

FAQs About TGCT

1. What is TGCT?

Tenosynovial Giant Cell Tumor (TGCT) is a rare, noncancerous, locally aggressive tumor that occurs in a joint, bursae, or tendon leading to functional impairment and damage to neighboring tissue. In 2013, the World Health Organization classified pigmented villonodular synovitis (PVNS) and giant cell tumor of the tendon sheath (GCT-TS) as TGCT. TGCT has two subtypes: localized (sometimes called nodular) and diffuse.

2. Is PVNS the same thing?

TGCT is now an umbrella term for giant cell tumor of the tendon sheath (GCT-TS) and pigmented villonodular synovitis (PVNS).

3. Is TGCT cancerous?

TGCT is a type of non-cancerous tumor. TGCT is not life-threatening but can be life-limiting and lead to damage to surrounding joint tissue. In severe cases, it can invade healthy tissue. TGCT is treated at cancer centers by specialists who treat sarcoma but it is not cancerous or life-threatening. These specialists are trained to treat difficult tumors.

4. Will it spread?

Generally, TGCT only occurs in a single joint and will not spread to any other part of the body. However, TGCT can worsen which can cause damage to surrounding regions of the joint.

5. Is this genetic? Is this hereditary?

TGCT occurs sporadically. There is no occupational, dietary, genetic, or lifestyle risk that has been identified to predispose anyone to getting this disease. TGCT cannot be passed down.

6. How does the disease destroy the joint and bone?

TGCT leads to swelling and can put pressure on bones leading to impairment and pain. Bone erosion can occur over time as the tumors grow.

7. What are the recurrence rates?

TGCT symptoms and recurrence can vary by patient. TGCT can grow slowly or quickly. In localized TGCT, the recurrence is around 15%, whereas in diffuse TGCT it is closer to 50%. Recurrence rates may increase following the first recurrence. It is important to be treated by an experienced multidisciplinary team at an expert center.



To learn more, go to tgctsupport.org

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FAQs Treating TGCT

1. What are the treatment options?

TGCT is often initially treated with surgery. In some cases, surgery can be curative, especially when localized. In other cases, drug options, such as Turalio and imatinib, can be used. There are also clinical trial options available globally.

2. Does a joint replacement reduce recurrence?

Joint replacements are used when there is bone and tissue damage that is beyond repair. It does not eliminate recurrence and TGCT can still occur around the replacement.

3. What are the risks of surgery?

Consult with your healthcare team about the risks associated with surgery. Risks vary depending on TGCT location, extent of disease, and surgical techniques. Multiple surgeries can lead to scar tissue buildup and recurrence risk increases after the first recurrence.

4. Is monitoring the tumors a treatment option?

Depending on the patient, surgery is not always immediately needed. In asymptomatic TGCT with minimal surrounding damage, monitoring is a preferred approach. Consult with your healthcare provider about proper monitoring schedules to catch any growth.

5. Is radiotherapy effective?

Due to the lack of effectiveness demonstrated in research studies and the risk of radiation-induced sarcoma, radiation is generally avoided. Radiation can also lead to scar tissue formation, joint damage, and nerve pain. However, each patient and institution varies.

Consult with your healthcare team on what's most effective for your care.

6. Is there a place I can get more information?

Go to www.tgctsupport.org for more information.



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FAQs Living with TGCT

1. What symptoms are common?

TGCT patients often report pain, stiffness, popping or locking, and limited range of motion. Some patients experience a lot of symptoms, others may have no symptoms at all. Each person may vary in their presentation.

2. Can lifestyle or dietary changes help my disease?

In general, research into the impact of lifestyle and diet is scarce in TGCT. More research is needed to determine how anti-inflammatory diets and low-impact exercise may influence the disease.

3. How does TGCT affect exercising?

High-impact exercise is generally avoided following diagnosis to preserve the joint. Physical therapy can be used to strengthen the muscles surrounding the joint and promote joint stability. Consult with your healthcare team for the best exercises for you.

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