



our mission:

cure desmoid tumors

ANNUAL REPORT 2025



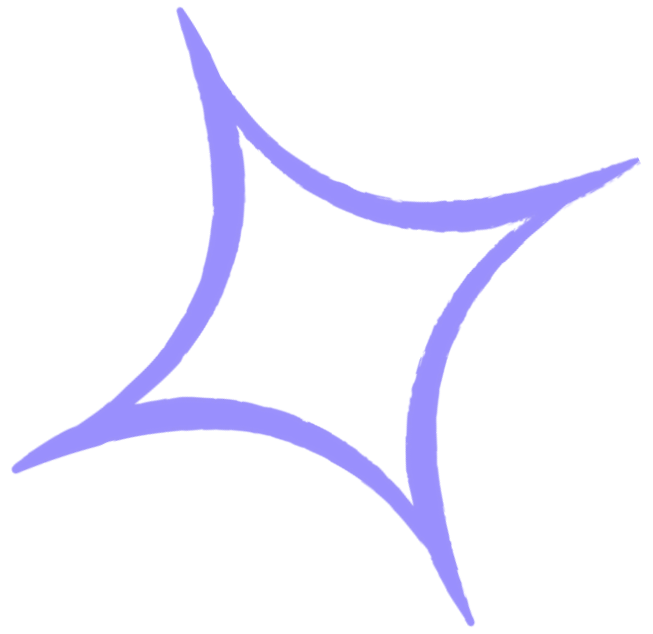


TABLE OF CONTENTS

NOTE FROM EXECUTIVE DIRECTOR	1
NOTE FROM INCOMING EXECUTIVE DIRECTOR	2
WHAT WE DO	3
WHY IT MATTERS	4
DTRF IMPACT REPORT	5
2025 HIGHLIGHTS	6
ONGOING PROJECTS	9
CLINICAL TRIALS	10
CONFERENCES FEATURING DESMOID TUMORS	11
DTRF NATURAL HISTORY STUDY AND PATIENT REGISTRY	12
2025 DTRF-FUNDED RESEARCH GRANTS	13
RESEARCH EVENTS AND INITIATIVES	14
EDUCATION, ADVOCACY AND AWARENESS	17
MEDICAL EDUCATION AND CME OPPORTUNITIES	25
FUNDRAISING	26
FINANCIALS	27
OUR TEAM	28



A Note From Lynne Hernandez, DTRF Executive Director

Dear DTRF Community,

After much reflection and with immense gratitude, I announce that I tendered my resignation as Executive Director of the [Desmoid Tumor Research Foundation \(DTRF\)](#) and will step down at the end of 2025.

Leading the DTRF over the past two years has been the most meaningful, challenging, and deeply rewarding experience of my professional life. I have grown so much personally, and I'm so proud of what we've achieved together as a community since I accepted the position in November of 2023.

Since that time, we've hosted our first September Weekend outside of Philadelphia, we've aligned with and amplified the patient experience powerfully through our Spread the Word campaign, and we've launched an Ambassador Program for patients to serve their own local communities with education and resources. We have rolled out a targeted RFP to learn more about the cause of spontaneous tumor regression. We have seen greater interest from the pharmaceutical industry in developing therapies for desmoid patients, and we have partnered with two new companies to ensure that patients are involved in the drug development process. This is just the beginning.

The path ahead holds incredible opportunities to advance research, elevate patient advocacy, and expand our impact within the desmoid community. With fresh perspective and new leadership, the DTRF is poised for the next phase of its evolution—and I am so excited for what lies ahead.

At the end of 2025, I will pass the baton to [Katie Doyle Myers](#), who has decades of experience in executive leadership and lived experience with a desmoid tumor. She has fundraised for the DTRF since being diagnosed in mid-2023 (she is currently being monitored), and has been a guiding light over the past two years as the Foundation has continued to evolve internally.

The DTRF continues to be the leading convener of the desmoid tumor patient and professional communities, with a dedicated team, a clear mission, and a community of supporters like you who make this work possible.

Going forward, the DTRF will be leaning into more meaningful and fruitful collaborations with partners who are eager to join hands and work toward our common goal of improving the lives of patients.

Thank you for your continued partnership and trust in the Foundation.

Only looking forward,

A handwritten signature in black ink, appearing to read 'Lynne Hernandez'. The signature is fluid and cursive.

