

Sotos Syndrome

What patients and Drs should talk about



Psychology/Developmental

- Autistic Traits or diagnosis of Autism
- Cognitive Delays mild-severe, but can be in the typical range
- Delayed speech
- Low-tone (Hypotonia)
- Sensory processing disorder / Auditory processing disorder
- ADD/ADHD is common
- Feeding difficulties early on

Endocrinologist

- Over-growth beginning in the womb
- Hyperinsulinemia in the newborn period but usually resolves
- Puberty early side of average common
- Advanced bone age

Orthopaedics

- Higher risk of Scoliosis, infantile and through teen growth spurt, which can be earlier for those with Sotos
- Kyphosis also common
- Hypotonia

Primary Care (GPs)

- Frequent Respiratory Infections in early years
- Dental issues common (over-crowding due to jaw structure, low enamel)
- Difficulties regulating temperature (Rosie cheeks)

Neurology

- Macrocephaly almost always present
- True Hydrocephalus is extremely rare
- Seizures can occur, often triggered by a fever
- Frontal bossing in childhood

Ear, Eyes, Nose and Throat

- Conductive Hearing loss common
- Visual impairment requiring glasses is common
- Sleep Apnea (obstructive due to jaw size)

Cardiology

- Dilation of the aorta
- Occasional congenital heart malformation

Nephrology

- Vesicoureteral Reflux
- UTI's common
- Kidneys problems common

Gastroenterology

- Gastroesophageal Reflux
- Constipation with megacolon common

This document is a guide only, not all patients will exhibit all symptoms or require all tests.