

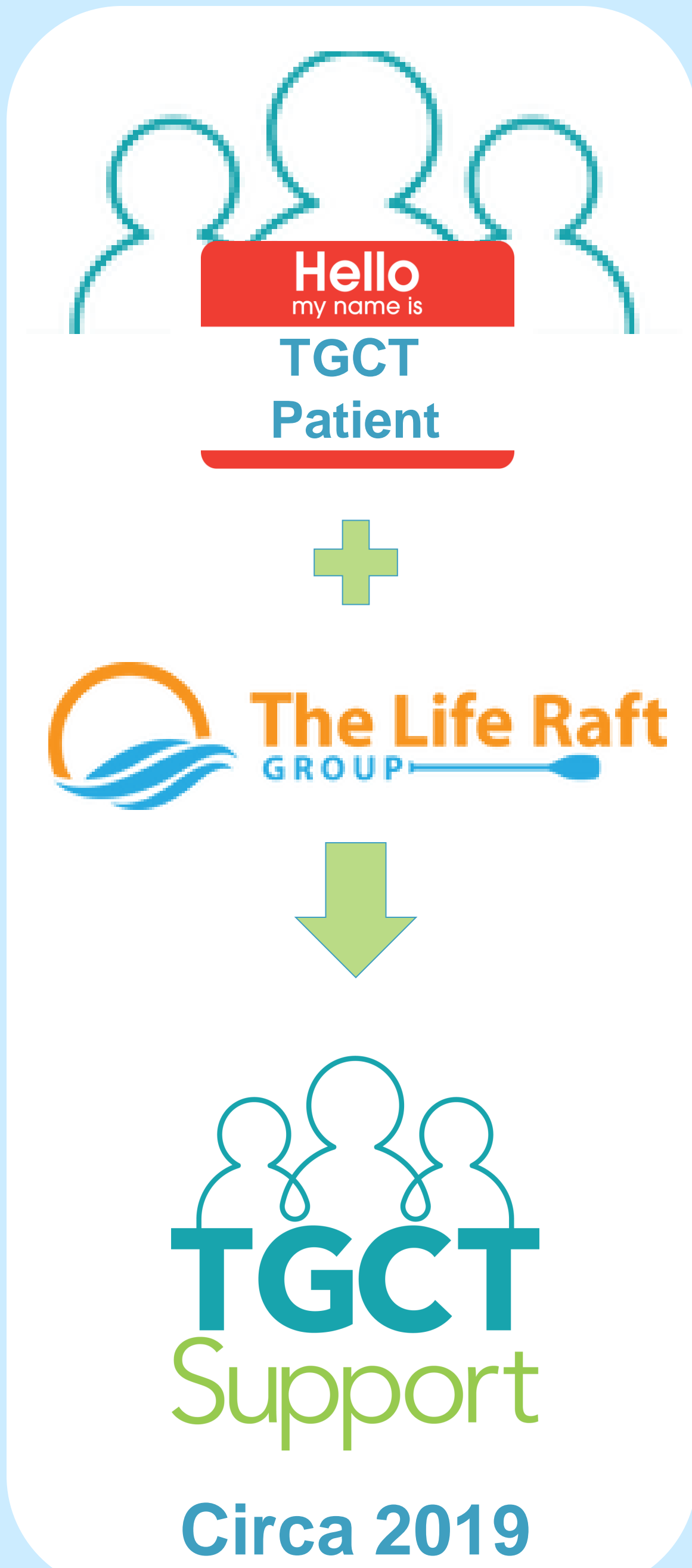


TGCT Support is a program of

A true patient-physician collaborative effort for greater support for patients with Tenosynovial Giant Cell Tumor (TGCT)

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).

