

Down Syndrome News

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NEWSLETTER OF THE



NATIONAL
DOWN SYNDROME
CONGRESS

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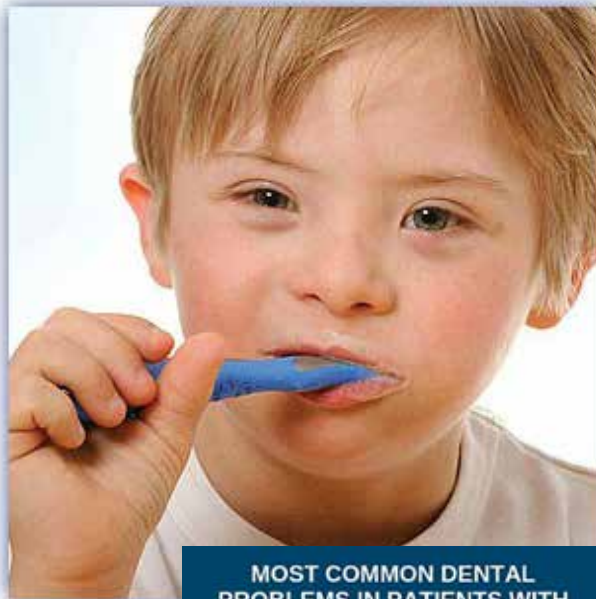
Dental Care & Down Syndrome

When it comes to heading to the dentist, many have feelings of stress and anxiety. For patients with Down syndrome, these feelings can be much more intense. The dental experts at Dentably Magazine, Dr. Greg Grillo and Dr. Andrew Jordan, have spent many years working with patients and caregivers to prepare for dental visits and providing them with tips and instruction for instilling good oral hygiene habits.

Patients with Down syndrome may have dental issues that are different from those without Down syndrome. For example, young patients with Down syndrome often will have both baby and permanent teeth later in life due to delays in eruption. Some dental problems that are seen in patients with Down syndrome are due to genetics, but other issues may be present as a result of hygiene habits, issues with the jaw or bite formation, complications with chewing, or other factors.

Finding the Right Dentist

Although it is unusual to find anyone who enjoys visiting the dentist, patients with sensory issues, including some with Down syndrome, can have a greater fear of going to the dentist. For example, someone who is generally wary around new people and does



MOST COMMON DENTAL PROBLEMS IN PATIENTS WITH DOWN SYNDROME

- Malocclusion
- Malformed teeth or microdontia
- Congenitally missing teeth
- Crowding and/or Impacted teeth
- Problems with the jaw and bite
- Complications with chewing
- Inefficient natural cleansing action
- Periodontal disease
- Cavities
- Dental Caries
- Gingival hyperplasia

Dentably
MAGAZINE

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Letter From the President

Hello all,

I can't believe that we are almost half way through 2019 - what a busy year it has already been so far at the NDSC! The new Center for Outreach & Education has kept us on the road delivering services and programs to populations that may not readily have access to all that the NDSC provides. I personally had the opportunity to attend and speak at the Outreach Summit in Fort Wayne, Indiana. My fellow Board members and NDSC staff have been busy on the road, traveling to McAllen and South Padre Island, TX; St. Louis, MO; New Orleans, LA; and, even Mexico and Colombia delivering resources, providing families with Adult Sibling and Family Care Toolkits, and promoting the 47th Annual NDSC Convention. We have provided information, when requested, in both English and Spanish. In addition to serving families directly, the NDSC co-hosted an Educator Training in Nashville, Tennessee and our Policy Team has literally been from coast to coast providing advocacy training and presenting from Washington, D.C. to the state of Washington, and beyond our borders, in Tobago.

Put simply, we are working to bring resources to people wherever they are! We have hosted several webinars with topics ranging from How Your Nonprofit Organization Can – and Why it Should – Engage in Grassroots Advocacy; Transitioning to Adulthood Without Falling off a Cliff; and Convention 101 (a webinar to guide convention attendees through a smooth registration for the 47th annual NDSC Convention); and, together with the Autism Society of America, we hosted a webinar discussing the co-occurring diagnosis of Down syndrome and autism. We have shared so much information, but the best is yet to come!

In just a few short weeks we will come together for the 47th Annual NDSC Convention, in my hometown of Pittsburgh, PA. I am getting excited to see many of you again and to meet new families and self-advocates attending for the first time. I cannot wait to hear your feedback as you experience this one-of-a-kind “family reunion.” This will be a special family reunion for me as my brother and our whole family will be at the Convention this year! If you haven't registered, there is still time. Just take a few minutes to look at the incredible line up of pre-conference session and workshop presenters, and you will see why you don't want to miss this event. There is no other place that you will have access to so many professionals of this caliber in one place. I also remind you to consider the invaluable networking and relations building opportunities that come from attending the convention.

If you are unable to attend, you can stay in touch with all that is happening at the 47th NDSC Convention via our social media pages. We are on Facebook, Instagram, and Twitter and will be posting throughout the weekend of our big event.

The NDSC Board of Directors and staff are honored to serve as your national organization focused on families and creating a better world for individuals with Down syndrome. We will not stop until we accomplish our goal!

Sincerely,

Kishore Veebody

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Join us & Show Your NDSC TEAM Pride!

Friday, June 28

**All NDSC Convention attendees invited
No additional ticket required**

**NDSC 32i DANCE!™
JERSEY PARTY**



**Purchase your NDSC Team Jersey beginning May 12th
at ndsccenter.org or at the 47th NDSC Convention**
(Sizes and colors will be limited at Convention)



**47th Annual NDSC Convention
Workshop & Keynote Speaker
Recordings**

**3 Packages to choose from
Starting at \$59 - through June 4th
ndsccenter.org**

Playback Now

Convention From Your Couch

Not able to attend the convention in Pittsburgh this June? You can still access the workshops and keynote presentations from the comfort of your home or office.

