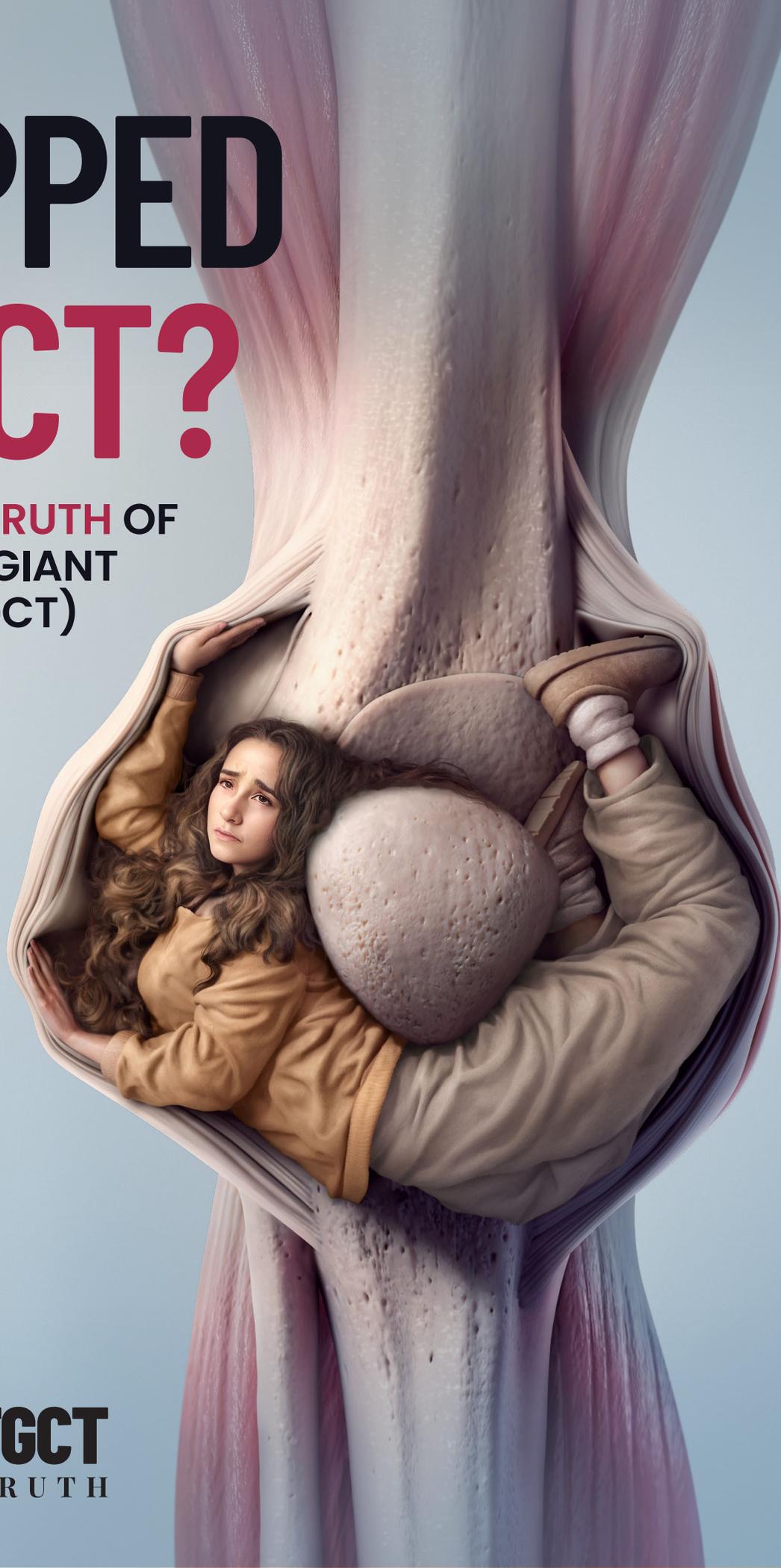


# TRAPPED BY TGCT?

UNTANGLE THE TRUTH OF  
TENOSYNOVIAL GIANT  
CELL TUMOR (TGCT)



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**TGCT**  
TRUTH

# WHAT IS TGCT?

TGCT is a disease where tumors form in the body's joints that cause pain, inflammation, and loss of function. While non-cancerous, the disease can permanently damage the joint and surrounding tissue.

## WHAT CAUSES TGCT?

TGCT forms when cells abnormally produce too much of a protein called colony stimulating factor 1 (CSF1), leading to tumor formation. This protein attracts immune cells expressing colony stimulating factor 1 receptor (CSF1R), leading to inflammation and potentially permanent joint damage.