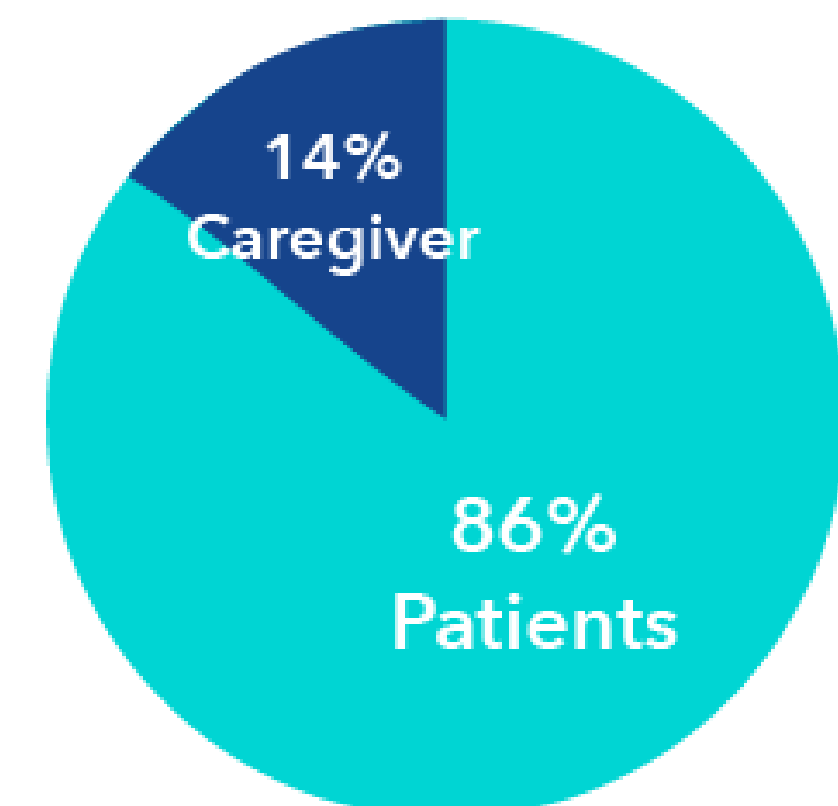


OUR MISSION

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



REACH OF TGCT SUPPORT



393 PATIENTS HAVE ATTENDED THE TGCT SUPPORT GROUP

168 TGCT PATIENTS IN THE MENTORSHIP PROGRAM

110 TGCT VOLUNTEERS

102 TGCT PATIENTS PART OF FUNDRAISING PROGRAM

Patients in 22 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 experience
- Some clinicians may underestimate the problematic nature of the disease
- Often patients are not referred to specialty centers until post-surgical recurrence, if at all
- Lack of direct mechanisms to educate HCPs
- Most patients affected by TGCT are young; 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. This has changed my life, I don't feel alone"

"For the 14 years that I have had TGCT, I never knew there were other options besides surgery"

"I got the chance to ask experts questions that I would have never gotten to otherwise"



