nuevas actividades cotidianas. Comíamos más porque teníamos pleno acceso a nuestras despensas domésticas, y pastoreábamos más porque no teníamos los horarios fijos que estábamos acostumbrados a tener desde que trabajábamos y aprendíamos fuera de nuestras casas y hacíamos las cosas a horas inusuales.

Ahora, si ha dejado de lado el cuidado dental regular a causa de la pandemia, ¡es hora de ponerse al día! Mantener una salud bucal óptima es de vital importancia para los niños con síndrome de Down, ya que muchos nacen con defectos cardíacos congénitos. El descuido de los dientes puede dar lugar a una proliferación de bacterias en la boca. Este crecimiento excesivo de bacterias orales podría viajar en el torrente sanguíneo y poner al niño en riesgo de endocarditis, que es una infección del revestimiento interno del corazón. Por lo tanto, para proteger a su hijo de esta posibilidad, es importante asegurarse de que la caries dental, las infecciones orales y las enfermedades de las encías sean siempre tratadas.

Los consultorios dentales son y han sido instalaciones sanitarias muy seguras. Los consultorios siempre han estado a la vanguardia en el uso de equipos de protección personal (EPP), y el único cambio que muchos hicieron fue simplemente mejorar el nivel de EPP que utilizaban con los pacientes. Hasta la fecha, no se ha conocido ningún caso de infección por COVID-19 que se haya atribuido a un consultorio dental. Y lo que es más importante, los dentistas fueron algunas de las primeras personas que podían recibir la vacuna contra el COVID-19, ya que trabajan en la boca, y muchos se han vacunado.

Así que, mientras planificas el resto del verano, asegúrate de que está lleno de actividades que promueven una buena salud bucodental: cepillarse dos veces al día, usar el hilo dental, evitar aperitivos azucarados y beber mucha agua. Pero lo más importante es que llame y programe esas revisiones para asegurarse de que sus días están llenos de sonrisas sin caries.

Referencias:

- https://doi.org/10.1016/j.adaj.2021.02.001
- https://www.cdc.gov/healthywater/hygiene/disease/dental_caries.html

¡Marque su calendario! Le invitamos a unirse a nosotros en la segunda gala anual de la NDSC Soiree de Estrellas el jueves 21 de octubre de 2021. Este evento honrará y celebrará a las ESTRELLAS de la comunidad del síndrome de Down. La recaudación del Soiree de Estrellas financiará programas que abordan las necesidades de la comunidad del síndrome de Down en las áreas de inclusión, educación y empleo.

NDSC AUTO DEFENSOR DESTACADO

“El Hombre” John T Farley

John T Farley es una de esas personas que conoces e inmediatamente sabes que has encontrado un amigo. Es el tipo que siempre te hará sonreír y te mantendrá en movimiento. John T tiene amor por la vida y aprovecha cada día al máximo.

Nacido en Memphis, TN, en 1986, John T es el único hijo de Brenda y Jerry Farley. A John T le encanta Memphis y todavía vive allí con su madre y su padre. Es bien conocido por muchos debido a su amplia participación en su comunidad. John T fue a la escuela en el área de Memphis y se educó en un aula de educación general. Hace treinta y cinco años, no era habitual tener a un alumno con síndrome de Down en un aula de educación general, pero sus padres insistieron. Como resultado, John T fue el primer niño con síndrome de Down que asistió a su escuela primaria. John T no sabía entonces las barreras que estaba rompiendo; sólo estaba encantado de poder viajar en el autobús amarillo grande y asistir a la escuela con su mejor amigo, Wells.

Poco después de empezar la escuela, John T encontró una pasión para toda la vida cuando empezó a bailar. A los seis años se inscribió en su primera clase de baile. Al principio de su adolescencia, el amor de John T por la danza inspiró a su madre a ayudar a crear una compañía de danza, la Compañía D, donde John T se convirtió en miembro de los Night Fever Dancers. Un dato curioso: John T ha impartido talleres de danza y los Night Fever Dancers actuaron una vez en la Convención de la NDSC.

A los doce años, encontró un nuevo interés en la gimnasia, pero siguió bailando. Sin embargo, fue en la escuela secundaria cuando John T realmente floreció y comenzó a explorar nuevos intereses. Hizo nuevos amigos y probó nuevos deportes y actividades cada vez que podía. Durante su tiempo en la secundaria, John T luchó, empezó a levantar pesas y fue porrista. Uno de los momentos culminantes de la secundaria fue cuando John T se presentó al concurso de talentos de la secundaria, donde fue descubierto por un miembro de una agencia de talentos que le invitó a actuar en la Feria del Medio Sur. Uno de los momentos más memorables de John T fue cuando bailó “Night Fever” en el mismo escenario en el que actuó Elvis. En la actualidad, John T sigue asiste 8 horas de clases de baile a la semana en Fred Astaire.

