



Desmoid
Tumor
Research
Foundation

**Patient
Registry**
dtrf.iamrare.org

We need YOU!

You could help reveal a connection never drawn before about desmoid tumors, or add more nuance to something we thought we already knew by sharing your unique story with the DTRF Patient Registry at [DTRF.iamrare.org](https://dtrf.iamrare.org).

Join DTRF's Patient Registry

The DTRF Patient Registry, at dtrf.iamrare.org, is a powerful opportunity for individuals with desmoid tumors and their family members to contribute directly to research that will enhance our understanding of the disease, thus facilitating the development of new diagnostic and treatment options. Participation is especially vital given the rarity of desmoid tumors - every patient's experience is unique and invaluable.

The more patients we have participating in the Natural History Study (NHS), the more researchers can learn about desmoid tumors. Information gleaned can be vitally important to physicians, researchers and companies developing new therapeutics.

About Us

The Desmoid Tumor Research Foundation (DTRF) is a 501(c)(3) nonprofit organization responsible for sparking the desmoid tumor research movement that has grown into a thriving global effort to find a cure for this rare disease. We aggressively fund research, advocate for patients and families and spread awareness to cultivate an empowered global community anchored in empathy and powered by purpose.

The DTRF Patient Registry is part of a cooperative project with the FDA and NORD.

Why is it important?

The DTRF Patient Registry is the data collection tool for DTRF's Natural History Study (NHS). By entering your information into the patient registry, you're supporting the study, helping us learn about the natural history of desmoid tumors.

Registry participants complete surveys about their own disease experiences, and also learn about other participants' experiences by viewing aggregated survey data. (All data is de-identified to protect your privacy.) Participation in the DTRF Patient Registry is free and voluntary, and participants may withdraw at any time.

Who can participate?

If you have ever had a desmoid tumor, you can participate! If you are the guardian or caregiver of someone who has ever had a desmoid tumor, you can register and complete surveys on their behalf.

How do I participate?

To start, simply set up an account at dtrf.iamrare.org and begin completing the online surveys. We hope that you'll complete all surveys available to you, answering as many questions as possible, but you don't have to do it all at once! We encourage you to complete what you can, save your progress, take a break, and return to the surveys at your convenience.

Learn more at:
dtrf.org/patient-registry.

Reach out with questions to
registry@dtrf.org.

[DTRF.iamrare.org](https://dtrf.iamrare.org)

