The Desmoid Project

STRENGTH THROUGH CONNECTION

Support and Resources for People Affected by Desmoid Tumors

MENTAL HEALTH • COMMUNITY • ADVOCACY

Desmoid patients often fall between traditional oncology and chronic illness support systems. Many report feeling isolated, misunderstood, or emotionally unsupported, even when receiving excellent medical care.

We are a **patient-led nonprofit** advancing mental health, psychosocial support, and advocacy through professionally facilitated programs, evidence-informed resources, and partnerships. While we don't provide medical advice, we partner with healthcare professionals and researchers to ensure patient voices inform care and research.

In our community needs assessment, **67% of patients reported symptoms of mental distress** as a direct result of desmoid diagnosis



Programs

- **Support groups** led by certified professionals who are desmoid patients
- **Topic-centered Gathering Tree educational and peer support sessions** for both patients and caregivers that foster belonging and break isolation
- **Practical tools** to manage stress, build resilience, and live with uncertainty
- **Patient retreats** offering connection, reflection, and shared understanding
- **Peer-to-peer mentorship** pairing patients and caregivers with trained volunteer mentors through Imerman Angels partnership
- **Advocacy support** to navigate access to care and resources, while ensuring patient perspectives are represented in desmoid research, care, and policy

All programs and resources are offered at **no cost** to patients and caregivers, thanks to the generosity of donors and partners.

For Organizations & Partners

We partner with healthcare teams, researchers, industry partners, and advocacy organizations to ensure the patient voice is represented where decisions are made.

Through collaboration and our **trauma-informed training program**, we translate lived experience into:

- Better research and clinical conversations
- Patient-centered policy and improved access to care
- More compassionate, patient-centered engagement

Partner with us to join a movement rooted in *Strength Through Connection*, transforming lived experience into insight, impact, and change.
Your partnership strengthens patients, families, and the global systems that shape desmoid care.



Learn more about our programs

thedesmoidproject.org
360-504-6332
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Refer a patient or caregiver