There are  
**11 to 50 cases**  
of TGCT per million people  
each year

## SYMPTOMS

People with symptomatic TGCT often suffer from:



Pain



Swelling



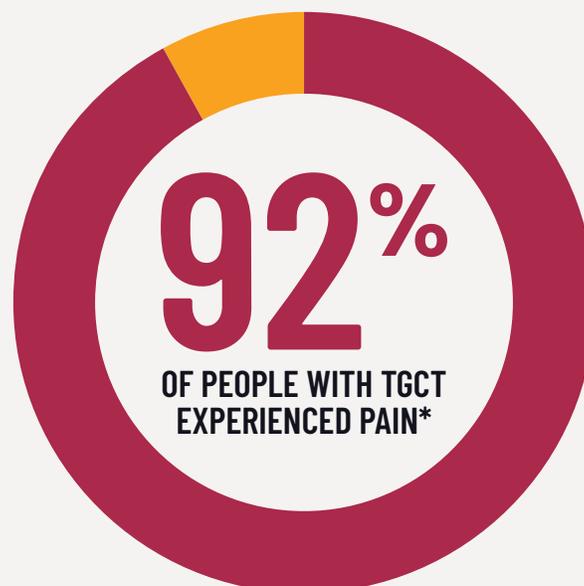
Stiffness



Instability



Reduced range  
of motion



\*According to a survey of 497 patients with TGCT.

# TYPES OF TGCT

Localized/nodular TGCT tends to be smaller tumors inside of the joint while diffuse tumors are larger, without distinct boundaries.

## LOCALIZED/NODULAR TGCT

-  More common
-  Lifetime recurrence rate: up to 15%
-  Usually single, well-defined tumor, usually nodular
-  Often does not cause pain or joint dysfunction

### Tumor location:

-  Tends to impact smaller joints like hands, fingers, wrists, feet

## DIFFUSE TGCT

-  Less common
-  Lifetime recurrence rate: up to 72%
-  Ill-defined tumors that invade the joint
-  Can extend out of the joint and damage surrounding bone

### Tumor location:

-  Tends to impact larger joints like knee, hip, ankle

## TREATING TGCT TYPES

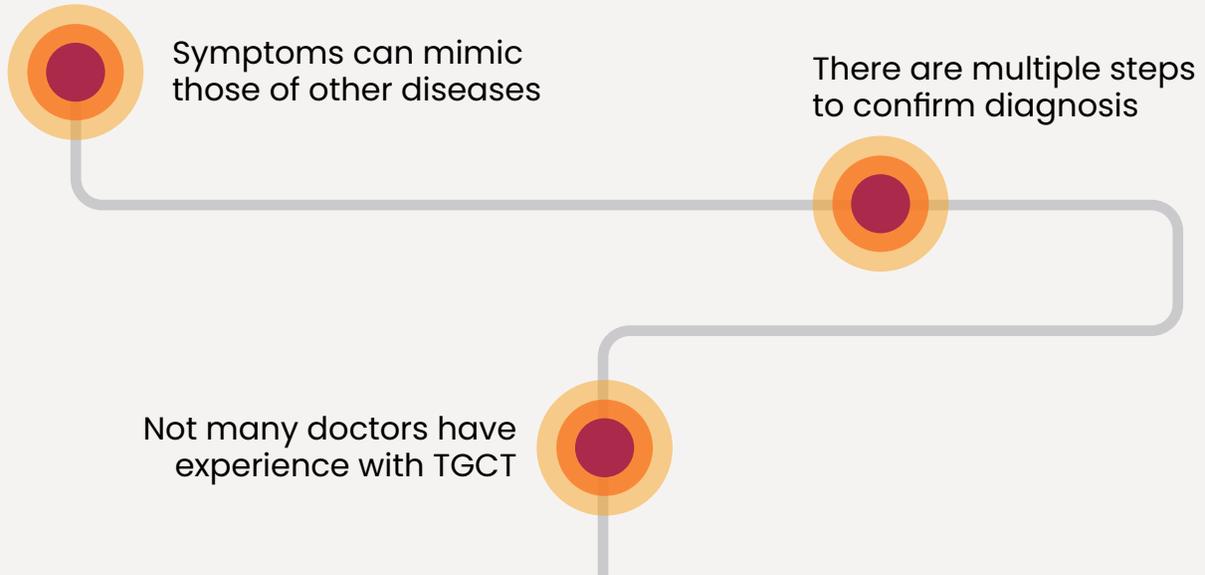
Localized/nodular TGCT can typically be treated with surgery. Diffuse TGCT, however, may be more difficult to remove and is more likely to return after surgery.

