社團法人台灣年輕病友協會 TAIWAN YOUNG PATIENT ASSOCIATION

CTOS 2026

Patient Advocacy Poster Wall

From Patient Voices to Action

Sarcoma and rare tumors in Taiwan

A patient survey with a focus on Desmoid Tumors (DT)



OUR PROJECT

Patients with sarcoma and rare tumors often have trouble finding disease information, medical care, and support. TYPA conducted a survey to understand patients' needs and share their experiences with doctors and policymakers.

69 Respondents

Soft Tissue Sarcoma: 40
Bone Sarcoma: 13
Desmoid Tumor (DT): 12
Giant Cell Tumor of Bone: 3
Other: 1

Survey sources: TYPA social media (60) and hospital clinics (9).

What Our Survey Found

53.6%

Early Symptoms Were Seen as Minor

37 of 69 patients said doctors thought their early symptoms were minor and did not arrange further tests.

91.2%

Worried About Their Tumor Coming Back or Getting Worse

62 of 68 patients reported this concern.

98.6%

Want Better Financial and Care Support

68 of 69 patients supported clearer financial help and healthcare protection for patients with long-term needs.

A Closer Look at Desmoid Tumors

12 of the 69 patients had DT. The numbers below show their experiences compared with other patients.

50.0%

One Year or Longer to Get a Diagnosis

6 of 12 DT patients
Other patients: 17.5% (10 of 57)

83.3%

Long-Term Pain or Nerve Pain

10 of 12 DT patients
Other patients: 40.4% (23 of 57)

91.7%

Problems Getting a Catastrophic Illness Certificate*

11 of 12 DT patients reported difficulties because their tumors were not classified as malignant.

**In Taiwan, this certificate helps patients with certain serious illnesses pay less for healthcare under National Health Insurance. Patients can still receive covered medical care without it.*

Our Three Advocacy Priorities

01 Earlier Diagnosis

Help doctors recognize symptoms earlier and refer patients to the right specialists. Improve disease records, using DT as an example.

02 Better Long-Term Care

Connect specialist teams with local hospitals. Support patients with pain, daily activities, and emotional needs.

03 Better Insurance Protection

Close gaps in public and private insurance so patients can get support for their long-term care needs.

Turning Survey Results into Action

Patient Survey → Expert Discussions → Patient Education → Policy Advocacy

Young Patients, Brighter Tomorrows

About TYPA

TYPA supports young patients through patient support, education, advocacy, and international collaboration. We help their voices be heard and their needs understood.

Patient Support | Health Education | Policy Advocacy | Global Engagement

View our Website

View the Patient Survey