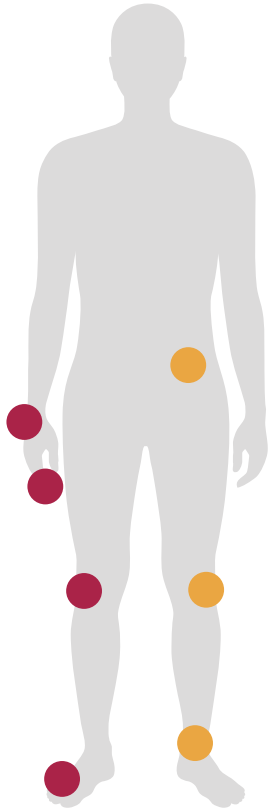
MORE CAN BE DONE TO OPTIMIZE TGCT PATIENT CARE

TGCT (TENOSYNOVIAL GIANT CELL TUMOR) IS A RARE NON-MALIGNANT TUMOR AFFECTING THE JOINTS[1,2]

TGCT is sometimes known as PVNS (pigmented villonodular synovitis)[3]



INCIDENCE:
5–45 PER MILLION PERSON-YEARS
diffuse-type TGCT (D-TGCT) and nodular-type (N-TGCT), respectively*[2]

AGE AT DIAGNOSIS:
35–50 YEARS[3]

COMMON SYMPTOMS:
PAIN, SWELLING, STIFFNESS AND LIMITED RANGE OF MOTION[3]

TWO CLINICALLY DISTINCT SUBGROUPS:

N-TGCT†	D-TGCT
• ≈90% of cases[4]	• ≈10% of cases[4]
• Impacts smaller joints[5]	• Impacts larger joints[5]
• Well-defined mass[5]	• Poorly-defined mass[5]
• Does not typically cause pain or joint dysfunction[5]	• More aggressive and destructive[5]

TGCT CAN LEAD TO CONSIDERABLE PHYSICAL AND PSYCHOLOGICAL BURDEN[6-8]

Physical and psychological burden[6,7]

92% (n=457/497) REPORTED PAIN‡[6]

85% (n=423/497) REPORTED LIMITED RANGE OF MOTION‡[6]

83% (n=410/497) REPORTED JOINT STIFFNESS/TIGHTNESS‡[6]

19% (n=25/135) PRESENTED WITH AT LEAST MODERATE ANXIETY OR DEPRESSION¶[7]

Disruption to professional and social life[6,8]

63% (n=187/299) WERE UNABLE TO PERFORM SPORT ACTIVITIES§[8]

23% (n=115/497) CHANGED OCCUPATION OR RETIRED PREMATURELY DUE TO TGCT‡[6]

*Incidence rates in The Netherlands (2009–2013).[2] †N-TGCT, also known as localized-type TGCT, is best referred to as nodular TGCT per the International Clinical Consensus.[3] ‡The TGCT Support Registry (launched 2022), collected questionnaire data every six months on patients' experiences. N=497 across 32 countries: diffuse (n=355), localized (n=94) and unknown subtype (n=48). Data cutoff: October 6 2022–December 6 2023.[6] ¶Outcome from an EU subgroup analysis of TOPP (N=137), a prospective, observational study of patients with D-TGCT. Data was collected at baseline (12-month period prior to entry) and after 12 months of follow-up.[7] §Members of the TGCT Facebook group, PVNS is Pants!!, completed a 6-month e-survey. Total: 337 responses from 30 countries (N-TGCT n=72; D-TGCT n=237; unknown subtype n=28).[8]
D-TGCT, diffuse-type TGCT; N-TGCT, nodular-type TGCT; PVNS, pigmented villonodular synovitis; TGCT, tenosynovial giant cell tumor; TOPP, TGCT Observational Platform Project.

deciphera® a member of ONO PHARMA

MEDIAN TIME TO A TGCT DIAGNOSIS IS ≈18 MONTHS[9]

CLINICAL PRESENTATION

Symptoms are generally non-specific[1]

IMAGING

Contrast MRI (gadolinium-enhanced)[3]

SUSPECTED TGCT

BIOPSY

A biopsy may be required for complex cases to confirm diagnosis[3]