Después de la escuela secundaria, John T asistió a la Universidad de Memphis. Poco después de matricularse como estudiante, el amor de John T por los deportes y su experiencia dieron sus frutos cuando se entrevistó con el entrenador principal de béisbol de la universidad, Daron Schoenrock, que le invitó a ser asistente de los directivos.

John T también ocupó un puesto con el entrenador de fútbol americano Tommy West como recuperador de tees. John T todavía trabaja con el equipo de béisbol de la Universidad de Memphis y siempre está ahí para animar a los jugadores. John T fue una fuerza impulsora de la energía que llevó a los Tigres al Torneo de la Conferencia 2021. Estuvo orgulloso de viajar con su equipo a Clearwater para el torneo el pasado mes de mayo.

John T está deseando que llegue el otoño para volver a trabajar en la escuela primaria de Farmington como asistente de enseñanza. Este año marca su séptimo año como Asistente de Maestros. Empezó a enseñar como voluntario pero fue recomendado después de su primer año para un puesto pagado. Ha enseñado a niños en el jardín de infantes, 1er, 2do y 4to grado, pero siempre como la mano derecha de la Sra. Caryne Sheets-Daugherty, quien insiste en que John T sea colocado en su aula cada año. John T está dispuesto a trabajar con cualquier profesor cuando es necesario y pasa tiempo ayudando en las clases de preescolar y como asistente de educación física, pero en el aula de Sheets-Daugherty es donde llama casa.

Enseñar es una de las mayores alegrías de John T, el considera trabajar con niños un honor, por lo que no le cuesta nada poner el despertador, prepararse e ir a trabajar. A John T le encantan los niños y algún día espera tener su propia familia.

John T ha formado parte de la familia de la NDSC desde muy joven. Asistió a su primera Convención de NDSC a los dos años, cuando la convención anual se celebró en Memphis. La

NATIONAL DOWN SYNDROME CONGRESS

Búsqueda de Director Ejecutivo

Búsqueda del nuevo director ejecutivo de la NDSC

La Junta Directiva del Congreso Nacional del Síndrome de Down está buscando un líder con talento y cualificado para ser el próximo Director Ejecutivo de la organización. El Director Ejecutivo dependerá de la Junta Directiva y será responsable de proporcionar una visión/liderazgo estratégico y de ejecutar/impulsar los objetivos y programas basados en esta visión.

El próximo Director Ejecutivo de NDSC será un líder fuerte y visionario que tenga experiencia en organizaciones sin fines de lucro y un historial de fortalecimiento de organizaciones, de obtención de resultados innovadores y de establecimiento de la dirección para el crecimiento sostenible y el impacto en el futuro. Se tendrán en cuenta candidatos con formación variada, aunque los candidatos ideales habrán demostrado experiencia y éxito en las siguientes áreas:

- **De diez a quince años de experiencia profesional creciente en una función de liderazgo con éxito y logros demostrados.**
- **Los candidatos preferidos tendrán experiencia en la gestión de una organización igual o mayor o poseerán una experiencia profesional en la dirección de grandes equipos con éxito.**
- **Se prefiere, aunque no es necesario, que el candidato tenga experiencia en gestión en el sector sin fines de lucro, con especial interés en aquellos que procedan de los servicios humanos, la comunidad de discapacitados o la comunidad del síndrome de Down.**
- **Experiencia, comprensión y conexión con la comunidad de discapacitados.**

El Congreso Nacional del Síndrome de Down ha contratado a Spencer Stuart para que le ayude en esta selección. Para nominar a una persona, expresar su interés personal en el puesto o comunicar comentarios, preguntas o sugerencias al comité de búsqueda, no dude en utilizar el buzón de búsqueda confidencial ndsced@spencerstuart.com.

Se enviará una descripción completa del puesto si se solicita o se puede encontrar en **https://www.ndsccenter.org/wp-content/uploads/NSDC-ED-Search-Announcement.pdf**.

madre de John T era la presidenta de la entonces Downs Parents of Memphis (ahora DSA of Memphis), por lo que su familia fue una parte intrínseca de la planificación de la convención de ese año. John T fue elegido miembro de la Junta Directiva de la NDSC en 2012 y fue miembro de la autodefensa hasta 2015. Ha sido miembro del Consejo de Autodefensa desde 2015. Ayudar con el Proyecto de Libros para Autogestores ha sido una de las cosas que más disfruta John T de ser miembro del SAC. Su amor por los libros viene de mucho tiempo. Ha participado en un club de lectura a través de su biblioteca local durante los últimos 16 años, y aunque le gusta leer muchos géneros, dice que sus libros favoritos son los del Dr. Seuss porque le encanta leerlos a sus alumnos.

