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DTRF Natural History Study and Patient Registry Launch and Update

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The Desmoid Tumor Research Foundation DTRF Patient registry provides a convenient online platform for participants and caregivers to self-report cases of desmoid tumors and develop a communications registry (e.g., to notify patients of additional research studies and clinical trials). The NHS goals are to characterize and describe the desmoid tumor patient population, enhancing the understanding of disease prevalence and phenotype, as well as the rate of progression of disease characteristics. The study results will assist the desmoid tumor patient community through the development of recommendations and defining standards of care. Researchers will be able to use the results to study the pathophysiology of desmoid tumor, retrospectively collate intervention outcomes, and design prospective trials of novel treatments. We will provide an update on the registry launch and initial results of the NHS.