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DTRF Natural History Study Update

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The Desmoid Tumor Research Foundation (DTRF) launched the patient registry and natural history study (NHS) in 2017. The study objectives were to provide a convenient online platform for participants (or caregivers) to self-report cases of desmoid tumors, characterize and describe the desmoid tumor patient population as a whole, enhancing the understanding of disease prevalence and phenotype as well as the rate of progression of disease characteristics, assist the desmoid tumor patient community with the development of recommendations and standards of care, and be a case-finding resource to be used for researchers who seek to study the pathophysiology of desmoid tumor, retrospectively collate intervention outcomes, and design prospective trials of novel treatments. Since the update provided at the DTRF Research Update in 2019, there has been the study team growth, a successful presentation at the DOD Rare Disease CDMRP launch meeting, a significant data cleaning effort in collaboration with NORD, and two posters to be presented in October 2020 at the NORD Virtual Summit on diagnostics and treatments in desmoid tumors. The presentation will describe these updates, the growth of the study participation, on-going efforts in data interpretation, and expanding study recruitment in minority populations.