



# our mission: cure desmoid tumors

As the world's leading foundation dedicated to desmoid tumor research, advocacy, awareness, and support, the Desmoid Tumor Research Foundation (DTRF) cultivates a community anchored in empathy & powered by purpose.

**Lynne V. Hernandez**  
Executive Director

**Jeanne Whiting**  
Executive Director Emeritus

## Research Funding

The priority of the DTRF is to facilitate cutting-edge collaborative research by funding research projects at the world's top sarcoma centers. Guided by our Advisory Boards, comprised of top multidisciplinary experts from prestigious global institutions around the world, the DTRF funds both established and early career research aimed to advance desmoid tumor science and drive the development of new treatment options.

## Collaboration & Connection

As a key thought leader and advocate in the desmoid tumor landscape, we are in the unique position of seeing things from the point of view of the patient, clinician, and researcher. This allows us to identify and advance initiatives that benefit our entire community, including:

- DTRF Patient Meeting and networking events
- DTRF Int'l Desmoid Tumor Research Workshop
- Clinical trial support
- DTRF Coordination Core Projects
  - DTRF Patient Registry & Natural History Study
  - Desmoid tumor cell lines
  - PRO tool in desmoid tumors (GODDESS©)
- DTRF Virtual Tumor Board

*Our efforts have brought about breakthrough results in record time for a rare disease. We are proud to have advocated for the progression and recruitment of the clinical trials for nirogacestat. If approved, it will be the first FDA-approved therapy for desmoid tumors.*

## Awareness

Throughout the year, and particularly during September, (Desmoid Tumor Awareness Month), the DTRF hosts virtual events, promotes fundraising, and shares patient stories, fostering worldwide awareness of desmoid tumors.



## Education & Support

Patients are not fighting this disease alone. Researchers and clinicians also benefit from our foundational events and resources, including:

- The annual DTRF *Together We Will* Weekend provides opportunities for both education and connection, drawing patients, clinicians and researchers from around the world.
- Our website, DTRF.org, is a hub of educational information, videos, published research, and other resources for our entire community.
- CME-accredited programs for the medical community, facilitated by the DTRF

## Contact Us

[info@dtrf.org](mailto:info@dtrf.org)

Socials

- [facebook.com/desmoid](https://www.facebook.com/desmoid)
- @DTRFoundation on X and Instagram
- The Desmoid Tumor Research Foundation (DTRF) on LinkedIn



**DTRF.ORG**