Choose from 3 packages:

- The 2019 Fast Pass (the same package that is provided to all convention attendees)
- The 2019 Season Pass
- The 2019 USB Works

not like to be touched may find that having a stranger's hands with tools in their mouth may be an overwhelming situation.

Finding the right dentist for those with additional support needs is extremely important. There are a number of things to consider when searching for a dentist and it is important to be diligent in your search and to not give up until you've found someone who is a good fit for your loved one. Talking with a dentist prior to a visit is a good first step in preparing everyone for the visit. Some questions that you may ask when deciding on a dentist for your loved one include:

1. Are you comfortable working with someone who has Down syndrome?

The dentist you choose should be comfortable working with patients with additional needs. If the patient is a child, start by searching for pediatric dentists. They have 2-3 years of extra schooling and may be better at providing needed accommodations.

2. What experience do you have working with patients who have Down syndrome?

When asking a potential dentist this question it's best to listen for specific examples of when they worked with patients with additional needs. A dentist with previous experience is more likely to know how to ensure a visit runs smoothly and that your loved one is at ease.

3. Can any special accommodations be made?

A good dentist should answer yes to this question. It should be their goal to make the patient as comfortable as possible and ensure their visit goes well. Some accommodations that you may want to request may include being able to stay near the patient throughout their visit or requesting a specific flavor of toothpaste. These may seem like small requests but can make a difference in the overall experience.

It is important to find a dentist who will allow family members or others providing support to be involved with the visit. They should also encourage you to ask questions. The more information you have, the better the appointment will be for all. Finally, ask your friends, family, doctor, or someone you know with a loved one who has additional support needs for recommendations.

Once you've chosen a dentist and scheduled an appointment, it will be time to prepare for the visit. It is important to prepare ahead of time so your loved one has an idea of what to expect during their visit. To help the patient feel more comfortable and prepared for their appointment, consider the following:

1. Find ways to visualize what happens at the dentist.

Using visuals is a great way to see what happens at the dentist. This can be done with books or videos and gives the future patient a way to make a connection between the visual and their dental appointment.

2. Visit the dentist early.

Scheduling an introduction visit with the dentist prior to the visit can be beneficial. It allows patients to familiarize themselves with the environment such as seeing the lights and hearing the sounds. You and your loved one can meet the office and staff members and go over any accommodations that may need to be made prior to the appointment so that everyone is better prepared.

The best way to avoid trips to a dental urgent care center or (worse) an emergency room, is to begin practicing good oral hygiene habits at home. Instilling habits from a young age is best, but it's never too late to start practicing good dental hygiene.

Shared with permission from www.Dentably.com

The Question of Sedation

Many patients opt for sedation during dental procedures, not just those with Down syndrome. Patients with additional support needs may sometimes benefit from being sedated with general anesthesia during an appointment. Sedation may be necessary if a patient's health is at risk or they are overly fearful of the dentist. Sedation dentistry, or "sleep dentistry", helps relax and calm patients. There are different types of sedation that may be available. The most common include:

- **Inhaled minimal sedation:** Breathing in nitrous oxide combined with oxygen to help the patient relax. Your dentist is in complete control of sedation that is given.
- **Oral sedation:** Can range from minimal to moderate. In its mildest form medication is delivered in pill form that normally makes the patient drowsy. A more moderate dose may be given if it is best for the patient to be in a "sleep" state.
- **IV moderate sedation:** A sedation drug is given intravenously. This type of sedation works more quickly and the dentist is able to continually adjust the sedation levels.
- **Deep sedation & general anesthesia:** Medication is given intravenous that will make the patient nearly or totally unconscious. The patient will remain under general anesthesia until the effects of the medication wear off or are reversed by the dentist.

SELF-ADVOCATE SPOTLIGHT

Tracy Hile

Tracy Hile grew up near Houston, Texas leading a very active life playing golf, listening to music, singing in her church choir, and enjoying time with friends. It was in these young years that Tracy learned to volunteer as she wrote letters to our troops and helped pack treat baggies to send to them each month. In the later years in Houston, Tracy worked at three different school districts in the area as a teacher's assistant and as an aide for a Teen Parenting Program which helped young mothers earn their diplomas.

In 2008, after retiring, Tracy's parents moved to Murfreesboro, Arkansas, where Tracy's father was raised. Their goal was to do the best for Tracy to prepare her to live as independently as possible. Tracy's parents updated her grandparents' home and gave Tracy a place to call her own and for the first time, she was living on her own.

Tracy was thrilled about the opportunity to live independently, and took the challenges that came with it head on. Independent living meant that Tracy was now responsible for picking up her mail and doing her own grocery shopping. She quickly mastered cooking in her crockpot, and still enjoys decorating her house for Christmas each year. She has her own computer which she uses to stay in touch with her many friends. Tracy attends a Sunday night Bible study and enjoys singing in the church choir, listening to music, doing word searches, working out, riding her bike, and reading while sitting on her porch swing. Tracy lives independently but does not live alone. She shares her home with her dog Charlie and enjoys their almost daily walks together.

Tracy has worked at the Queen of Diamonds Inn in Murfreesboro for the past decade. She is an active member of the Murfreesboro Chamber of Commerce and the Methodist Church. She participates in Cheer Makers classes, volunteers at the Mission House, participates in the annual Cookies with Mrs. Claus program, and has initiated a book project with the local library and South Pike County schools.

Tracy and her family have been part of the National Down Syndrome Congress family for more than 30 years. Tracy attended her first NDSC Conferences when she was in the 10th grade. Tracy says that attending the workshops, dances, and seeing all of her friends at the convention is the high point of each year and considers it a great honor to have been elected by her peers to serve on the NDSC Board of Directors from 2003-2006.

