The Desmoid Project

STRENGTH THROUGH CONNECTION

Support the Whole Patient

Partner with The Desmoid Project to ensure desmoid patients feel supported, understood, and connected

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.

The Desmoid Project is a patient-led nonprofit focused on mental health, community, and advocacy. We partner with professionals and organizations who share a commitment to patient-centered, trauma-informed care. We do not provide medical advice or clinical treatment, but we work alongside the systems that shape care to ensure patient voices are heard.

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

What We Offer

- Mental health support specifically for people living with a desmoid tumor
- Trauma-informed resources for navigating the emotional impact of diagnosis and long-term care
- Support groups led by certified professionals who are also desmoid patients
- Topic-centered standalone Gathering Tree peer support sessions
- In-person patient retreats
- Patient advocacy that supports individuals in navigating care and amplifies lived experience across research, care, and policy

Refer a patient or caregiver

Learn more about our programs

Why It Matters

Many people living with a desmoid tumor experience significant emotional distress, yet few receive dedicated mental health support. We help bridge that gap.

A Trauma-Informed Approach

Our work is trauma-informed, aligned with SAMHSA guidelines, and recognizes the impact of rare disease, medical uncertainty, and long-term care experiences.

We create environments that:

- Support nervous system regulation
- Prioritize psychological safety
- Validate lived experience
- Foster meaningful connection

All programs and resources are currently 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, we translate lived experience into:

- Better research and clinical conversations
- Patient-centered policy and improved access to care
- Trauma-informed patient engagement strategies

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.

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