

Down Syndrome Association OF NORTHEAST OHIO



Medical News

June 7, 2023

Message from Dr. Laura Cifra-Bean

Being immersed in the community of people with Down syndrome (Ds) and their families is a privilege. DSANEO recently had its first in person baby night since Covid started and it was great to see the moms talking and having fun with their kids. We also had an Earth Day celebration with teens and adults with Ds and medical students from Ohio University Heritage College of Medicine. They played corn hole, planted flowers, did some improv games and got to know each other as people. Hopefully, this will lead to the students being more comfortable with people with disabilities as patients. We are deep in planning for our annual Buddy Walk. Thanks for supporting the people with Ds that you know and reach out if you need resources or have a family that needs support.



Learn more about the Buddy Walk
[HERE](#)

Saturday, August 5, 9:00 am

Tri-C Western Campus

**Registration is
NOW OPEN**



Down syndrome and Obstructive Sleep Apnea (OSA)

Obstructive sleep apnea is very common in children and adults with Ds. The AAP guidelines recommend a sleep study for all children with Ds by age 3-4 even if there are no signs of disordered breathing. Common treatments include adenotonsillectomy in children and CPAP at many ages. **Recently the FDA approved Inspire, a hypoglossal nerve stimulation device for people with Ds age 13 and older, who have an apnea hypopnea index (AHI) between 10 and**

50, are not candidates for adenotonsillectomy (likely have already had one), have not benefitted from CPAP, and who do not have concentric airway collapse. The device works by stimulating the muscles at the base of the tongue to move it forward during inspiration. Read a brief overview of information related to the FDA's approval to market this product [HERE](#)



Stenerson ME, Yu PK, Kinane TB, Skotko BG, Hartnick CJ. Long-term stability of hypoglossal nerve stimulation for the treatment of obstructive sleep apnea in children with Down syndrome. *Int J Pediatr Otorhinolaryngol.* 2021 Oct;149:110868. doi: 10.1016/j.ijporl.2021.110868. Epub 2021 Aug 5. PMID: 34371294.

This was part of the larger study below and followed 4 patients for at least 44 months. Two patients had a complete resolution of OSA per sleep study when the device was on but still significant obstruction if the device was off. The other two patients had over 50% reduction in their apnea hypopnea index.

Yu PK, Stenerson M, Ishman SL, Shott SR, Raol N, Soose RJ, Tobey A, Baldassari C, Dedhia RC, Pulsifer MB, Grieco JA, Abbeduto LJ, Kinane TB, Keamy DG Jr, Skotko BG, Hartnick CJ. Evaluation of Upper Airway Stimulation for Adolescents With Down Syndrome and Obstructive Sleep Apnea. *JAMA Otolaryngol Head Neck Surg.* 2022 Jun 1;148(6):522-528. doi: 10.1001/jamaoto.2022.0455. PMID: 35446411; PMCID: PMC9026239.

This multicenter study followed 42 adolescents with Ds and CPAP intolerance who had hypoglossal nerve stimulator implantation because of severe OSA after adenotonsillectomy. Results showed that **65.9% of patients had a 50% decrease in AHI** and also improvements in quality of life assessments.

Resources for families

This recorded webinar is great for families and clinicians. It includes a young man with Down syndrome describing his experience with Inspire.

<https://adsresources.advocatehealth.com/advancements-in-the-treatment-of-obstructive-sleep-apnea-webinar-recording-1182021/>



Down syndrome and Autism

It is estimated that at least **16-18% of people with Down syndrome also have autism**. It is important to identify a child with a dual diagnosis because it can change the focus of different therapies, educational strategies, and supports for the child and family.

Spinazzi, N.A., Velasco, A.B., Wodecki, D.J. et al. Autism Spectrum Disorder in Down Syndrome: Experiences from Caregivers. *J Autism Dev Disord* (2023). <https://doi.org/10.1007/s10803-022-05758-x>

This study was based on surveys from 47 parents whose children had confirmed diagnoses of Down syndrome and autism and were part of the DS-ASD Connection Facebook group. It found that evaluation of autism was pursued because of stereotypy, and/or significant difficulty with communication or behavior. It took several years to get a second diagnosis and many parents felt their initial concerns were not given attention by the child's doctor. Parents of children with dual diagnosis report feeling stress and social isolation.

Spinazzi NA, Santoro JD, Pawlowski K, Anzueto G, Howe YJ, Patel LR, Baumer NT. Co-occurring conditions in children with Down syndrome and autism: a retrospective study. *J Neurodev Disord.* 2023 Mar 2;15(1):9. doi: 10.1186/s11689-

This study reviewed a database from Boston Children's Down Syndrome Program. People with Ds and autism were more likely to be male, and had higher rates of constipation, GERD, feeding issues, **infantile spasms (OR 6.03)**, and scoliosis. They did not have higher rates of heart surgery, autoimmune thyroiditis, celiac disease, anxiety, or ADHD.

Resources:

If a family is concerned that their child with Ds is having significant behavior issues, serious feeding problems, or language delays, then evaluation by a developmental-behavioral pediatrician is warranted. We are fortunate to have several great resources in our area.

Nancy Roizen MD at Rainbow Babies & Children's Hospital

- 216.844.7700

Irene Dietz MD at MetroHealth

- 216.778.5198

Mary Wong MD at Cleveland Clinic

- 216.448.6110

Diane Langkamp MD at Akron Children's

- 330.543.2778

DSANEO has a specific group for those with a dual diagnosis. It is called DS+. There is a private Facebook group. <https://www.facebook.com/groups/613617485413435>
There is also a webinar on August 9th for this group.

Navigating and Advocating for your child in the schools

By Shari DeCarlo

6:30-7:30 zoom

RSVP debbie@dsaneo.org

Online resources:

- <https://sites.google.com/view/charlies-clinic/learningdevelopment/autism?authuser=0>
- <https://ds-asd-connection.org/>
- <https://www.dsrf.org/resources/the-lowdown-podcast/dual-diagnosis-the-down-syndrome-and-autism-connection/>

Down Syndrome Medical Interest Group ECHO

<https://www.dsmig-usa.org/Project-Echo>



Down Syndrome ECHO

- ✓ Health care providers of individuals with Down syndrome are invited to attend. These may include physicians, nurse practitioners, psychologists, social workers, nurses, therapists, and others.
- ✓ Health care providers who are seeking input on the care of a person with Down syndrome will present a de-identified case study. All attendees in the session are invited to participate in a discussion of the case.
- ✓ There is no cost to participate in program

 **Monthly Sessions**
5:00 PM EST

 **Find out more here:**
dsmig-usa.org/Project-Echo

DOWN SYNDROME MEDICAL INTEREST GROUP - USA

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