During Tracy's first year as a Board member, she proposed an idea to provide a way for self-advocates to make an impact and give back to the community. With careful planning and hard work, Tracy led the charge to develop the NDSC Self-Advocate Book Project. Through the Book Project, self-advocates raise money to purchase books that positively portray individuals with Down syndrome. Each year they present these books to school libraries in the NDSC Convention host city. Beyond the benefits of the recipient libraries, the project accomplishes several other goals set by self-advocates. These goals were simple and clear from the beginning:



- **That the public see self-advocates as productive and as giving back to the community**
- **That self-advocates increase disability awareness for students K-12**
- **That they increase leadership opportunities for self-advocates**
- **That they help schools and communities become more inclusive places for people with Down syndrome**

For many years Tracy has led NDSC Convention workshops. Her presentations have been exceptionally successful because she is creative, plans well, and gives generously of her time and many talents. For more than a decade Tracy has been also been advocating for, and with, her peers. "Her passion for others has made the world a better place", said Carlene Mattson, previous NDSC Youth & Adult Chairperson.

Carlene is not the only one to recognize the gift that Tracy is to the world. In 2005 Tracy was awarded both the NDSC Meritorious Service Award and the Board Service Award. In 2006 she received an ABCD (Above and Beyond the Call of Duty) award and a beautiful corsage at the local School Board meeting. On December 29, 2018, Tracy celebrated her 50th birthday and the city of Murfreesboro declared the day "Tracy Hile Day". The proclamation recognized Tracy for "the contributions and volunteerism to the city, county, and state by promoting good character and citizenship to her community, surrounding areas, and tourists."

Book Review—Off to a Good Start: A Behaviorally Based Model for Teaching Children with Down Syndrome

I have to start by thanking Dr. Jones and Dr. Feeley for taking the time to put together a book on the science of Applied Behavior Analysis (ABA) and Down syndrome.

The science of behavior has always been a science of human behavior. ABA became popular as a treatment for autism because research was done to show the strong impact it had, but that was not to say that it was a treatment only for children with autism. These principles are the same for all of us and can help all of us! Behavioral programs have supported people with DS for decades to improve all aspects of their lives and this book has done a great job introducing the field of ABA to many people in our community who have never considered using these techniques before.

Dr. Jones and Dr. Feeley provide great detail about the concepts and principles of ABA and tie it to the strengths and needs of children with Down syndrome. They have also provided pages of research references to show that ABA is a proven effective intervention for children with DS.

Perhaps most importantly, the book emphasizes teaching and learning. Children with good skills do not have problem behaviors. The key to preventing and treating problem behaviors is effective teaching programs so children with Down syndrome can learn the skills they need to be successful at home, at school and in the community. This book helps families and professionals develop that important foundation for learning by providing a better understanding of effective teaching practices.

In order to be most effective, it is important to track progress and work together as a team. The authors guide you through both of these processes, which can be challenging and overwhelming at times. If the data sheets included in the book do not work for you, don't give up. Data is important and there are a lot of ways to collect it to ensure your programs and plans are effective.

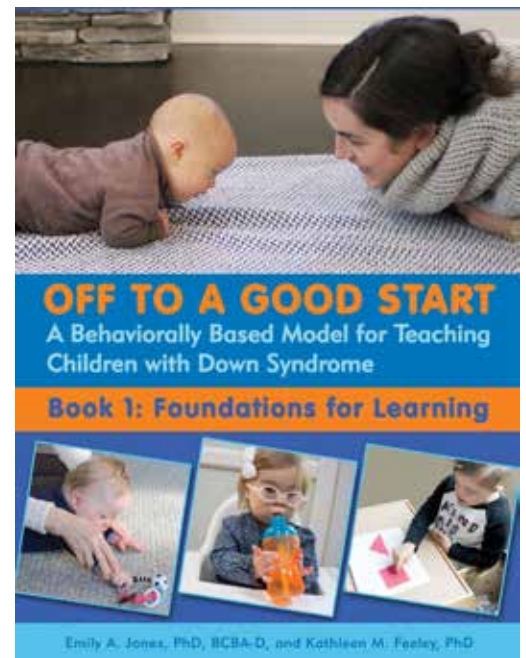
If you are looking for a book that provides curriculum and teaching programs, be on the lookout for book 2 in the series. The success stories and photos included are a great source of information and inspiration. These serve as a great reminder that while all of our successes and futures may look different, ABA can be a great resource to help us achieve our goals. I am glad that this book is now part of our community and I hope it serves as a valuable resource to families and professionals.

Review by: Stacy Taylor, MA, BCBA, President, Advance Behavior & Learning and Advance Learning Academy, daughter with DS, Orlando, FL

Off to a Good Start: A Behaviorally Based Model for Teaching Children with Down Syndrome Book 1: Fact Sheet

Distinguished from other books about Down syndrome by its ABA approach, the authors describe how to use prompts and reinforcement to teach skills and take advantage of the behavioral phenotype (characteristic strengths and weaknesses of Down syndrome) to shape children's learning. Book 1 covers:

- **What ABA methods entail**
- **Why children with DS need special teaching**
- **How to use a DS learning profile to overcome deficits**
- **The importance of inclusion**
- **How to choose target skills to teach and in what setting**
- **How avoid inadvertent reinforcement of undesired behavior**
- **Why it's important to generalize skills learned in one setting to another**
- **Monitoring you child's progress; tracking forms included**
- **How to handle challenging behavior**
- **How to encourage early intervention and ABA methods**
- **Success stories by families who've used the authors' teaching methods**



About the authors:

Emily A. Jones is a Licensed Behavior Analyst and Associate Professor in the Department of Psychology, Queens College, and The Graduate Center, City University of New York. In Dr. Jones's research, she examines interventions to improve outcomes for children with developmental disabilities and their families.

Kathleen M. Feeley is Professor in the College of Education, Information, and Technology and the founding Director of the Center for Community Inclusion at Long Island University. Dr. Feeley has dedicated her career to examining interventions that enable children with disabilities to be successful alongside their typical peers.

