

OUR MISSION

Cure Desmoid Tumors

The Desmoid Tumor Research Foundation (DTRF) empowers and unites everyone committed to finding answers for the desmoid tumor patient community.

Each year, we build extraordinary momentum in advancing our mission. Through sustained research, collaboration, and patient advocacy efforts, we helped achieve the FDA approval of the first-ever medical therapy for desmoid tumors, along with the establishment of ICD-10 codes, milestones that continue to strengthen care and research for the desmoid community.

The DTRF is the only foundation in the country solely dedicated to funding desmoid tumor research and finding treatments for this rare disease.

STRATEGIC AREAS



The personal stories and experiences from desmoid tumor patients around the world inform the DTRF's annual strategic plan and collaboration efforts.

Research

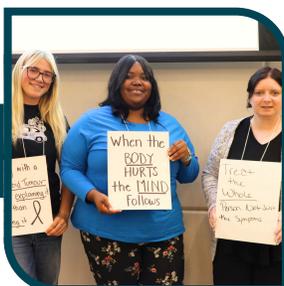
- Funds research projects at the world's top sarcoma cancer research centers in both basic science and clinical trials; led by the DTRF Scientific & Medical Advisory boards
- Seeks to determine what goes wrong in cells to generate desmoid tumors, what systemic and local treatment options work best, and what drugs or treatment modalities could provide better patient outcomes
- Aims to learn more about spontaneous tumor regression
- Facilitates collaboration among researchers
- Presents collaborative research findings at professional conferences

Patient Support

- Hosts Annual DTRF *Together We Will* Weekend, for patient networking, support and learning
- Offers 1-on-1 support to patients seeking guidance
- Provides digital outreach & education
- Hosts dynamic website, featuring the latest news and research about desmoid tumors
- Runs virtual events hosted by staff with patients, clinicians, and researchers
- Hosts quarterly International Virtual Tumor Board in collaboration with leading desmoid tumor specialists
- Programming informed by patient community

Education & Collaboration

- Convenes researchers, clinicians and industry at in person events like Annual DTRF *Together We Will* Weekend; hosts DTRF International Research Workshop
- Hosts online educational events
- Online hub features published research, conference publications
- Manages multiple research initiatives through DTRF Research Coordination Core
- Partners to produce accredited CME Programs
- Collaborates with patients to power research via:
 - Tissue donation through Pattern.org
 - DTRF Desmoid Tumor Patient Registry



BY THE NUMBERS

Discoveries made through desmoid tumor research can potentially have an impact on common cancers such as breast, colon, ovarian, and others.

1

NEW FDA-Approved Drug ✨
OGSIVEO (nirogacestat)
First drug with desmoid tumor indication

1

NEW Desmoid Tumor Cell Line

1

Revised Global Consensus Paper ✨
Partially funded treatment guidelines for desmoid tumor management

3

Desmoid Tumor Awareness Facebook Live Events
Highlighting the desmoid tumor patient experience

5

2025 DTRF-Funded Research Grants

1

Desmoid Tumor Natural History Study ✨
Published two posters at ESMO 2025 Sarcoma and Rare Cancers Congress and ISPOR

21

Medical Institutions and Industry Partners
Represented at DTRF Research Workshop

102

Registrants at the DTRF Annual Together We Will Weekend

29

Recorded Scientific/Educational Videos Featured on DTRF.org
Created for patients, clinicians and researchers

15

Cases Presented at DTRF Int'l Virtual Tumor Boards

31

International Medical Advisory Board Members
Guiding DTRF's research priorities

171

Attendees at DTRF Virtual Events
Educating patients and caregivers

2,090

Participants in Desmoid-Specific CME Accredited Programs
Educating clinicians



As we **uncover answers**, we work tirelessly to provide patients and caregivers with the resources, information, and opportunities needed to be **informed advocates** in their care.

I have never seen a group of people able to mobilize companies and the FDA like this!!

JEAN PATY, PHD
VP, PATIENT CENTERED ENDPOINTS, IQVIA

We are undaunted.