Figure 1. First TGCT Day of Learning (TDOL) on Sept 22, 2022 in NYC

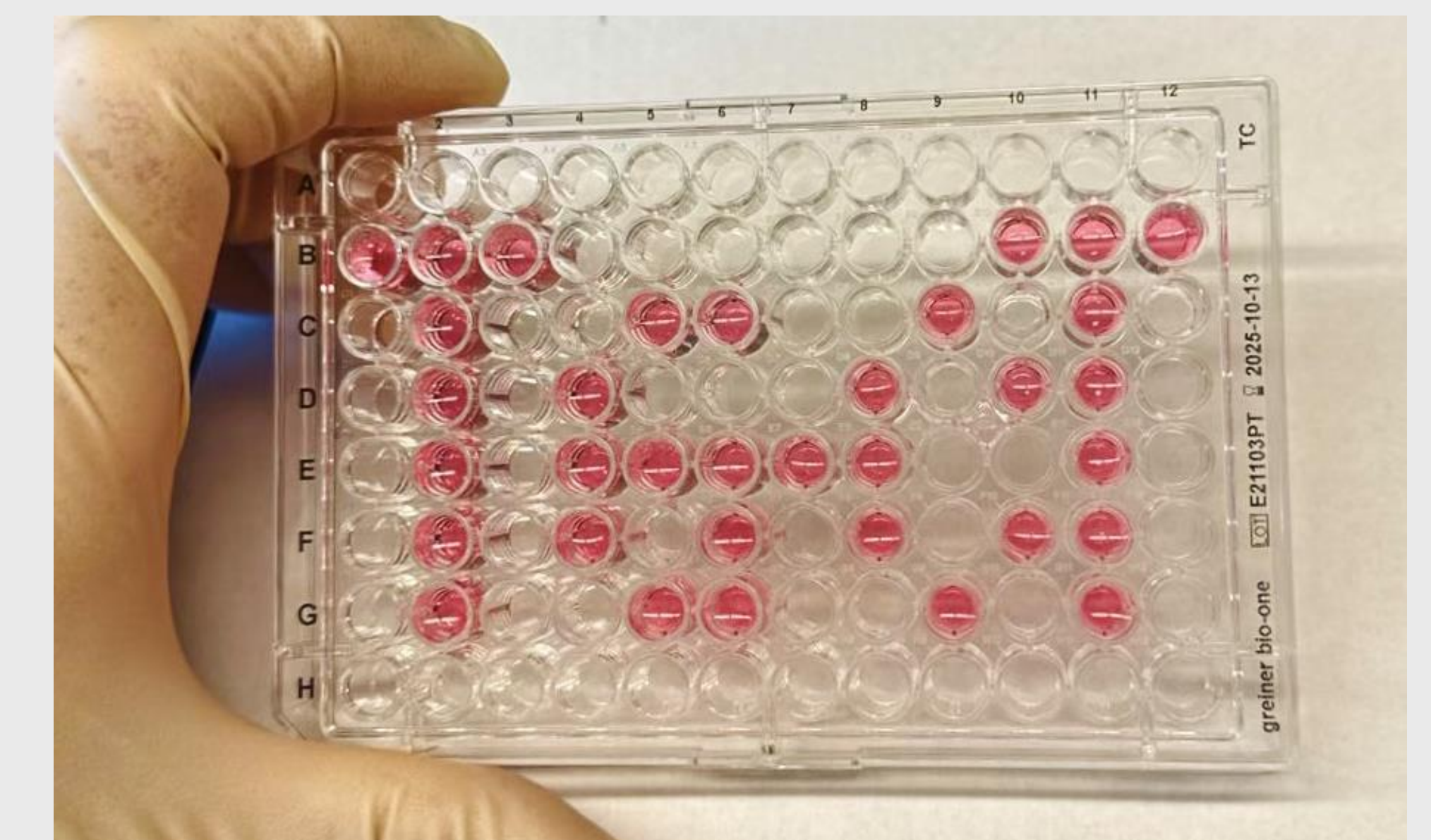


Figure 2. Second TGCT Day of Learning (TDOL) conference at The James Ohio State University Comprehensive Cancer Center on Sept 23, 2023

RESEARCH

We have two registries, one for patients with TGCT and the other for patients with giant cell tumor of the bone, to understand trends in each disease population. The registry captures information such as history of diagnosis, misdiagnoses, rating symptoms and impact, providers, treatments, side effects, use of analgesics, quality of life measurements for cognition, pain, social and emotional well-being, perception on health, and much more.