CONFIRMED DIAGNOSIS

DELAYED DIAGNOSIS

- **TGCT is a slow, progressive disease** with subtle radiographic changes, making early detection difficult[9,10]
- Patients often visit multiple HCPs before receiving a TGCT diagnosis[1]

MISDIAGNOSIS

- **TGCT can be mistaken for other conditions** (e.g., rheumatoid arthritis)[1,11]

UNTREATED PATIENTS

- **If left untreated, TGCT can become debilitating.** Significant functional impairment is a potential complication[9]

ADVANCED DISEASE

- **Diagnosis delays may result in disease progression,** and further joint destruction[11,12]

SURGERY IS THE STANDARD OF CARE FOR SYMPTOMATIC TGCT BUT IS NOT ALWAYS CURATIVE[3]

N-TGCT

- Risk of recurrence: up to **15%**[13–16]
- Typically allows total resection[10]
- Generally, patients report excellent or good clinical results with surgery[10]

D-TGCT

- Risk of recurrence: **72%**[6]
- Incomplete tumor removal is common, leading to worse clinical outcomes[17]

Patients may not be eligible for surgery for a number of reasons:

- **TUMOR LOCATION/ COMPLEXITY**[3,18]
- **REPEATED SURGERY CAN CAUSE FURTHER JOINT DAMAGE**[17]
- **COMORBIDITIES**[19,20]

Challenges in the management of TGCT

CHEMOTHERAPY

Not indicated for TGCT[3]

RADIOTHERAPY/CRYOTHERAPY

Insufficient data to support the treatment of TGCT[3]

SYSTEMIC THERAPIES

Availability of therapies may differ across countries[3,18]

SCAN THE QR CODE TO VISIT THINKTGCT.EU

PATIENTS AFFECTED BY TGCT SHOULD BE MANAGED WITHIN EXPERT CENTERS BY A DEDICATED, EXPERIENCED SARCOMA MULTIDISCIPLINARY TREATMENT TEAM[3]

D-TGCT, diffuse-type TGCT; HCP, healthcare professional; MRI, magnetic resonance imaging; N-TGCT, nodular-type TGCT; TGCT, tenosynovial giant cell tumor.

References: 1. Bernthal NM, et al. *Orphanet J Rare Dis*. 2021;16(1):191. **2.** Mastboom MJL, et al. *Acta Orthop*. 2017;88(6):688-94. **3.** Stacchiotti S, et al. *Cancer Treat Rev*. 2023:112:102491. **4.** Robert M, et al. *Front Immunol*. 2022:13:820046. **5.** Choi WS, et al. *Cancers (Basel)*. 2024;16(2):402. **6.** Stern S, et al. *Future Oncol*. 2025;21(12):1501–1510 **7.** Lopez-Bastida J, et al. *Orphanet J Rare Dis*. 2021;16(1):294. **8.** Mastboom MJL, et al. *Interact J Med Res*. 2018;7(1):e4. **9.** Ansel S, et al. *J Med Case Rep*. 2023;17(1):419. **10.** Gouin F, Noailles T. *Orthop Traumatol Surg Res*. 2017;103(1S):S91–S97. **11.** Fecek C, et al. Pigmented Villonodular Synovitis. In: StatPearls. StatPearls Publishing; 2022. **12.** Wu CC, et al. *Ther Radiol Oncol*. 2019;3:17. **13.** Ehrenstein V, et al. *J Rheumatol*. 2017;44(10):1476–83. **14.** Palmerini E, et al. *Eur J Cancer*. 2015;51(2):210–7. **15.** Chiari C, et al. *Clin Orthop Relat Res*. 2006;450:172–8. **16.** Siegel M, et al. *PLoS One*. 2021;16(12):e0260795. **17.** Spierenburg G, et al. *J Surg Oncol*. 2022;126(6):1087–1095. **18.** TGCT UK Consortium. *Bone Jt Open*. 2026;7(4):482–490. **19.** Kolh P, et al. *Eur J Vasc Endovasc Surg*. 2016;51(6):857–66. **20.** Ziegelmann M, et al. *Transl Androl Urol*. 2017;6(4):609–619.

deciphera® a member of ONO PHARMA