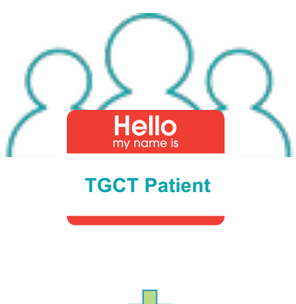
Tenosynovial Giant Cell Tumor (TGCT): A Patient-Led Collaborative Effort

TGCT Support is a program of The Life Raft GROUP

SUMMARY

TGCT Support is comprised of a group of passionate individuals from the Tenosynovial Giant Cell Tumor (TGCT) community, previously known as pigmented villonodular synovitis (PVNS).

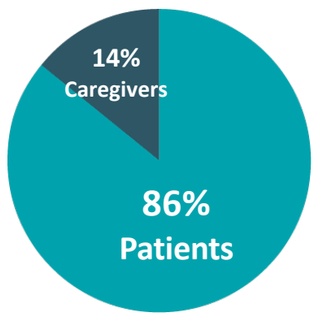


OUR MISSION

The mission of TGCT Support is to enhance treatment options and quality of life for TGCT patients through patient-powered research, education, empowerment, and global advocacy efforts.



REACH OF TGCT SUPPORT



1108 Patients have attended the TGCT Support Group

TGCT Patients in the Mentorship Program **397**

203 TGCT Volunteers

TGCT Patients Part of Fundraising Support **171**

Patients in 58 Countries



Top 5 Countries:
1) USA, 2) United Kingdom,
3) Australia, 4) Canada,
5) Germany

UNMET NEEDS IN TGCT

Rare diseases, including TGCT, are often misdiagnosed, misunderstood and are not widely supported by research funding. Awareness is a key factor in resolving these issues.

Key Issues:

- Most clinicians have limited familiarity
- Some clinicians may underestimate or overestimate the problematic nature of TGCT
- Often patients are not referred to specialty centers until post-surgical recurrence
- Lack of direct mechanisms to educate HCPs
- **Most patients affected by TGCT are young, and the disease and its treatment may impact quality of life**

Check out our CME on November 19, 2026 @ 6:45 pm

TGCT CONFERENCES

TGCT Support proudly hosts conferences that bring together patients, providers, and experts to foster awareness, education, and connection within the TGCT community. These gatherings create space for learning, empowerment, and belonging.

Here's what patients have shared about their experiences:

- *"When I started my TGCT journey, I never imagined meeting others with my disease. Now, TGCT doesn't feel like a life sentence anymore."*
- *"I've lived with TGCT for a decade believing I was alone. My doctor said I'd never meet anyone else and now I've met a whole room full of people who understand."*
- *"Through TGCT Support, I was able to ask questions directly to experts I would have never met otherwise."*



Figure 1. Most recent TGCT Day of Learning (TDOL) on July 27, 2024, in Colorado



Figure 2. Second TGCT Day of Learning (TDOL) conference at The James at Ohio State University Comprehensive Cancer Center on Sept 23, 2023

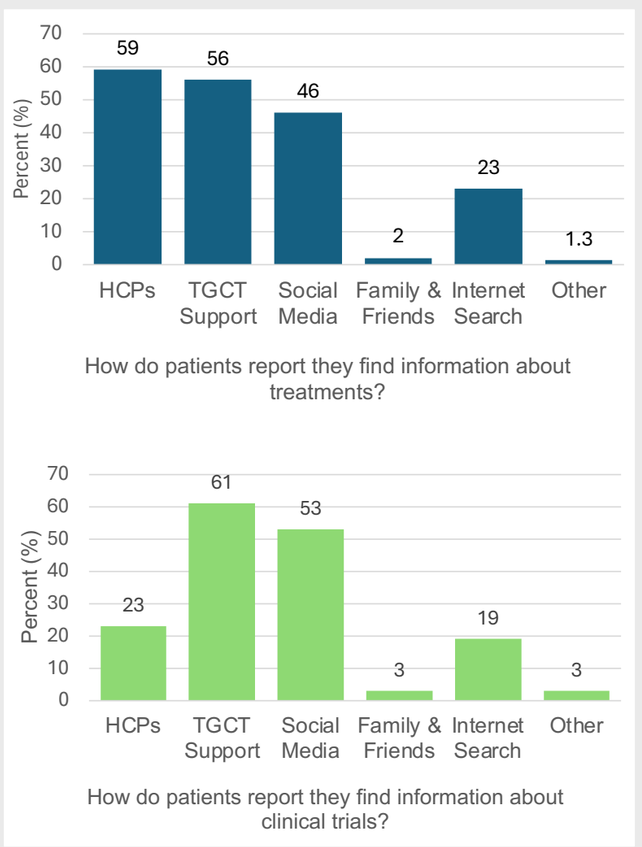


Figure 3. Out of 990 surveyed TGCT patients from our patient registry, majority of patients got their information about treatments and clinical trials from TGCT Support.

RESEARCH

We maintain two registries: one for TGCT and another for giant cell tumor of the bone, designed to capture and analyze trends within each disease population.

Two registries:
TGCT: +2513 respondents
GCT: +628 respondents

Check out our Abstracts #2431398 on TGCT Patient Preferences and #2459761 Real-world Denosumab use for Giant Cell Tumor of Bone on Thursday, November 19th, from 5:30 PM to 6:30 PM



NEXT STEPS

As we work together to raise awareness and improve education for both providers and patients, here is what patients want providers to truly hear:

- *"This disease impacts every part of my life, not just physically, but mentally and emotionally too."*
- *"We need more informed providers so we can be actively part of our healthcare."*
- *"Listen deeply to patients, even when we don't have the words to describe our pain."*

CONTACT INFO

We encourage you to get in touch!

@TGCT Support

@TGCTSupport

@TGCTSupportorg

CHECK OUT OUR WEBSITE