2 registries:
 TGCT: +683 respondents
 GCTB: +150 respondents



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"

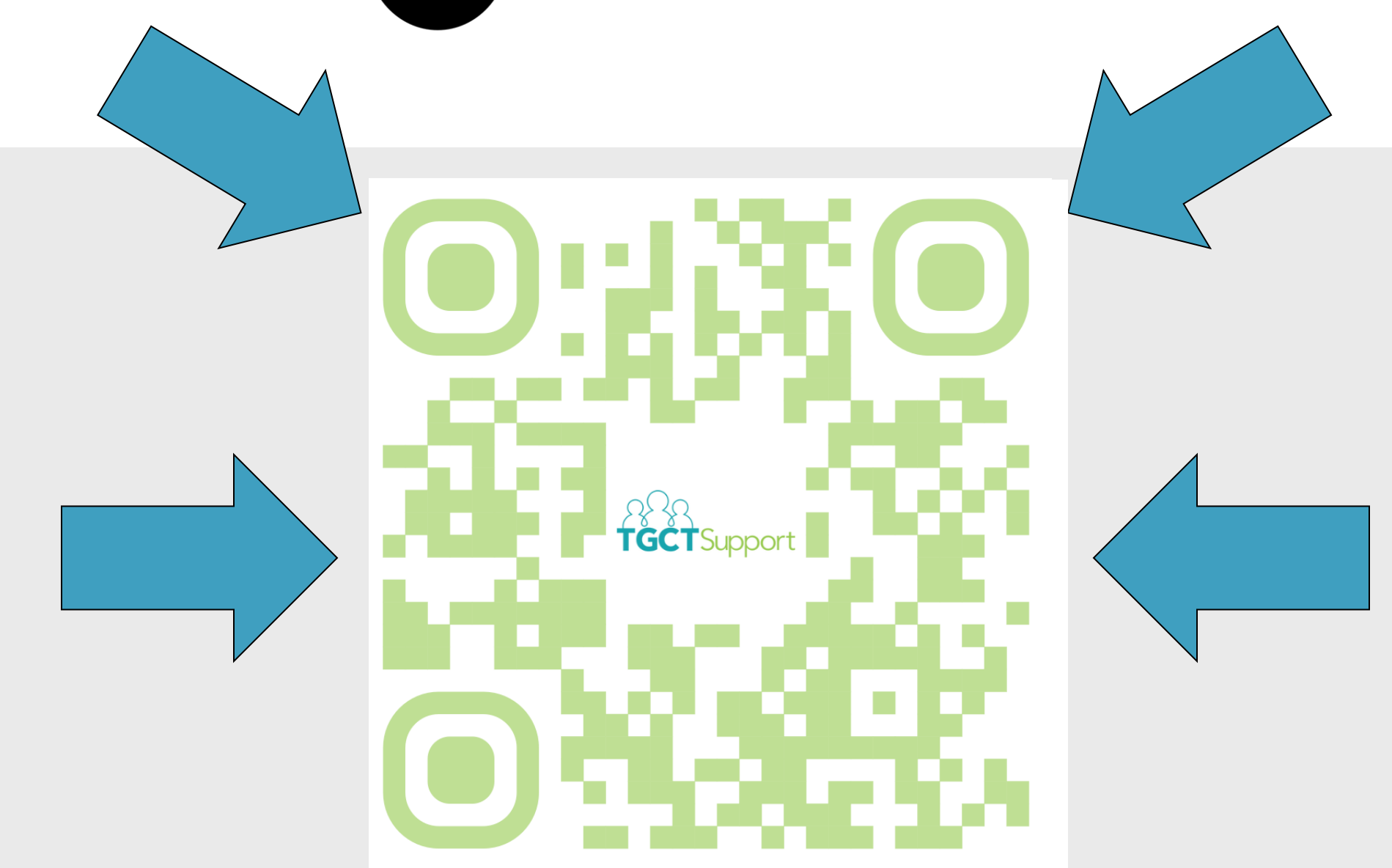
"Refer to specialists and allow patients to be part of their decision-making"

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

CONTACT INFO

We encourage you to get in touch!

