

www.kbgfoundation.org
info@kbgfoundation.com



The KBG Foundation is dedicated to providing support, assisting in research programs and advocating to raise awareness about the syndrome.

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**INTERNATIONAL
KBG
SYNDROME
AWARENESS
DAY JUNE 11TH**

Tethered Cord
Syndrome
in KBG syndrome

What types of Tethered Cord exist in KBG syndrome?

Tethered cord syndrome (TCS) is a neurological syndrome caused by the attachment of the spinal cord to a structure within the spine. This limits, and in advanced stages, prevents the spinal cord from moving freely within the spinal canal.



Occult tethered cord differs by rarely showing confirmative radiological findings.

INCIDENCE

Research into TCS* in KBG syndrome shows 11% of individuals with the syndrome have been diagnosed with a tethered cord. Another 24% have strong symptoms but have not been diagnosed.

PROGNOSIS



Early repair can remedy almost all TCS symptoms.

TREATMENT

Cord release surgery is the only treatment with permanent results. Cords have been known to re-tether and should be always be followed by your doctor.

THINGS TO LOOK FOR

The most common symptoms supporting a diagnosis of Tethered Cord Syndrome are listed by manifestation frequency.

Orthopedic

Sacral dimple
Gait changes
Rigid legs/spasticity of legs
Scoliosis



Gastrointestinal

Severe
Constipation
Bowel changes

Urological

Bladder changes
Frequent UTI's

Neurological (subjective)

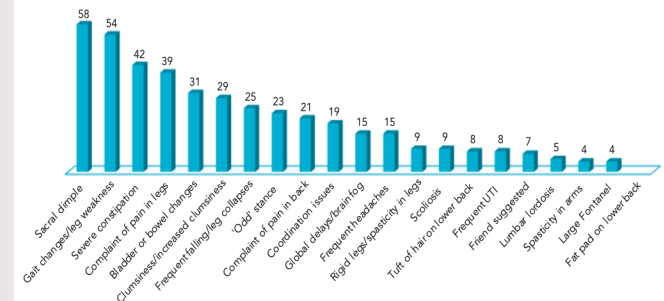
Global delay and brain fog
Complaints of leg pain
Decreased sensation
Lower extremity weakness



Neurological (objective)

Coordination issues
Clumsiness or increased clumsiness
Frequent falls or leg collapse
Asymmetry in neurological deficits

Symptoms of Tethered Cord present in KBG Syndrome patients



Specialist to visit

Only see a Neurosurgeon with experience in tethered cord syndrome.

Testing

Specialists in TCS use symptoms as the primary diagnostic tool. This is followed with urodynamics testing and finally lumbar MRI. Clinical evaluations are key to a correct diagnosis.

Specialists and patients have found MRI-only diagnosis are not accurate.



Information presented in this document has been verified by the KBG Foundation Scientific Advisory Board and specialists in the field of Neurosurgery

* Hills S, Pugacheva A, Weltin P, Maughan A, Morton SU, Feldman HA, Klinge PM, Agrawal PB. Tethered cord syndrome in KBG syndrome. Am J Med Genet A. 2023 May;191(5):1222-1226. doi: 10.1002/ajmg.a.63128. Epub 2023 Feb 1. PMID: 36722669