



Questions for your Doctor

Understanding your TGCT

- Do I have Localized or Diffuse TGCT?
- What should I expect?
- How many patients do you see with this type of TGCT?
- Once it is removed, what are the chances of it coming back?

Treating your TGCT

- What are the risks and benefits of surgery?
- What does the follow-up care look like? Recovery time?
- Is a joint replacement an option for me?
- What are the risks and benefits of a drug therapy?
- How many healthcare providers should be a part of my team?

Living with your TGCT

- Can I continue to exercise? Are there any limitations?
- Does stress have an effect on my disease?
- Are there preferred pain control methods?
- Does draining/aspirating the fluid help at all?

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 and diffuse.

To learn more, go to www.tgctsupport.org

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 a type of non-cancerous, often called non-malignant, tumor. TGCT can lead to damage to surrounding tissue and joint but does not invade healthy tissue.

4

Will it spread?

Most often, 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.

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. There is no research to suggest this disease can 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 is the recurrence rates?

TGCT tumor 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%.

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 pexidartinib and imatinib, can be used. There are also clinical trial options producing effective responses.

To learn more, go to www.tgctsupport.org

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.

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 can be a strategy. 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. However, each patient 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

FAQs Living with TGCT

1

What symptoms are common?

TGCT patients often report pain, stiffness, popping or locking, and limited range of motion. 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. 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.

4

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