**PVNS AND  
GCT-TS  
IS TGCT.**

TGCT used to be referred to as pigmented villonodular synovitis (PVNS) and giant cell tumor of the tendon sheath (GCT-TS). In 2013, the World Health Organization reclassified GCT-TS, PVNS and the diffuse subtype of giant cell tumor under one name: **TGCT**.

# DIAGNOSING TGCT

Getting diagnosed with TGCT can be a journey in itself.



“

ON GETTING DIAGNOSED

It took me 5 years to be diagnosed. Providers weren't open minded to the idea of doing an MRI. By the time I finally got to a specialist, I was exhausted.

– Person living with TGCT

”

MRI=Magnetic Resonance Imaging.

## WHAT YOU CAN DO

Find a specialist with experience treating TGCT. They can help you explore a full range of options with a multi-disciplinary team of experts.

# THERE ARE MULTIPLE STEPS TO A TGCT DIAGNOSIS, WHICH CAN INCLUDE THE FOLLOWING:



Physical exam



Full analysis of medical history



X-ray



MRI



CT scan



Biopsy

CT=Computed Tomography.



## DECIDING YOUR CARE

While there are various options for imaging, **MRI is recommended for diagnostic testing, followed by a biopsy.** A definitive diagnosis of TGCT is normally obtained through a biopsy, and will help you and your care team understand what treatment option may be best for your specific TGCT.

# HOW IS TGCT TREATED?

TGCT is often treated with surgery.



Surgery isn't right for everyone, and not all tumors can be removed.

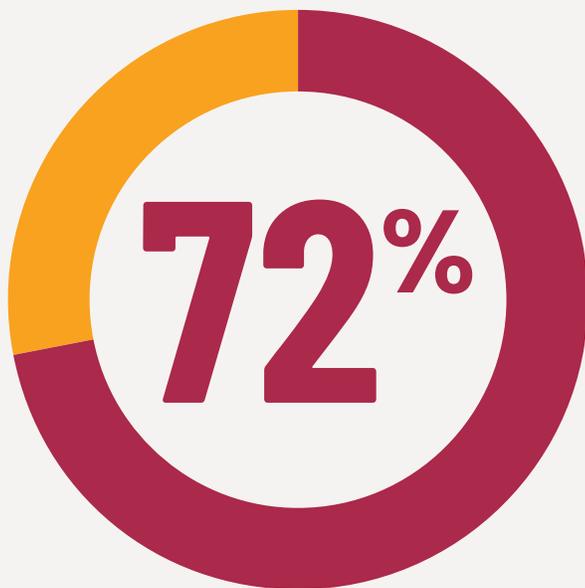


The risk of recurrence following surgery is high for people who have diffuse TGCT.



Each additional surgery increases risks of complications and other health challenges.

IN A SURVEY OF 289 PEOPLE LIVING WITH TGCT,



**OF PEOPLE WITH  
DIFFUSE TGCT HAD AT LEAST  
1 RECURRENCE AFTER SURGERY**



## THE CYCLE OF SURGERY

Recurrence can cause people to get stuck in a **cycle of surgeries that interrupts their lives**, so it's important to consider the risks and benefits of each treatment when choosing a path forward.

“

I can't tell what causes more pain, the disease or surgery itself. We need more options.

– Person living with TGCT

”

## THE GOOD NEWS? THERE ARE MORE OPTIONS BEYOND SURGERY.

### ORAL PRESCRIPTION OPTIONS ARE AVAILABLE



The choice between surgery and prescription treatment is up to you and your doctor



The decision can be made based on **physical or non-physical reasons**



**Radiation is usually not recommended** since there is limited evidence to support its usage



**Active surveillance** may be recommended for those without symptoms

### WHEN DISCUSSING YOUR TREATMENT OPTIONS, ASK YOUR CARE TEAM ABOUT:



How well the treatment **shrinks tumors, and improves symptoms like pain and stiffness**



If the treatment **improves joint mobility or ability for everyday tasks**



Any **side effects**, and how the treatment **fits into your daily life**



# YOU'RE NOT ALONE ON YOUR TGCT JOURNEY

## We're here for your journey.

Join our communication list to get important updates, information, and support to help you in your unique TGCT journey.

## WANT MORE ON TGCT? CONNECT WITH US



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