Publishing Contact: Beth Binns at bbinns@woodbinehouse.com or 800-843-7323.

School's Out For Summer!



In recent years there has been much debate about the “ideal” school year. Some schools have experimented with year-round school schedules. Many have tested the 45 days on then 15 off, while others have tried a 60-20 or 90-30 split. Some schools and parents lean toward the traditional side of longer summer breaks; a time for vacations making treasured family memories, or enjoying time with friends at summer camp, or making new friends while on church retreats, believing that kids need a break but also have concerns about “summer slide,” “brain drain,” or “summer learning loss,” that occurs when students are not receiving formal instruction during the summer months.

You may have heard the saying “If you don’t use it, you lose it”. There is much research to support the summer learning loss is to be expected during the summer. This research shows that children experience learning loss as measured by differences in grade-level equivalent scores at the end of one school year versus scores at the beginning of the following school year.

Just as learning varies among all children, so does learning loss. This so called summer slide does not take place equally across all academic areas or for all students. Students diagnosed with learning disabilities and/or receiving special education services appear to be at greater risk of learning loss than other students. And just as there are distinct differences in the impact of summer vacation on different students, there are differences in the academic skill areas that this loss impacts. Greater learning loss appears to occur in the area of math than in the areas of reading and language arts.

So what is a parent to do? You know your child better than anyone and of course, learning at home on a more relaxed schedule is different from learning at school, but there are things that you can do to narrow the learning loss gap.

We have looked at what the experts say and have constructed a list of ways to help you help them continue to learn, and thrive while enjoying their summer break.

1. Disguise learning as fun or play

Did you ever sneak veggies into your kids’ meals to maximize nutrition? You know those days when you would shred carrots and add them to the meatloaf – Now think along those same lines when it comes to summer learning.

If you try and pass off a plate of math camp or add a heaping portion of debate team to your kids’ summer menu, it might not go over too well if math or debate aren’t really their thing (If they are, then by all means, pile them on!). The tricky part is to incorporate the things your kids like to do and what are they interested in. Perhaps it is social media or video games, or maybe it’s their smartphone and the many apps that come along with it. Believe it or not, there is a camp for all of those things, and many can be found locally at community colleges, YMCAs and supplemental learning centers.

2. Introduce a new skill for learning

Much of K-12 education is memorization based. Everything from dates in history, the names of states and their capital cities, to math formulas, scientific principles,

and more. For many memorizing is a battle. There are ways though to cultivate minds so they maintain such knowledge. One way to do so is to start building a new skill foundation. By shifting the focus from memorization to areas like problem-solving or creativity kids are encouraged to engage with a skill that keeps their minds active. One idea is to encourage drawing or coloring a map to learn the states or countries. This is especially helpful if this was part of the past year’s, or will be part of the upcoming year’s curriculum.

3. Introduce something new! It may turn into a hobby or passion

Along the lines of the previous idea of introducing a new skill is the idea of introducing something completely new! “You won’t know if you like it unless you try” are the words many parents utter as they introduce new foods, but it also applies as we start thinking of inventive paths to learning.

While these words are often used to coax a picky eater into trying a new food, the same is true when it comes to finding a passion or hobby. If your child has never expressed an interest in sports, try signing them up for swim lessons or joining a summer soccer league. They may be surprised to find that they like these activities and physical activity is also good for continued brain stimulation.

Join NDSC's NDAC Program and Advance Your Advocacy Efforts!

The National Down Syndrome Advocacy Coalition ("NDAC") is a member service of the National Down Syndrome Congress ("NDSC"). NDAC is a grassroots advocacy service that is designed to educate individuals with Down syndrome, their family members and other allies about policy issues and give them the advocacy tools and techniques they need to effectively engage with their legislators to advocate for change.



Simply submit a brief online application and receive access to:

- Quarterly calls to provide legislative updates
- The NDAC-specific Facebook group
- The NDAC Member Meet-Up at the annual NDSC Convention
- Webinars
- Training opportunities

In addition, NDAC provides timely information on the latest policy topics so members can stay up-to-date on the latest legislative issues.

For more information and to become an NDAC member visit ndsccenter.org.



For more information including ideas and strategies to keep your children learning this summer you can visit <https://link.springer.com/search?query=summer+learning+loss> and <https://www.oxfordlearning.com/summer-learning-loss-statistics/>.

4. Limit down time and avoid boredom

We all like a good viral video, but for most of us, we find ourselves reaching for our phones, or plopping in front of the TV when we have nothing better to do, right?

While the first week or so of summer for most kids is generally met with a genuine enthusiasm to just chill and do whatever, most of the rest of the summer is filled with participating in whatever is convenient; whatever is in front of them—TV, video games, phone, computer, etc. Even the most involved kids and teens face summer boredom after a few weeks without structured activities in place.

Summer camps help fill the void and allow kids to interact with other kids and less with electronics. A benefit of summer camp is the fact that it is providing a break from summer break! They have something to do! Many parents report that after a day of camp, their child is begging to go back each day.

Camps do not have to be all day every day. During summer vacation, two to three hours per week are needed to prevent summer learning loss. Eliminate boredom, and eliminate the need to resort to "mindless" activity, freeing up time to engage in active learning.

5. Invest in the right kind of screen time

Screen time is not the enemy – but investing in the right kind of screen time that is the key. As parents, we aim to balance technology and life, but also, we can embrace the screen—video games and smartphones can be learning tools as much as they are entertainment devices.

The trick is to change the mindset. While most kids just sit and play games, get them thinking about other things while they're playing. The first step is to encourage kids to go from playing to questioning. The questioning can be simple- What is a character's name in the game that they are playing? How do they spell their name? You can also search for apps that involve "playing" as a means to learning such as one that identifies those states with "rewards" for doing so.

