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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



**Occult Tethered
Cord Syndrome
in KBG**

What is Occult Tethered Cord Syndrome?

Tethered cord syndrome 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 IN KBG SYNDROME

Patient reporting in KBG Syndrome shows 11% of individuals with the syndrome have been diagnosed with a tethered cord. Another 27% have strong symptoms but have not yet been diagnosed.



PROGNOSIS

Early repair remedies almost all OTCS symptoms.

TREATMENT

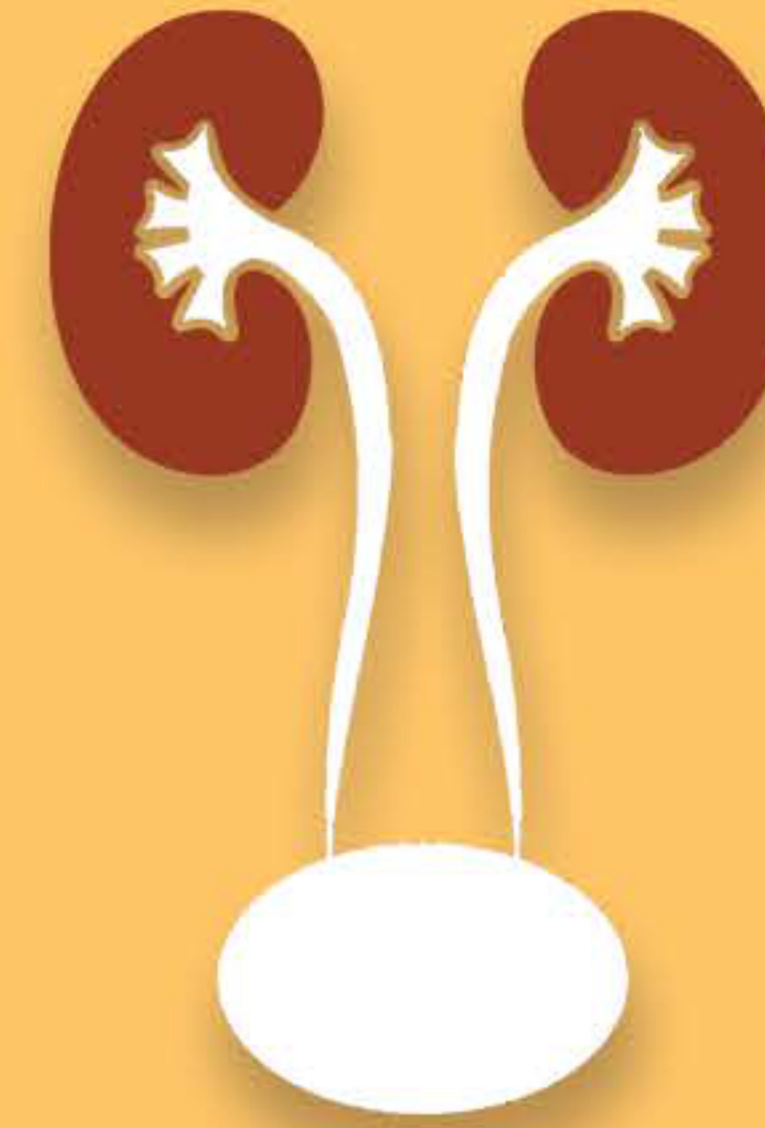
Cord release surgery is the only treatment with permanent results. Cords have been known to re-tether and should be always be followed by your Doctor.

Things to look for:

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

UROLOGICAL

- + leaking/incontinence
- + urine retention
- + constipation
- + fecal incontinence



ORTHOPEDIC

- + back pain
- + foot/ankle deformities
- + scoliosis
- + gait changes
- + sacral dimple

NEUROLOGICAL (SUBJECTIVE)