- @TGCT Support
- @TGCTSupport
- @TGCTSupportorg



WEBSITE

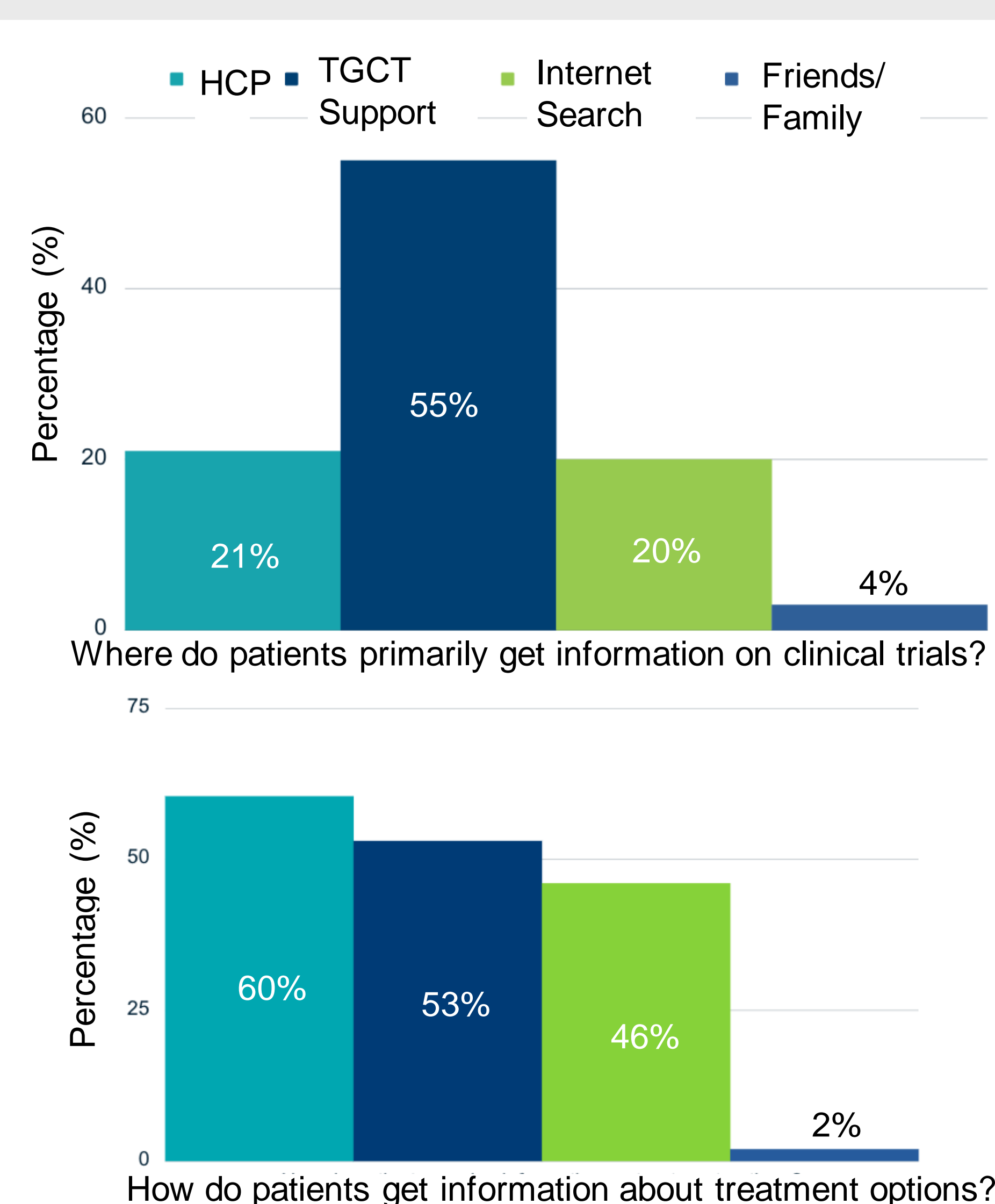


Figure 3. Out of 683 surveyed patients with TGCT from our patient registry, majority of patients primarily got information about clinical trials from TGCT Support (single response) and 53% of patients note they received information regarding all treatment options from TGCT Support (check all that apply).