When screen time is purposeful it can help decrease the summer slide. Screen time needs to shift from playing, to learning, to doing. When this is done, minds stay sharp, kids are excited to actually learn during the summer, and then they roll back into school reinvigorated and in a better position to pick up where they left off.

Kids and teens can still very much enjoy their summer, while laying a foundation to help them succeed throughout the rest of the year, too. We hope that these tips will help parents help their children minimize summer learning loss.

Marifiez-Lora A.M., Quintana S.M. (2010) Summer Learning Loss. In: Clauss-Ehlers C.S. (eds) Encyclopedia of Cross-Cultural School Psychology. Springer, Boston, MA



NDSC Immediate Past President Honored on World Down Syndrome Day

As part of a celebration for World Down Syndrome Day, the Down Syndrome Partnership of North Texas honored NDSC Immediate Past President, Dr. Marilyn Tolbert, with the Legacy Award in recognition of her dedication—both personally and professionally—for her service for the Down syndrome community.

Marilyn is a longtime staff member at KinderFrogs School at TCU, currently serving as the Director of KinderFrogs and the Jean W. Roach Chair of Laboratory Schools, an early-intervention educational program for children ages 18 months to six years with developmental delays such as Down syndrome. She is a three-time TCU graduate with a Bachelor's degree in Elementary Education, a Master's degree in Administration, and a Doctorate in Educational Leadership.

"The Down Syndrome Advocacy Awards honor individuals who go above and beyond their formal job responsibilities to fight for inclusion and the rights of individuals with Down syndrome," said Kim Rocha, Executive Director for DSPNT. "Marilyn was chosen from hundreds of nominations submitted by their peers as well as members of our staff."

The Down Syndrome Partnership of North Texas provides support to individuals with Down syndrome and their families.

We are honored and appreciate all that Marilyn has done through the years to serve the Down syndrome Community and the NDSC.

NDSC Senior Policy Advisor, Stephanie Smith Lee, Speaks in Trinidad and Tobago for World Down Syndrome Day Conference

NDSC Senior Policy Advisor, Stephanie Smith Lee, spoke in Trinidad and Tobago at the United Nations World Down Syndrome Day Conference hosted in part by The National Down Syndrome Advocacy Coalition (a member service of the NDSC) Group member, Down Syndrome Family Network.

Stephanie spoke at the United States Embassy in Trinidad and Tobago on World Down Syndrome Day to Embassy staff, the media, and non-profit organizations about policy advocacy to create inclusive schools. As a featured speaker, Stephanie shared her knowledge of the lessons learned in the United States, about inclusive education, and the key role of family and self-advocates in creating positive change.





Coming to a City Near You!



**Catch Us This Fall in
Wilmington, DE or Orange County, CA**

For more information or to see where we are headed next visit ndsccenter.org

Research indicates that more students with intellectual disabilities are being included in general education classrooms than ever before, making it imperative that proper training and instruction on teaching techniques are passed on to the professionals working in these classrooms.

The NDSC has made it a priority to provide continuing education for teachers, paraprofessionals, and therapists working directly with students with Down syndrome and other intellectual disabilities like autism. We are working with affiliate subscribers to bring this highly sought-after training to communities around the country.

Official Announcement of the 2019 NDSC General Membership Meeting

The annual meeting of the NDSC General Membership will take place Friday, June 28, 2019, at 4:00 PM, in room 305 of the David L. Lawrence Convention Center, located at 1000 Ft. Duquesne Blvd., Pittsburgh, PA 15222.

This General Membership Meeting will include updates and an overview of activities from NDSC Executive Director, David Tolleson. Reports from the NDSC Treasurer and the NDSC Foundation Trustees will be presented. The NDSC Nominating Committee will present its slate of candidates for election to the NDSC Board of Directors and we will announce the newest self-advocate board member elected by his/her peers at the Youth & Adults Conference kick-off.

Members will vote on the proposed changes to the NDSC Bylaws listed below. It is proposed that the items stricken through are to be removed from the bylaws and, where applicable, replaced with the proposed underlined verbiage. These changes reflect the current location of the organization's offices; and, reflecting changes to the Partnership Alliance, returns the Board structure to what it was prior to 2011. NDSC's Board of Directors, which recommends these changes to the membership, remains committed to working closely with our local and regional affiliates in a manner that's useful to these valued partners, while not being a burden to their busy leaders.

ARTICLE I. Name and Offices

Section 1.2 CORPORATE OFFICES. The principal office of the Corporation shall be located in DeKalb Fulton County, Georgia, unless otherwise directed by the Board of Directors. The Corporation may from time to time establish such other offices as the Board of Directors may designate or as the affairs of the Corporation may require.

ARTICLE III. Board of Directors

Section 3.2 NUMBER, ELECTION, TERM, AND QUALIFICATIONS. The Board of Directors shall consist of twenty-three (23) not more than twenty-one (21) elected members of the Corporation; and the immediate past president, in cases where that person's term has expired; and, any person serving under the provision outlined in Section 4.2.3. Three of the 23 21 positions shall be self-advocates nominated according to section 3.4.; ~~two positions shall be representatives from the Partnership Alliance.~~

Elections for the Board of Directors may be held at the Annual meeting or by mail or e-mail, as prescribed by the board. Each Director shall be elected to serve a term of three years and shall hold office until his or her successor is elected and qualified, or until his or her earlier death, resignation, or removal.

No person shall be elected to the Board of Directors for more than three consecutive terms, and no person who has been appointed to serve more than half of an unexpired term of a



previous director may serve for more than two consecutive terms following their partial term. After a break from Board service of at least 1 year, former Directors are again eligible to serve on the Board of Directors for up to three additional consecutive terms, or if appointed to serve more than half of an unexpired term of a previous director, not more than two consecutive terms following their partial term.

Employees shall be excluded from positions on the Board of Directors.

