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Natural History Study and DTRF Patient Registry

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The Desmoid Tumor Research Foundation was chosen in April 2016 to participate in a Natural History Study (NHS) by the National Organization of Rare Disorders (NORD). The DTRF NHS will provide a convenient online platform for participants (or caregivers) to self-report cases of desmoid tumors, develop a communications registry within the DTRF Patient registry (e.g., to notify patients of research studies and clinical trials), 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.

We will provide a brief goals and an overview of the DTRF NHS progress at the DTRF Patient Meeting.