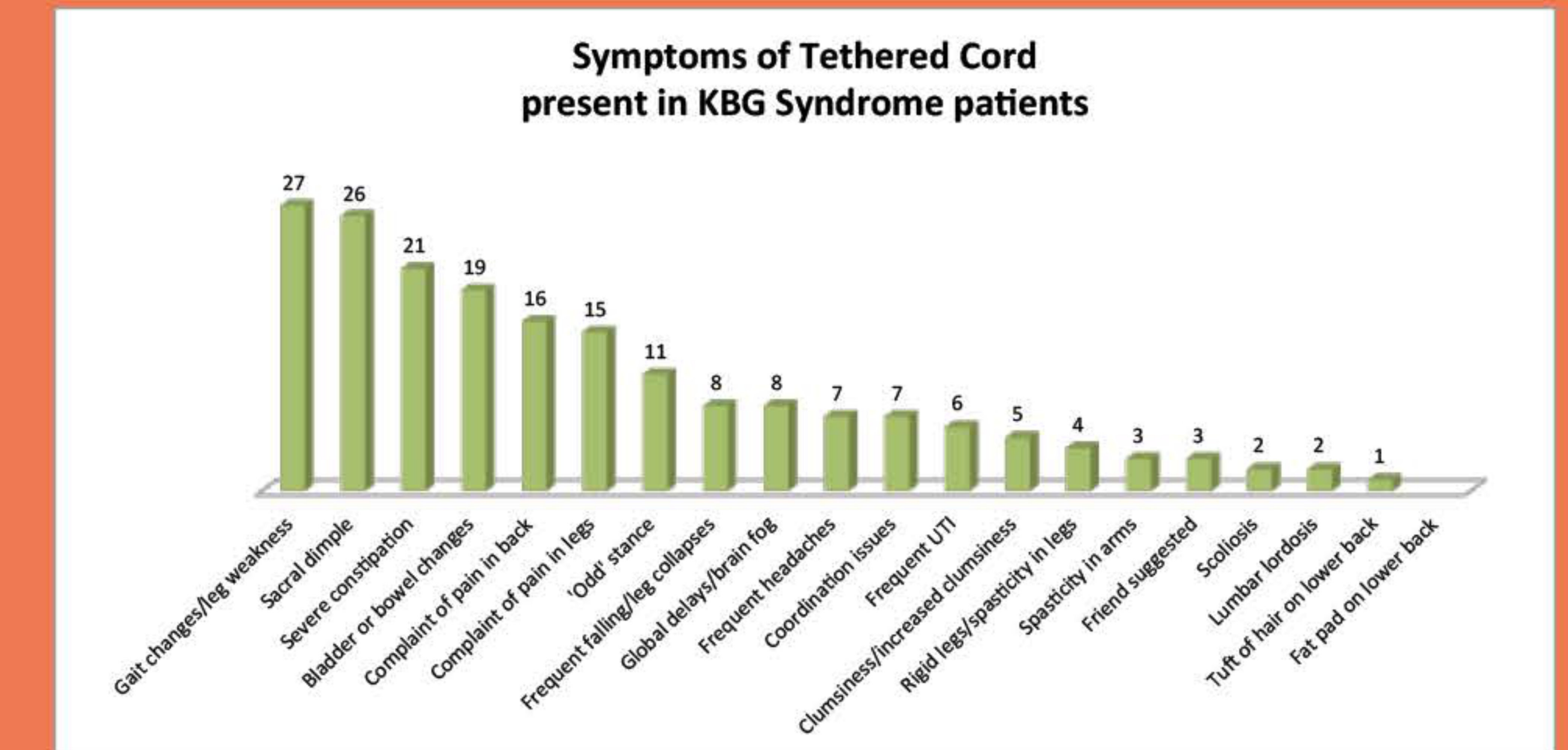
- + lower extremity pain
- + lower extremity weakness
- + decreased sensation



NEUROLOGICAL (OBJECTIVE)

- + Asymmetry in neurological deficits
- + hyperreflexia/clonus
- + lower extremity weakness
- + decreased or missing reflexes

How OTCS presents in KBG Syndrome



Specialist to visit

Neurosurgeon ONLY

Tests?

Since MRI findings are often declared normal, how is a tethered cord diagnosed?

Specialists in OTCS 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. Recent studies highlight the importance of Radiologists using descriptive language detailing the conus terminale and filum and avoiding statements such as: Tethered Cord is or is not confirmed.

This change in radiology reporting allows the Neurosurgeon to use unbiased differential diagnosis to determine the course of treatment.