Section 3.4 NOMINATION OF DIRECTORS. Recommendation for Director nominees may be submitted by any member to the Nominating Committee. The self-advocate Director nominee will be made by the self-advocates at the annual Youth and Adults Convention of the NDSC or by mail or e-mail, as prescribed by the Board. ~~The Partnership Alliance nominee shall be nominated by the Partnership Alliance, per the Partnership Alliance Policies, as approved by the Board of Directors.~~ The Nominating Committee shall present a slate of Director-nominees to the Board and members.

ARTICLE VIII. Miscellaneous

Section 8.11 DISSOLUTION. On dissolution of the Corporation, all of its net assets shall be paid over or transferred to one or more exempt organizations of the kind described in Internal Revenue Code Section 501(c)(3). The organization to receive such property shall be designated by the Board of Directors. Any assets not so disposed of shall be disposed of by the County Court in and for the County of DeKalb Fulton, Georgia, exclusively for one or more exempt purposes within the meaning of Internal Revenue Code Section 501(c)(3), or to such organization or organizations as such court shall determine, which are organized and operated exclusively for such purposes.

Other business will be conducted as warranted. All NDSC members are invited to attend.

Is College in Your Son or Daughter's Future?

If you are considering a post-secondary program for your young adult with Down syndrome, then the College Fair at the NDSC Convention in Pittsburgh is the place to be. Colleges from around the country will showcase on and off campus post-secondary education programs for individuals with intellectual disabilities at the NDSC College Fair on Friday, June 28, from 3:00 PM–5:00 PM.

The College Fair is hosted in collaboration with Think College, the national organization dedicated to developing, expanding, and improving higher education options for people with intellectual disabilities. This event is designed for self-advocates and their families to gain information about available programs, tuition, fees, and criteria to apply, and is free to all NDSC Convention registered attendees.



Visit with representatives from higher education programs from around the country offering postsecondary education opportunities for students with intellectual disabilities.

Friday, June 28, 2019 • Pittsburgh, PA
3:00 p.m. - 5:00 p.m.
West Atrium, 3rd Floor

For a list of colleges exhibiting visit
<https://www.ndsccenter.org/annual-convention/college-fair-at-the-convention/>



EDUCATOR CONFERENCE

Effective Practice for Students with an Intellectual Disability, Including Down Syndrome and Autism

FRIDAY, JUNE 28 • 8:30 AM – 4:30 PM

David L. Lawrence Convention Center • Spirit of Pittsburgh Ballroom
1000 Ft. Duquesne Blvd, Pittsburgh, PA 15222

\$100 - Includes CEU's

Featured Guest Speaker: OSEP Director, Laurie Vanderploeg

For more information, speaker bios, agenda and to register:
<https://www.ndsccenter.org/outreach-education/educator-conference/pittsburgh-2019/>



**LITERACY
SKILLS**



Chris Lemons, PhD



BEHAVIOR



David Stein, PysD



TECHNOLOGY



Sean Smith, PhD



**TEACHING
TOOLS**



Dana Halle, JD



NATIONAL
DOWN SYNDROME
CONGRESS

Pittsburgh, Pennsylvania June 27-30, 2019

It's time to **EDUCATE**, **ADVOCATE** and **CELEBRATE** in Pittsburgh

It's not too late to register for the largest gathering in the world for people with Down syndrome, their families, and the professionals who serve them. Convention registration will re-open on-site, at 4:00 PM, Thursday, June 27, in the West Atrium of the David L. Lawrence Convention Center.

Come Early or Stay Longer – Pittsburgh has so Much to Offer!

Pittsburgh has so much to offer families attending the 47th NDSC Annual Convention with many family-friendly attractions such as the Carnegie Science Museum and the Pittsburgh Zoo and Aquarium, which are sensory-inclusive certified. For more about Pittsburgh and all the city has to offer visit www.visitPittsburgh.com.

Advocacy Training Boot Camp at the NDSC Convention

Thursday, June 27, 2019

8:00 AM–12:00 PM

- Designed to be an Advocacy 101 mini-course
- Define advocacy
- Overview of basic government processes (state vs. federal, appropriations)
- Discuss how to effectively engage with legislators
- Hear panels of advocates (including self-advocates) share their tips and experiences



Feature speaker and NDSC member, Julie Rothholz, will talk about her experiences in advocacy and more!

Free to NDSC Convention registered attendees but registration is required.

**ADVOCACY
BOOT CAMP**

THURSDAY, JUNE 27, 2019
8:00 AM – 12:00 PM
PITTSBURGH, PA
47TH ANNUAL NDSC CONVENTION

#AdvocacyBootcamp



Es tiempo de EDUCAR, ABOGAR, Y CELEBRAR en Pittsburgh

Todavía hay tiempo para registrarte para la reunión más grande del mundo para personas con síndrome de Down, sus familias y a los profesionales quienes los sirven. Inscripción reabrir a las 4:00 PM, jueves 27 de junio en el atrio oeste del Centro de Convención David L. Lawrence.

Llega temprano o quédate más tiempo – ¡Pittsburgh tiene mucho que ofrecer!

Pittsburgh tiene mucho que ofrecer a las familias que asistirán la 47ª Convención Anual de NDSC. Hay muchas atracciones para familias como el Museo de Ciencia Carnegie y el Zoológico de Pittsburgh y el Acuario, que son certificados en ser inclusivo sensorial. Para más información sobre Pittsburgh y todo lo que la ciudad tiene que ofrecer visite: visitPittsburgh.com

BAILE 321™
PIESTA DE CAMISETA
DEPORTIVA

Compre su camiseta deportiva del NDSC a partir del 12 de mayo en nuestro sitio web, ndsccenter.org, o en la Convención
(compre su camiseta deportiva del NDSC en línea para garantizar su talla y color)

Habrá representantes de programas de educación superior de alrededor del país ofreciendo oportunidades de educación postsecundaria para estudiantes con discapacidades intelectuales.

