



TGCT Support is a program of the



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).



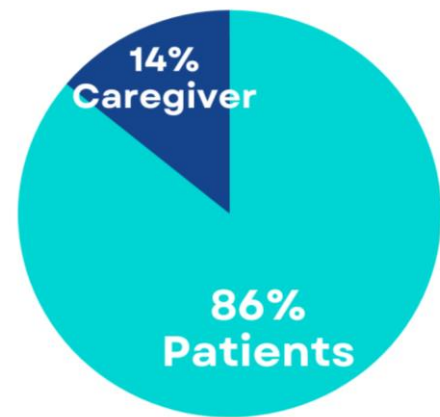
OUR MISSION

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.



A true patient-physician collaborative effort for greater support for patients with tenosynovial giant cell tumor (TGCT)

REACH OF TGCT SUPPORT



519 PATIENTS HAVE ATTENDED THE TGCT SUPPORT GROUP

250 TGCT PATIENTS IN THE MENTORSHIP PROGRAM

129 TGCT VOLUNTEERS

128 TGCT PATIENTS PART OF FUNDRAISING SUPPORT

Patients in 48 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**

TGCT CONFERENCES

TGCT Support has hosted conferences to promote awareness, education, and support within the TGCT Community. This brings in experts for a full day of discussion on aspects of the treatment of the disease. Here are some quotes from patients who have attended:

"When I started my TGCT journey, I would have never imagined meeting others with my disease. TGCT doesn't feel like a life sentence anymore."

"I have had TGCT for a decade and thought I was alone. My doctor said I'd never meet anyone else and now I've met a whole room full!"

"I got the chance to ask experts questions that I would have never met without TGCT Support."



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

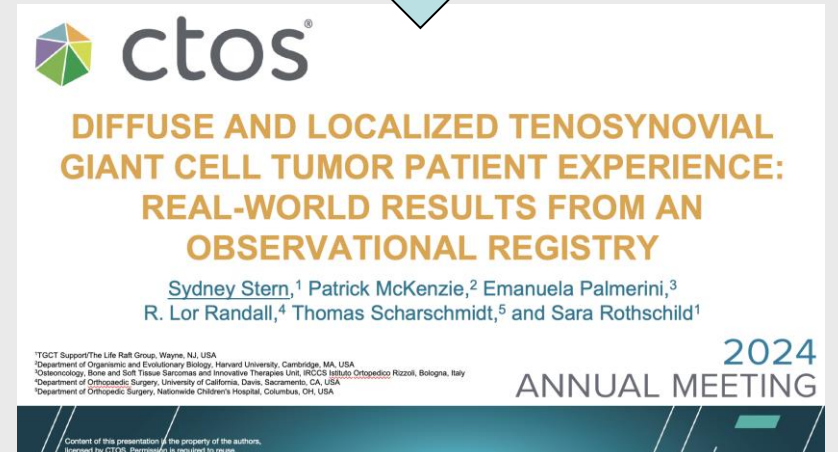
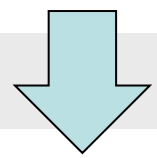
RESEARCH

We have two registries, one for TGCT and the other for giant cell tumor of the bone to understand trends in the disease population.

Two registries:
TGCT: +1151 respondents
GCT: +284 respondents



Check out our podium presentation (Paper 109) in the Harbor Ballroom as part of Session 16 at 4:30-5:30pm on Saturday, Nov 16, 2024



NEXT STEPS

As we continue to promote awareness and education for providers and patients, patients would like providers to know:

"I want them to understand that this disease takes a huge mental and emotional toll, as well as a physical one"

"Refer to specialists and allow patients to be part of their decision-making"

"Listen to patients. Even when they're silent"

CONTACT INFO

We encourage you to get in touch!

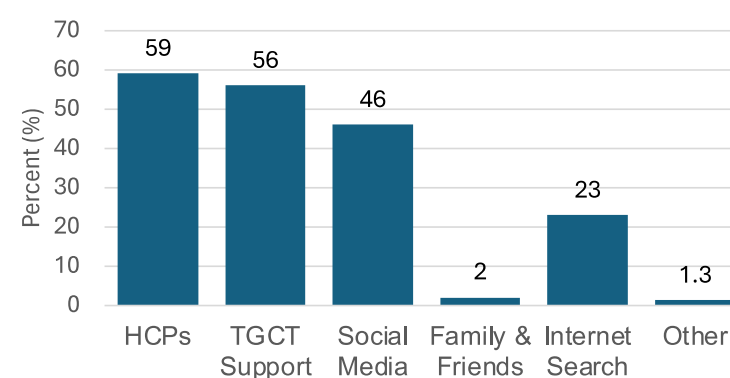
@TGCT Support

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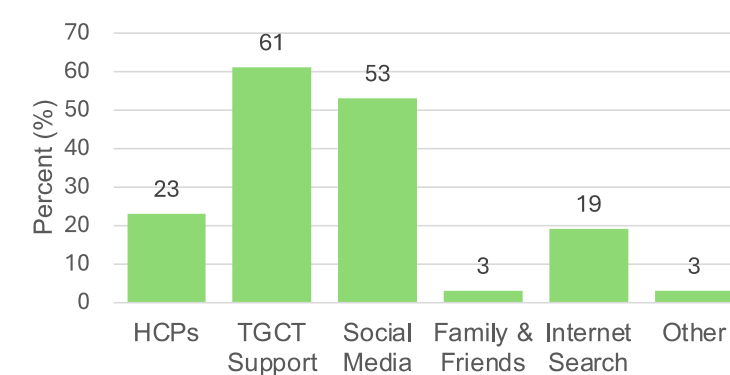
@TGCTSupportorg



CHECK OUT OUR WEBSITE



How do patients report they find information about treatments?



How do patients report they find information about clinical trials?

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.