

Case study of 4-year-old with Down syndrome and sleep apnea suggests procedure can be effective at young ages

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While Obstructive Sleep Apnea (OSA) affects about 5% of the general pediatric population, 80% of children with Down syndrome experience OSA. Continual OSA results in poor health, including disruptions to

cognitive development and functioning, leading physician-researchers from Mass General Brigham to investigate better methods to treat these patients as early as possible to maximize their health outcomes.

In a new case study published April 11 in *Pediatrics*, they report on a 4-year-old boy with Down syndrome and OSA who underwent a procedure to implant a hypoglossal nerve stimulation device, and experienced improvements thereafter.

Currently, adenoidectomies and tonsillectomies are among first-line treatments for pediatric OSA, however they are not always effective for children with Down syndrome because OSA can recur. Additionally, [continuous positive airway pressure](#) (CPAP) treatment, which streams compressed air into airways during sleep, is often not tolerated by children with Down syndrome due to sensory sensitivities.

The hypoglossal nerve stimulation device by Inspire has been an option increasingly used to treat OSA in adults since its 2014 FDA-approval. The device detects when the airway is blocked and sends an electrical pulse to the hypoglossal nerve that controls the tongue, causing it to move forward in the mouth, thereby opening the airway.

Positive treatment data in adults first led lead study author Christopher Hartnick, MD, director of Pediatric Otolaryngology at Mass Eye and Ear, to wonder whether the treatment may help his patients with Down syndrome whose lives were impacted by OSA.

With Mass General Brigham colleague Brian Skotko, MD, MPP, the Emma Campbell Endowed Chair on Down Syndrome at Massachusetts General Hospital, they organized a clinical trial looking at the safety and effectiveness of the procedure in children between the ages of 10 and 22 with Down syndrome.

[Results of a 42-patient trial](#) showing the benefits and safety of the procedure were published in 2022, leading to FDA approval for the device for adolescents with Down syndrome over the age of 13 nearly a year later.

These results spurred the researchers to examine whether the procedure could benefit [younger children](#) who are impacted by the physical and neurocognitive effects of OSA during pivotal developmental years.

Hartnick and Skotko identified a patient candidate, 4-year-old Theodore "Theo" Scott of Knoxville, Tenn., who had been on CPAP therapy since he was 1 year old.

After Hartnick and his team had extensive discussions about potential risks with colleagues in other medical specialties and Theo's parents, Rachel and Andrew Scott, a surgery took place in May 2023. The surgery was successful without complications, and the procedure was modified to allow for Theo's continued growth.

After one month, Theo experienced an improvement in sleep, and his obstructive apnea-hypopnea index (a measure of apnea severity) decreased by 40%. Additional follow-up care will take place for Theo to monitor effects of the procedure on neurocognition and surveillance of the device as he grows.

"The most significant change we have seen is the amount of sleep Theo is now getting, routinely over 10 hours a night versus what we experienced with CPAP where he would pull his mask off up to fifteen times a night. Theo sleeping through the night has also benefitted us as parents since we would need to get up and assist him, and we could each feel the toll poor sleep was taking on our health," Rachel and Andrew Scott said in a statement.

"We have also noticed Theo wakes up more easily in the morning and has a longer attention span than before the surgery, and his [language development](#) has accelerated from one-word statements to multiple word sentences. This procedure has absolutely been a game-changing intervention in Theo's life and in our family's."

Hartnick and Skotko are currently leading an NIH-sponsored 4-year trial examining the impact of upper airway stimulation on neurocognition and language in young patients with Down syndrome.

"Children with Down syndrome are disproportionally affected by [obstructive sleep apnea](#) and often don't benefit from traditional interventions, and research shows this impacts their [cognitive development](#) and IQ scores," said Hartnick.

"The potential long-term impact on neurocognition was a major driver of our team and the family's shared decision-making to pursue this treatment, and this case suggests it may be a possible option for some families.

"In our Down Syndrome Program, I see first-hand how frustrated families become when their child with Down syndrome runs out of options to treat significant sleep apnea," said Skotko. "Theo now opens up a new frontier for research and potential clinical care."

More information: Hypoglossal Nerve Stimulation for Obstructive Sleep Apnea in a Young Child With Down Syndrome, *Pediatrics* (2024). [DOI: 10.1542/peds.2023-063330](https://doi.org/10.1542/peds.2023-063330)

Provided by Mass General Brigham

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