

Rethinking Desmoid Tumors:

MEDIA FACT SHEET

About Desmoid Tumors

Desmoid tumors are rare, locally aggressive tumors that form in the connective tissues of the body.^{1,2} Sometimes referred to as aggressive fibromatosis, or desmoid fibromatosis, desmoid tumors can cause severe pain, limited function and mobility, disfigurement, and compromised quality of life.¹⁻⁶ Desmoid tumors can be difficult to control and sometimes debilitating for people living with them.²⁻⁴ They can have an unpredictable nature and high likelihood of recurrence and can have a significant impact on people's lives.^{4,7,8} These invasive, tendrill-like growths can wrap around nearby tissue and compress vital organs, muscles, vessels, and nerves.^{2,3,9} When vital organs are impacted, desmoid tumors can be life-threatening.^{2,9}

Quick Facts: Desmoid Tumors



Desmoid tumors are commonly diagnosed in people between 20 to 44 years of age.^{7,10}



Women are 2 to 3 times more likely to be diagnosed than men.^{7,10}



Recent pregnancy, injury, or surgery may increase the risk of developing desmoid tumors.^{11,12}



Early and accurate diagnosis may help improve outcomes for people living with desmoid tumors.

- Approximately 30 to 40% of desmoid tumors are initially misdiagnosed, in part due to their rarity and similarities to other diseases.¹³
- More than half of people do not receive an accurate diagnosis for more than a year, which may prolong time living with pain and other debilitating symptoms and delay needed care.^{4,5,13,14}



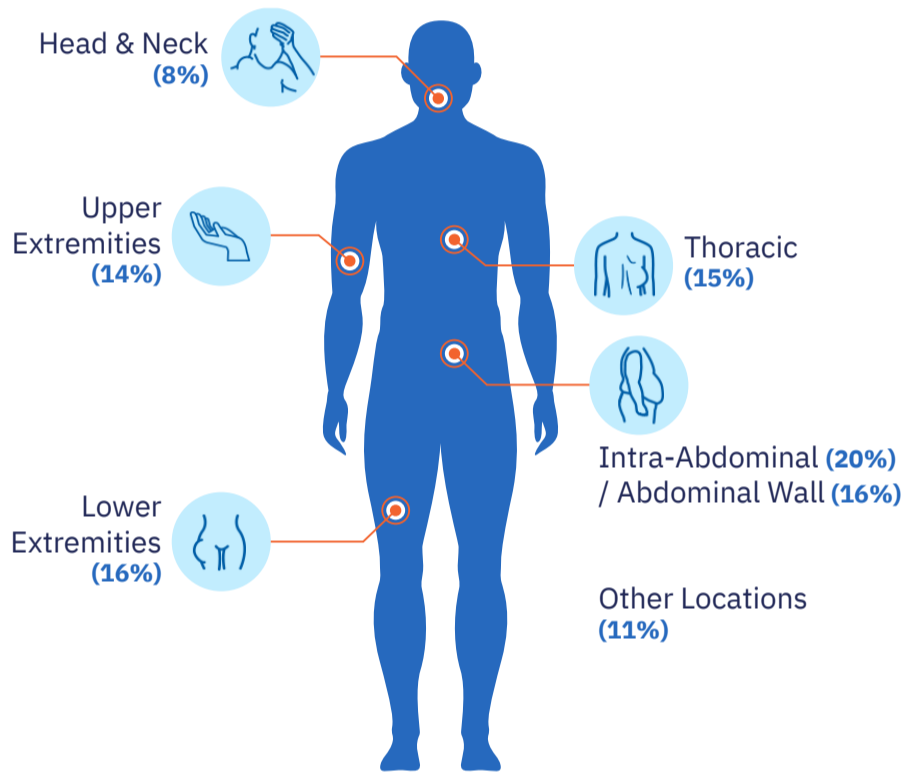
There are approximately 1,000 to 1,650 new cases of desmoid tumors diagnosed annually in the U.S.^{10,15,16}



According to recent guidelines, people with desmoid tumors should be evaluated by a multi-disciplinary care team with experience managing desmoid tumors.¹⁷

Desmoid Tumors Can Infiltrate Almost Any Part of the Body

While desmoid tumors can grow in almost any part of the body, the most common sites are:^{3,6,10,13}



Desmoid Tumor Symptoms Can Include^{3,5,6}

- ▶ Pain
- ▶ Changes to body shape and physical function
- ▶ Limited range of motion
- ▶ Change in sleep
- ▶ Shortness of breath
- ▶ Fatigue

For some people, the pain and symptom burden can have psychological consequences, including:^{5,6}

- ▶ Anxiety
- ▶ Depression
- ▶ Fear
- ▶ Worries about altered appearance
- ▶ Concerns about a lack of knowledge among healthcare professionals

Treatment of Desmoid Tumors

- ▶ Desmoid tumor experts and guidelines now recommend systemic treatment as first-line intervention instead of surgery for most tumor locations requiring treatment.^{17,18}
- ▶ Surgical resection is associated with increased rates of tumor recurrence, with up to 77% of patients experiencing recurrence following surgery.^{7,8*}

*Based on retrospective, observational data. Factors associated with local recurrence postsurgery include tumor location, age of the participant, tumor size, margin status, and prior recurrence.^{19,20}

For more information, visit

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