Viernes, 28 de junio 2019 • Pittsburgh, PA
3:00 p.m. - 5:00 p.m.
Atrio Oeste, 3er Piso

Para ver una lista completa de las universidades que estarán presentes visite:
<https://www.ndsccenter.org/annual-convention/college-fair-at-the-convention/>

¿La Universidad está en el futuro de tu hija o hijo?

Si están considerando un programa pos-secundario para tu joven con síndrome Down, vengan a la Feria Universitaria en la convención del NDSC en Pittsburgh. Universidades de alrededor del país estarán presentando varios programas de educación postsecundaria dentro y fuera del campus para individuos con discapacidades intelectuales en esta feria, se llevara a cabo el Viernes 28 de junio de las 3:00 PM-5:00 PM.

La Feria Universitaria será presentada en colaboración Think College, la organización nacional dedicada en desarrollar, expandir y mejorar las opciones de educación superior para personas con discapacidades intelectuales, y está diseñado para auto-defensores y sus familias para obtener información sobre programas, matrículas, cuotas y criterio para aplicar.

Para obtener más información sobre los talleres de la Convención del NDSC 2019 y la grabaciones, visite ndsccenter.org.

3 Precios Diferentes Desde \$59 Cuando lo Compras Antes del 4 de Junio

Convención del NDSC 2019

Anunciando la Convención General en español!

La Dieta del Síndrome de Down: Cambiando el 'Trayecto' a través de Nutrición

Jennifer Kimes, PsyD, Directora Ejecutiva de Educación y Servicios Clínicos, Síndrome de Down de Louisville, hija con SD, Louisville, KY

Como Reconocer Regresión en SD

Kristin Dalope, MD, MEd, Psiquiatra, Consultas de salud conductual pediátrica y servicios de enlace, Hospital de Niños de Pittsburgh de UPMC, Pittsburgh, PA y **Andrew McCormick, MD**, Director del Programa Transiciones Saludables, Centro de Síndrome de Down de Pennsylvania Occidental Hospital de Niños de Pittsburgh, Pittsburgh, PA

Recomendaciones adicionales en los cuidados de salud en las personas con síndrome de Down

Karla Adney Flores Arizmendi y Lidia del Carmen Gomez Puente, Pediatra/ Posgrado en Atención Integral a Personas con síndrome de Down, Instituto Nacional de Pediatría de la Ciudad de México, Jefe de la Clínica Down

Apnea obstructiva del sueño y problemas de oído, nariz y garganta en SD

Christine Heubi, MD, Profesor Asistente, Hospital de Niños de Cincinnati Children's Centro Medico, Cincinnati, OH

Aprender a enseñar: Estrategias para apoyar a mi hijo/a en el proceso lector y de cálculo matemático

Waleska Lisboa, Educadora Diferencial, especialista discapacidad cognitiva, Centro UC síndrome de Down, Pontificia Universidad Católica de Chile Santiago, Chile.

La Jornada a Comunicación

Eva Hampton, MA, CCC-SLP, Patólogo del Habla y Lenguaje, Terapia del Habla Hampton, hijo con SD, Spring City, TN

De la menstruación a la masturbación - abordar la pubertad en niños con síndrome Down sin frustración

Noemi Alice Spinazzi, MD, Médico de Cabecera en UCSF Benioff Hospital de Niños en Oakland; Directora Medica de la Clínica de Síndrome de Down en UCSF; Co-Directora de Rotación de desarrollo pediátrico y conductua en UCSF Benioff Hospital de Niños Oakland; y Profesor Clínico Asistente en Escuela de Medicina en UCSF

¡Echa un vistazo! Video modelado e instrucción en video: ¡una herramienta poderosa para aprender cosas!

Lindsay M. McCary, PhD, Psicóloga Licenciada, Directora de la Clínica de Autismo & Discapacidades del Desarrollo, y **Elizabeth M. Delsandro, MS, CCC-SLP**,

Patóloga del habla y lenguaje, ambas del Centro Waisman, Universidad de Wisconsin-Madison, WI

Formando Conductas Adaptativas para la vida

Silvia Maravilla Ávila y José Alberto Alonso García, Lic. en Psicología, especialista en Terapia Familiar, API, Centro de Asesoría Psicológica Integral

Defensa multidisciplinaria para niños con diagnóstico dual de DS y trastorno de la gama autista: desde el diagnóstico hasta la vida útil

Mary Pipan, MD, Pediatra de Comportamiento & Directora, **Audrey Vincent, MSW, LSW**, Trabajadora Social, ambas del Programa Trisomy 21, Hospital de Niños de Philadelphia, PA, y **Diane Perry**, Asesora, Centro PEAL, hijo con SD, Philadelphia, PA

Síndrome de Down: Vida Dependiente vs Vida Independiente

Teresa Aguilascho, Médico Ginecologa, Lic. en Psicología, Tanatologa Familia, Salud y Desarrollo en Síndrome de Down A.C.



Alcane Hispano

El Congreso Nacional de Síndrome de Down ha comenzado dos nuevos programas. El Programa de Alcance Rural es una conferencia de un día para reunir a los mejores ponentes, profesionales médicos y líderes en varios temas relacionados con el síndrome de Down, para que la comunidad hispana tenga acceso a la información. Otro programa que estamos iniciando es webinars en español. Estos webinars están diseñados para que usted escuche a expertos de todo el mundo desde la comodidad de nuestra computadora de su hogar u oficina.

Si está interesado en traer alguno de estos programas a su comunidad, envíe un correo electrónico a Mateo Fernández a matthew@ndsccenter.org



Cuidado Dental para Pacientes con Síndrome de Down

Sentir ansiedad al visitar al dentista es algo muy normal y le pasa a mucha gente, pero puede ser aun más retador para aquellos con Síndrome de Down. Los pacientes con síndrome de Down no siempre podrán comunicarle al dentista lo que necesitan, así que lo mejor es estar preparado para asegurarse que las personas involucradas tengan una buena experiencia. Es tentador posponer el cuidado dental dada la complejidad de la situación, pero para poder evitar un problema dental que requiera atención urgente, es importante encontrar un dentista en el que usted pueda confiar y al que pueda visitar periódicamente.