Aunque la mayor parte de su familia le llama John T, tiene muchos otros apodos. Algunos amigos cercanos y familiares le llaman simplemente J.T., y muchos compañeros de equipo de fútbol le siguen llamando Teeman. Piensa que tener diferentes apodos es bastante genial, pero el que más le gusta es el apodo de "Tizzle", que significa el epítome de lo COOL, y que se lo dio un compañero del equipo de béisbol de los Tigres de la Universidad de Memphis.

Además de dedicar su tiempo al trabajo y al equipo de béisbol de la Universidad de Memphis, a John T le gusta ir en canoa, escribir y leer en su tiempo libre. Le encanta ver el fútbol y el béisbol, y el tiempo que pasa en familia navegando, montando en el corredor de olas y en "Big Mable" detrás del barco de pontones en el lago Pickwick.

Conozca a nuestros líderes

Miembro de la Junta Directiva destacado

¡Conozca a **Megan Smulski!** Megan se desempeña como secretaria del Comité Ejecutivo de NDSC. Fue elegida para la Junta Directiva de NDSC en 2018 y fue nombrada para el Comité Ejecutivo en 2019. Megan vive en Pittsburgh, Pensilvania, donde también forma parte de la Junta Directiva de la Asociación de Síndrome de Down de Pittsburgh y también ofrece su tiempo y talento como voluntaria en los Programas Escolares de San Antonio, un entorno educativo inclusivo de base católica para niños de 5 a 21 años con síndrome de Down, trastorno del espectro autista y / o otras discapacidades intelectuales. Megan se dedica a servir a su comunidad tanto en su vida personal como profesional. Es responsable de grandes donaciones en la Fundación del Hospital Infantil de Pittsburgh.

Hacer malabarismos con sus múltiples funciones, como esposa y madre de dos hijos (el más pequeño tiene síndrome de Down) mantiene a Megan ocupada, pero dice que lo hace todo "para ayudar a que haya un impacto en familias como la nuestra". Una de las formas favoritas de Megan para pasar su tiempo libre es disfrutar de la cocina con los amigos y la familia. Megan lleva una vida muy activa y gran parte de su tiempo familiar lo dedica a asistir a los eventos deportivos de sus hijos, a esquiar, a correr y a montar en bicicleta. Un dato curioso sobre Megan es que hizo un gol de campo en el Heinz Field durante el descanso de un partido de los Steelers, en un concurso de lanzamiento de goles de campo.

Carta del Presidente

Queridas familias del NDSC,

Al cerrar la 49ª Convención Anual de la NDSC, me gustaría dar las gracias al personal, a la Junta Directiva, a los patrocinadores, a los socios, a los presentadores y a los voluntarios por todo el esfuerzo realizado en la planificación y ejecución de la convención. Siempre he sabido que se necesitan innumerables horas para llevar a cabo un evento tan grande, pero en este primer año como Presidente de la NDSC, mis ojos se han abierto a la realidad de la complejidad y la magnitud de los detalles necesarios para llevar a nuestras familias este evento único. Estoy más que impresionada con la energía, la creatividad y el compromiso de todos los involucrados y el agradecimiento no parece ser suficiente para expresar mi gratitud.

El 21 de mayo, se envió un correo electrónico a todos los miembros del NDSC anunciando que la Junta Directiva había iniciado un proceso de búsqueda para encontrar al próximo Director Ejecutivo del NDSC. Hemos contratado a la empresa de búsqueda de ejecutivos Spencer Stuart para coordinar y encontrar a nuestro nuevo Director Ejecutivo.

Durante casi 20 años, David Tolleson ha prestado un servicio honorable e inquebrantable como Director Ejecutivo del Congreso Nacional del Síndrome de Down. Echaremos de menos a David en el NDSC y le transmitimos nuestros mejores deseos. El último día de servicio de David en la organización será el 31 de octubre de 2021. Queremos agradecer a David los regalos de su tiempo, talento y pasión al NDSC y a la comunidad de la discapacidad.

Puede encontrar más información, incluida la descripción completa del cargo, en el sitio web del NDSC. El objetivo de la junta directiva es contar con un nuevo director ejecutivo a finales de otoño. Mientras tanto, la junta directiva y el personal siguen comprometidos con la excelencia de la misión y el aumento de nuestro impacto en las comunidades, organizaciones y personas a las que servimos.

El personal del NDSC ya está trabajando en la planificación y preparación de la 50ª Convención Anual del NDSC, que se celebrará del 23 al 26 de junio de 2022 en la increíble ciudad de Nueva Orleans. Estamos contando los días que faltan para volver a reunir a todos. Aunque se nos conoce por nuestra "Reunión familiar gigante" y por todo el aprendizaje, la creación de redes y los recuerdos que proporcionan esos cuatro días de Convención, recuerden que estamos aquí para ustedes los 365 días del año.

Sinceramente,

Shauntel Neal-Howe

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

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

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