



About TGCT Support

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.

What Do We Do?

TGCT Support is comprised of a group of passionate individuals in the TGCT community in collaboration with The Life Raft Group, a non-profit patient advocacy organization. Collectively, we provide up-to-date scientific and medical resources for patients, caregivers, and providers as well as offer support and facilitate patients on their TGCT journey.

What is TGCT?

Tenosynovial Giant Cell Tumor (TGCT), formerly known as pigmented villonodular synovitis (PVNS) and Giant Cell Tumor of the Tendon Sheath (GCT-TS), is a rare, locally aggressive tumor of the joint, tendon sheath, or bursae.

TGCT has two subtypes, localized/nodular and diffuse disease. The localized type is a tumor defined by a distinct boundary, while the diffuse type is defined by extensive and infiltrative involvement of the joint and/or tendon sheath. These subtypes influence recurrence risk and treatment options.

Our Efforts

Virtual TGCT Support Groups

We offer a variety of virtual support groups both online and through video conference platforms. These support groups facilitate communication of patients who speak five different languages (English, German, French, Italian, and Spanish) and accommodate patients globally, from the United States to Australia.

Mentor Program

The mentor program support patients with TGCT and their loved ones as they navigate their journey by pairing newly diagnosed patients and caregivers with selected patients that are exemplary advocates and expert patients. Mentor/mentee matches are selected based on geographical location, disease location, and other demographics that are shared.

TGCT Day of Learning (TDOL)

TDOL allows patients and providers to come together in a unique way to have bidirectional learning and support each other. These conferences include presentations by TGCT experts and Q&A sessions for patients to engage with the information in real-time.

Virtual Tumor Board

These case reviews are available for physicians and patients with challenging and complex cases, globally. TGCT Support facilitates the communication and organizes the panel of providers to discuss the case.

Educational Programs

Through our website, social media campaigns, educational materials, webinars, and TGCT Days of Learning, we empower patients to have meaningful involvement in their care. We also provide updated information to providers about changes in labeling, treatment advancements, and clinical trials.

Specialists List

One of our most valued resources, the Specialists List is a constantly growing directory of providers who are known to see patients with TGCT. This list is often regarded as the most trusted resource for patients to find providers familiar with the disease.

Research

Through the support of the patient and provider community, we contribute to the advancement of TGCT treatment and understanding by generating truly patient-centric real-world evidence and publishing our findings in peer-reviewed journals. We collaborate with global leaders to ensure the patient voice is focal to all research, from benchtop to bedside.

TGCT Patient Registry

The TGCT Support Patient Registry is the largest repository of real-world evidence with records from over 800 patients in 32 countries. Our registry tracks patients over time using validated patient-reported outcomes measurement tools to generate quantitative and qualitative evidence to describe the patient experience.

Advocacy

From facilitating access to and awareness of the most innovative treatments to affecting change with the inception of the first global TGCT consensus guideline, TGCT Support has a global footprint.

TGCT SUPPORT IS A PROGRAM OF 