



## **The Desmoid Tumor Research Foundation (DTRF) Natural History Study Publishes 2 Posters**

### ***DTRF publishes posters focusing on diagnostic and treatment data collected from Natural History Study in preparation for 2020 NORD Virtual Summit***

**September 4, 2020**— The Desmoid Tumor Research Foundation (DTRF) launched the patient registry and natural history study in early 2017. Since then, DTRF has submitted abstracts and posters to numerous conferences to share study findings. The Desmoid Tumor Research Foundation announces the publication of 2 posters for the NORD Breakthrough Summit running from October 8-9, 2020.

“The DTRF Desmoid Tumor Patient Registry continues to gain momentum,” said Jeanne Whiting, DTRF Co-founder. “With the support of other medical professionals, and under the leadership of Dr. Kelly Mercier, we look forward to gaining a greater understanding of the natural history of this rare disease.”

With regard to diagnosis, study findings show that patients with desmoid tumors report many methods of diagnosis for their diverse tumor locations, high rates of misdiagnosis, and increased rates of genetic mutation testing. Patients with desmoid tumors report many treatment types for their desmoid tumors with a wide range of efficacy.

The DTRF was selected in 2016 as one of 20 rare disease patient groups developed a natural history studies with the assistance of the National Organization for Rare Disorders (NORD), supported in part by a cooperative agreement with the U.S. Food and Drug Administration (FDA). It has been under this mechanism that the registry and study was launched and has continued to grow since 2017.

“We are very pleased at the continued recruitment and data collection from the desmoid tumor patients and caregivers,” shared Dr. Mercier. “With their help, we are starting to truly understand how their disease is being managed globally. We will continue our work in these two areas, diagnosis and treatment efficacy, over the next few months with our expanding research volunteers, Dr. Danielle Braggio and Ms. Amanda Lucas. With their assistance and the support of the DTRF, we will submit two publications for peer-review by the end of 2020.”

Desmoid tumors is a rare disorder that occurs in approximately 5-6 out of every 1,000,000 people and 900 people are diagnosed every year. Classified as a soft tissue sarcoma, desmoid tumors can occur virtually anywhere in the body. Currently, there are no FDA approved therapies for this disease.

For more information, visit <https://dtrf.iamrare.org>.

###

### **About The Desmoid Tumor Research Foundation (DTRF)**

The Desmoid Tumor Research Foundation (DTRF) is dedicated to funding research for a cure for desmoid tumors. DTRF funds desmoid tumor research projects at the world’s top cancer research institutions. It also offers patient support, awareness and education. The DTRF is a non-profit, 501(c)(3) tax-exempt organization whose mission is supported by donors, corporate sponsors, patients and volunteers. More at [www.dtrf.org](http://www.dtrf.org).

**About National Organization for Rare Disorders (NORD)**

An independent 501(c)(3) nonprofit organization, NORD is the leading advocacy organization representing all patients and families affected by rare diseases in the U.S. Established in 1983, NORD is committed to the identification, treatment and cure of the 7,000 rare diseases that affect 30 million Americans, or 1 in every 10 people, through programs of advocacy, education, research, and patient/family services. In addition to educational resources for patients, families, medical professionals and students available on its website ([www.rarediseases.org](http://www.rarediseases.org)), NORD represents 250 member organizations and collaborates with many others in specific causes of importance to the rare disease patient community.

Contact: Lynne Hernandez, [Registry@dtrf.org](mailto:Registry@dtrf.org), 215.760.3977