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The Desmoid Tumor Research Foundation Closes Care Gaps through Virtualized Multidisciplinary Cancer Care Platform

In honor of World Cancer Day, The Desmoid Tumor Research Foundation is celebrating the success of their virtualized tumor board program enabled through the OncoLens platform

Atlanta, GA: In honor of [World Cancer Day on February 4th](#), The [Desmoid Tumor Research Foundation](#) (DTRF) is celebrating the success of The DTRF Virtual Tumor Board program in closing care gaps and patient access barriers for rare tumors. The DTRF Virtual Tumor Board is an international, virtual meeting where physicians discuss de-identified, challenging desmoid tumor patient cases to develop a path forward for treatment. Since the program's launch in 2017, these meetings have helped 55 patients and engaged clinicians from around the globe. As recognition of the program's success has grown across the community, oncologists are looking to replicate the approach with other rare cancer types.

The DTRF was founded in 2005 to fund research toward a cure for desmoid tumors and improve the lives of patients through education, awareness, and support. Desmoid tumors are rare tumors of soft tissues in the body, can be locally invasive, and often have an unpredictable clinical course. The DTRF receives inquiries from healthcare professionals, patients, and family members for advice on treatment and management strategies for desmoid tumors. As is the case with many rare tumors, medical expertise and research programs for desmoid tumors are limited and often siloed across academic research facilities. To address gaps in access and improve shared knowledge, The DTRF runs The DTRF Virtual Tumor Board program quarterly during which three to four patient cases are discussed with physicians from multidisciplinary backgrounds. Attendance is global, and the sessions provide an invaluable opportunity to disseminate evidence-based consensus guidelines and education.

"Through The DTRF Virtual Tumor Board program, we created a pathway for connecting desmoid tumor experts, specialists, and patients around the globe. We often think of care gaps at the individual patient level, and what we know through our work at The DTRF is that gaps and barriers to access are amplified when it comes to rare cancer types. Being able to centralize, standardize, and facilitate the knowledge sharing that happens during these meetings is emerging as a best practice in rare tumor treatment and oncology more generally," said Lynne Hernandez, director of special events and operations for The DTRF.

With more than 55 patient cases discussed across providers representing countries including the U.S., Italy, Brazil, the U.K., Norway, Mexico, Germany, and Australia, The DTRF Virtual

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Tumor Board serves as a successful model that can be replicated for other cancer types. In addition to the live sessions, each meeting is recorded. Efforts are underway to curate this data and make it available through a knowledge base that can be accessed asynchronously. These data include treatment recommendations, outcome summaries, and follow-ups to ensure a complete view of the patient journey and outcomes.

“In general, rare tumors often face the challenge of limited clinical trial and research opportunities, which hinders the development of well-established management strategies. The DTRF Virtual Tumor Boards provide a unique and cost-effective way to reach more people and provide expert advice in a more formal scientific forum,” said Aaron Weiss, DO, director, medical advisory board for The DTRF and division chief, pediatric hematology-oncology for Maine Medical Center. “Using the multidisciplinary platform [OncoLens](#), we connect clinicians and lower access-to-care gaps at a global scale. And the data that we are collecting will help inform future research and guidelines.”

The DTRF Virtual Tumor Board program leverages the OncoLens [Multidisciplinary Cancer Care Continuum](#) platform to facilitate the virtualized meetings. The fully HIPAA-compliant solution enables patient data sharing, treatment discussions, and documentation for each patient case. Access is web-based, no local software needs to be installed, and the workflow is purpose-built for oncology and customized to cancer type.

“It has been an honor to work with The DTRF and to serve as the multidisciplinary care continuum backbone for this program,” said Anju Mathew, chief executive officer for OncoLens. “This project demonstrates the power of collaboration at an international level to lower barriers to care and address the challenges inherent to rare tumors. We look forward to our continued work with The DTRF and support for their mission.”

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About The DTRF

The mission of The Desmoid Tumor Research Foundation (DTRF) is to aggressively fund research to accelerate the development of improved therapies, and ultimately find a cure for desmoid tumors. The Foundation collaborates with dedicated researchers and clinicians worldwide to improve the lives of patients through education, awareness and support. The DTRF was founded in 2005 by Jeanne Whiting and Marlene Portnoy, "two women working from their kitchen tables", who over the years have transformed an entire rare disease community and research agenda.

About OncoLens

OncoLens is the single platform that enables multidisciplinary cancer care across the continuum. Through a streamlined, secure HIPAA-compliant infrastructure, OncoLens drives intra-enterprise, community, network, and affiliate participation in multidisciplinary care planning, tracking, and delivery. Using OncoLens, cancer providers can capture, disseminate, and track quality, best practices, and protocols. And with direct EMR and cancer registry integration, data and abstraction are automated and accelerated. The OncoLens platform allows providers to aggregate, create and track the comprehensive patient journey to optimize

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multidisciplinary care across the continuum. This includes maximized clinical trial participation, an extended referral stream, and the creation of a center of excellence that can be leveraged to support patient care and provider education. With OncoLens, providers can realize and expand their reputation to increase patient-driven referrals, decrease patient leakage and enhance their brand within the oncology community. More than 9,000 cancer providers and 36,500 cancer patients across the U.S. rely on OncoLens to support their cancer programs and the care delivered