Research, Advocacy, Awareness, and Support

ABOUT THE DTRF

We aggressively fund desmoid tumor research, accelerate the development of improved therapies, drive collaborations among clinicians and researchers worldwide, and support patients and doctors through education. **Our goal is to find a cure for each and every patient diagnosed with this rare disease.**

Every year we gain extraordinary momentum in our progress. Our research and collaboration efforts have led to FDA approval of the first-ever medical therapy to treat desmoid tumors, as well as other emerging therapies, new clinical trials, and important discoveries about the disease.

As we find more answers, we also work to provide patients and caregivers with the resources, information, and opportunities needed to be informed advocates for their care.

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Desmoid Tumor Research Foundation

our mission: cure desmoid tumors

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

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WHAT IS A DESMOID TUMOR?

1 Desmoid tumors (also known as aggressive fibromatosis, desmoid fibromatosis, and desmoid-type fibromatosis) are rare, locally invasive, soft tissue tumors that form in the connective tissues in the body. The World Health Organization (the "WHO") classifies them as an **intermediate (locally aggressive)** type of sarcoma. These tumors[1] can occur anywhere in the body, but common sites include the abdominal muscles, inside the abdomen, the head/neck area, trunk, breast, and the extremities.

2 Desmoid tumors do not have the ability to metastasize (i.e., spread through the blood or lymph system to other distant locations or organs), but in some rare cases, an individual can have more than one desmoid tumor[2] (also called "multifocal").

3 Although desmoid tumors do not metastasize, they can be locally aggressive and can severely damage surrounding tissues and vital structures as they grow. They also have a high rate of regrowth or "recurrence" after surgery, and should be monitored long-term in most cases.

1. Marta Sbaraglia, Elena Bellan, and Angelo P. Dei Tos, Pathologica 20221, "The 2020 WHO Classification of Soft Tissue Tumours: news and perspectives," page 71 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8167394.

2. Master SR, Mangla A, Puckett Y, et al. Desmoid Tumor. [Updated 2022 Nov 30]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2023 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK459231/.

Desmoid tumors are complex and the information on this page is a general overview and not intended as medical advice for any individual problem, or as a diagnosis, treatment plan, or recommendation for a particular course of action, and this information should not be used as a substitute for professional medical advice and services. Please do not delay in seeking professional medical advice regarding your individual circumstances.

DIAGNOSIS

To make a definitive diagnosis, a biopsy is performed to collect a sample of tumor tissue that is then examined by a pathologist in a lab. Using a microscope, a pathologist can look for characteristics of desmoid tumor cells. Unfortunately, due to the complexities in sarcoma pathology, a misdiagnosis is possible in the pathology process. Desmoid tumors can also be misdiagnosed as other more common diseases. **A second opinion by an expert soft tissue pathologist is recommended to confirm a desmoid tumor diagnosis.**

SIGNS & SYMPTOMS

Symptoms can differ based on where the desmoid tumor is located in the body. Some patients will be able to actually feel a palpable lump or see swelling. By contrast, some patients may have no symptoms at all and no visible physical manifestation of the tumor. Below are some other common signs and symptoms associated with a desmoid tumor depending on location:

- Pain
- Swelling
- Visible deformities
- Cramping and nausea for abdominal tumors
- Impact on mobility
- Impact on bodily function such as urinary or bowel function, breathing, or swallowing
- Fatigue

SCAN TO LEARN MORE:

FIND A SARCOMA SPECIALIST

It is important to seek out a sarcoma specialist where possible, as they are more likely to be knowledgeable about desmoid tumor diagnosis and care. These specialists can typically be found at major sarcoma centers within, or affiliated with, academic medical centers. They can help support patient care through a multidisciplinary medical team, often forming what is called a tumor board.

TREATMENT & MONITORING

The treatment of desmoid tumors can be complex, and what works for one person may not necessarily work for another. Experts are continually working toward standardizing protocols based on tumor location, symptoms, and aggressiveness.

SCAN TO LEARN MORE:

Be sure to download the **Global Consensus Paper on Desmoid Tumor Management** using the QR code below. It answers critical questions regarding approach to treatment, types of treatments, and pain management.

HIGHLIGHTS FROM THE GLOBAL CONSENSUS PAPER

- **Active surveillance (or "Watch and Wait") is the well-established primary approach to primary/recurrent sporadic/familial desmoid tumors.** ("Sporadic" desmoid tumors are not inherited while "familial" desmoid tumors can be inherited and occur with Familial Adenomatous Polyposis or F.A.P.)
- Surgery is the accepted second-line treatment only for sporadic desmoid tumors located in the abdominal wall failing observation
- Medical therapies are the second-line treatments for sporadic desmoid tumors located at all other sites and for all familial desmoid tumors failing observation
- Local ablative treatments such as cryotherapy or radiotherapy are options that can be considered as an alternative to medical therapies on an individual basis
- Pain control is paramount to improve quality of life, independently of the use of active treatment against the disease.

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