Al compararlos con niños que no tienen síndrome de Down, los dientes de leche y dientes permanentes de estos pacientes frecuentemente aparecen a una edad más tardía. La erupción retardada es uno de los ejemplos

más comunes dentro de los otros problemas dentales que son detectados en pacientes con síndrome de Down. Sin embargo, algunos de los problemas dentales más comunes son resultado de otros factores, como los genéticos. Esto puede dificultar la distinción entre lo que es resultado del síndrome de Down, genética, hábitos, o cualquier otro elemento.



Los pacientes con síndrome de Down pueden sentir mucho miedo de ir al dentista porque tal vez no entiendan que es lo que va a pasar. Por ejemplo, si desconfían de la gente que no conocen y no les gusta tener contacto físico, el hecho de tener las manos de un extraño con herramientas en su boca puede ser aterrador. Tomando esto en cuenta, es importante ayudar a su ser querido con su miedo y ansiedad lo mas que se pueda para asegurar que la visita resulte sin inconvenientes. Afortunadamente, hay varias maneras de hacer que la cita sea fácil para todos.

Encontrando al Dentista Ideal

Sin importar el escenario, es extremadamente importante encontrar al dentista ideal para sus seres queridos. Contar con un dentista que sea paciente y entienda su situación es el primer paso para tener una experiencia dental sin contratiempos. Busque a los dentistas que tengan un enfoque sistemático en todos sus exámenes y tratamientos. También le recomendamos



que les pregunte si tienen experiencia con pacientes con necesidades especiales. La programación flexible de citas también es un elemento que le sugerimos tome en cuenta.

Durante su búsqueda considere hacerse las siguientes preguntas:

- **¿El dentista y su equipo tendrán una interacción positiva con mi ser querido?**
 - **¿El dentista y su equipo tendrán paciencia, ofrecerán consuelo y empatía?**
 - **¿Mi familiar se sentirá cómodo en esta clínica?**
 - **¿El dentista, o su equipo, tiene experiencia o capacitación adicional con pacientes con necesidades especiales?**
 - **¿Esta clínica podrá ofrecernos programación flexible de citas en caso de que algo pase?**
 - **¿Esta clínica ofrece servicios adicionales diseñados específicamente para pacientes con necesidades especiales?**

Al tratar de encontrar a su dentista ideal, primero contacte a las clínicas locales dentro de su área. Pida recomendaciones a sus amigos, familiares, doctores o alguien que usted conozca que tenga experiencia con personas con necesidades especiales. <https://www.emergencydentistsusa.com/dentista-cerca-de-mi-casa-ubicacion/>

Preparar a nuestros seres queridos para su cita es de suma importancia sobre todo si nunca han asistido al dentista. Platique con ellos acerca de lo que es un dentista, que es lo que van a hacer (si conoce los detalles), y como es el proceso. Describa de manera positiva como es una visita promedio al dentista. Aunque sepa que va a haber ciertos aspectos negativos, no los comparta y enfóquese en aquello que motivara a su ser querido a tener una idea positiva de su próxima cita. Seria de mucha ayuda explicarles con apoyos visuales. Por ejemplo, les puede mostrar la página Web

del dentista, visitar la clínica con anticipación para saludar a los empleados, o compartir alguna visita suya con optimismo.

La Pregunta de la Sedación

Los pacientes con necesidades especiales a veces pueden beneficiarse de estar sedados con anestesia general durante la cita. La sedación en ocasiones es indispensable si es necesario realizar un tratamiento dental del cual dependa la relajación del paciente. A nadie le gusta tener a alguien utilizando herramientas en su boca, así que para facilitar la experiencia y minimizar el miedo y el dolor, la sedación es definitivamente una opción de la que usted puede hablar con su dentista. Esto es particularmente importante con cirugías dentales mayores, en este tipo de casos le sugerimos poner atención adicional a la opción de la sedación.

Prácticas de Higiene Bucal en Casa

Esto tiene la misma importancia que las visitas periódicas al dentista, si no es que mas. Sin embargo, dependiendo de las circunstancias, aquellos con necesidades especiales pueden tener mucha dificultad cumpliendo con las prácticas adecuadas de higiene bucal. Por esta razón, usted como responsable de los cuidados, debe ayudar con este importante elemento de la salud dental. Para los niños con síndrome de Down, el mejor lugar para empezar es demostrándoles los hábitos de higiene bucal a una edad muy temprana. Sin embargo, recuerde que nunca es tarde para empezar a cuidar de su higiene oral, ya sea en el caso de adolescentes, adultos o personas de la tercera edad.

Compartido con permiso de www.Dentably.com



V Congreso Iberoamericano

Nuestro compañero Mateo Fernández, Director de Programas Multiculturales tuvo el placer de asistir al V Congreso Síndrome de Down en Cartagena, Colombia. Fue una experiencia maravillosa el conocer a las familias y a tantos excelentes ponentes. Esperamos poder trabajar juntos con más familias para mejorar las vidas de las personas con síndrome de down.

Down Syndrome News

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Mission

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

Vision

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

Statement of Policy and Disclaimer:

This newsletter reports items of interest relating to Down syndrome and provides a forum for others. The NDSC does not promote or recommend any therapy, treatment, etc. NDSC will not espouse any particular political or religious view. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. The National Down Syndrome Congress works to educate, advocate and empower. We are the leading national resource of support and information for people seeking to learn about Down syndrome.

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Down Syndrome News

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To renew or join, visit ndsccenter.org.

To update your contact information, call 800-232-6372 or email info@ndsccenter.org.

When we **empower** individuals and families from all demographic backgrounds, we **reshape** the way people understand and experience Down syndrome.



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