

THE DESMOID TUMOR RESEARCH FOUNDATION RECOGNIZES SEPTEMBER AS DESMOID TUMOR AWARENESS MONTH

September 3, 2019 – The Desmoid Tumor Research Foundation (DTRF) today announced that it is formally recognizing September as Desmoid Tumor Awareness Month and initiating a worldwide, annual campaign to raise awareness of desmoid tumors and to support research that may lead to new treatment options.

Desmoid tumors, also known as aggressive fibromatosis, are rare soft tissue tumors that affect 5-6 per every 1 million people worldwide. Desmoid tumors arise in the connective tissues of the body and, although they do not metastasize, they can be locally aggressive and severely damage surrounding tissues and vital structures as they grow. These tumors can occur anywhere in the body (abdominal, intra-abdominal, and extra-abdominal locations) and approximately 5-10 percent arise in the context of a rare genetic condition known as familial adenomatous polyposis (FAP).

“We are thrilled to honor the desmoid tumor community this September and every September hereafter,” says Marlene Portnoy, co-founder of the DTRF. “Although rare, desmoid tumors can be devastating to those affected. Our hope is that the collective efforts of the DTRF and broader community will help improve the lives of people living with this condition through education, awareness and support, and ultimately, a cure.”

September was selected for Desmoid Tumor Awareness Month since it’s the month that the DTRF annually hosts two major signature events: the DTRF Annual Patient Meeting and the DTRF Running for Answers 5K. These events have been taking place for more than a decade and are part of the fabric of the desmoid tumor patient and caregiver community. They provide essential education and celebration of the progress that’s been made, while raising critical funds for research.

The DTRF is spearheading several activities in September for patients, caregivers and patient allies. In addition to national and local events, the DTRF encourages the desmoid tumor community to engage on social media, secure government proclamations, share personal stories publicly to raise awareness, and host fundraisers, among other things. Through these efforts – and by unifying under one cause – there is greater hope for discovering and developing new treatment options.

For more information about Desmoid Tumor Awareness Month and ways to get involved, visit <https://dtrf.org/awareness/>.

About the Desmoid Tumor Research Foundation

DTRF was founded in 2005 with the mission of facilitating and funding desmoid tumor research and supporting patients with information. The mission of The Desmoid Tumor Research Foundation is to aggressively fund research to accelerate the development of improved therapies, and ultimately find a cure for desmoid tumors. DTRF collaborates with dedicated researchers and clinicians worldwide to improve the lives of patients through education, awareness and support. Every year the foundation has gained momentum in its progress and has seen new clinical trials, emerging therapies and important new discoveries about the disease come to fruition. For more information on clinical trials for people with desmoid tumors, visit <https://dtrf.org/clinical-trials/>.

###