

TITLE: An Update on Diagnostic Data from the Desmoid Tumor Research Foundation Natural History Study

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BACKGROUND AND OBJECTIVES: The Desmoid Tumor Research Foundation (DTRF) launched the patient registry and natural history study in 2017. There are a many treatment options available to desmoid tumors. Here, we describe the types of treatments and the patient reported outcomes.

METHODS: The registry launched September 2017 and contains 15 surveys covering diagnostics, disease, treatment, care management, and quality of life. As of May 1, 2020, 308 patients or legally authorized representatives have completed the survey on desmoid tumor treatments.

RESULTS: Types of treatments included in the DTRF NHS were systemic treatments, surgery, radiation, high-intensity focused ultrasound, and watch and wait. For the patients who reported being prescribed systemic treatments, there were 25 options, of which None (13.5%, 51/376), Sorafenib (12%, 45/376), Sulindac (9.6%, 36/376) were described. Pain medication use was described by 404 respondents, were the 31% were using an NSAID. The surgery types described were complete resection (55%, 83/151), incomplete resection (23%, 35/151), amputation (11/151), bowel resection (7%, 14/151), and other organ resection (5%, 8/151). For those who did require an amputation, 50% (7/14) noted that they had a recurrence. Rates of recurrent desmoid tumors were pronounced following surgery compared to other treatments. Nearly 35% of patients who had surgery reported a recurrence (99/287), while only 6% (18/287), 6% (19/287), and 12% (35/287) reported a recurrence following radiation, surgery then radiation, and chemotherapy, respectively. 40.5% of respondents (116/287) did not document a recurrence following these treatment types. Most typically, surgery is the first treatment provided to participants (58%, 49/83), compared to chemotherapy (18%, 15/83), radiation (20%, 17/83), and HIFU (3.6%, 3/83).

CONCLUSION: Patients with desmoid tumors report many treatment types for their desmoid tumors with a wide range of efficacy. Data collection through the NHS is ongoing.