Lynne Hernandez
Executive Director



A Note from Katie Doyle Myers, DTRF Incoming Executive Director

Dear DTRF Community,

As the Desmoid Tumor Research Foundation enters its next chapter, I am filled with deep gratitude and excitement to step into the role of Executive Director. The success of the DTRF over the past twenty years is extraordinary. Under the leadership of Marlene Portnoy, Jeanne Whiting, and Lynne Hernandez, the Foundation has exemplified relentless patient advocacy, steadfastly advanced research, and achieved what many thought of as impossible. And — as I have heard these remarkable women say many times — we're just getting started. It is a true honor to carry this legacy forward.

From its earliest days, the DTRF has been *of and for* desmoid tumor patients and their caregivers. At the heart of the Foundation is a connected, supportive community where no one faces this rare disease alone and every voice helps advance science and care. I experienced this firsthand when I was diagnosed with a desmoid tumor. It feels profoundly meaningful for me to bring together my personal connection to this disease and my professional experience in nonprofit leadership.

I look forward to meeting all of you whose dedication drives DTRF's mission, and to working together to advance our shared goal: a cure for each and every desmoid tumor patient.

With gratitude,

A handwritten signature in cursive script that reads "Katie Doyle Myers".

Katie Doyle Myers
Incoming Executive Director

RESEARCH FUNDING

The DTRF is the only foundation in the country solely dedicated to funding desmoid tumor research and finding treatments for this rare disease. The funding of cutting-edge collaborative research continues to be our priority. We fund research projects at the world's top sarcoma cancer research centers in both basic science and clinical trials. DTRF-funded research seeks to determine what goes wrong in cells to generate these tumors, what systemic and local treatment options work best, and what existing drugs or potential new drugs or treatment modalities could provide effective treatments. The DTRF facilitates collaboration among researchers from multiple institutions to expedite the development of a cure for each and every desmoid tumor patient. DTRF-funded research has made significant advancements in our understanding of the disease. Discoveries made through desmoid tumor research can also potentially have a significant impact on common cancers such as breast, colon, ovarian, and others.

PATIENT SUPPORT

Patients are not fighting this disease alone. Our website provides information and helps direct patients to other sources for information, support, and resources. Our Annual Patient Meeting and informational webinars throughout the year provide a supportive environment for patient interaction and informative presentations by clinicians and researchers. Most of all, we seek to support patients by giving them hope through funding research. Our fundraising events around the country promote awareness and give patients and their families and friends a healing way to make a difference as proactive advocates for the cause.

EDUCATION AND COLLABORATION

The DTRF has established a successful annual Patient Meeting which brings patients, physicians, and researchers together for education, support, and collaboration. In connection with the Annual Patient Meeting, we hold the DTRF International Desmoid Tumor Research Workshop. This event brings together a diverse group of scientists from around the world including the brightest minds in desmoid tumor research, human genetics, drug development, and related fields. The Research Workshop facilitates an enthusiastic and collegial atmosphere as researchers across disciplines and institutions collaborate around the shared goal of improving treatments for desmoid tumor patients, establishing research priorities, and advancing toward answers for each and every patient. In addition, our website is a clearinghouse of information on desmoid tumors and published desmoid tumor research, reaching patients, physicians, and researchers around the globe.

The Desmoid Tumor Research Foundation (DTRF) empowers and unites everyone committed to finding answers for the desmoid tumor community.



DTRF is our lifeline and road to a cure.

DANA L.
Desmoid Tumor Patient, US

We aggressively fund desmoid tumor research, accelerate the development of improved therapies, drive collaborations among clinicians and researchers worldwide, and support patients and doctors through education.

Our goal is to find a cure for each and every patient diagnosed with this rare disease. Every year we gain extraordinary momentum in our progress. Our research and collaboration efforts have led to the 2023 FDA approval of the first-ever medical therapy to treat desmoid tumors, as well as other emerging therapies, new clinical trials, and important discoveries about the disease.



As we find more answers, we also work tirelessly to provide patients and caregivers with the resources, information, and opportunities needed to be informed advocates for their care.

I have an advocate trying to raise awareness and find a cure. The DTRF has made me feel hope.

LYNNE S.
Desmoid Patient, Tennessee, US

We know that our goal of a cure for each and every desmoid tumor patient is within reach...and we will get there together.



BY THE NUMBERS

Discoveries made through desmoid tumor research can potentially have an impact on common cancers such as breast, colon, ovarian, and others.

1

NEW FDA-Approved Drug ✨
OGSIVEO (nirogacestat)
 First drug with desmoid tumor indication

1

NEW Desmoid Tumor Cell Line

1

Revised Global Consensus Paper ✨
 Partially funded treatment guidelines for desmoid tumor management

3

Desmoid Tumor Awareness Facebook Live Events
 Highlighting the desmoid tumor patient experience

5

2025 DTRF-Funded Research Grants

1

Desmoid Tumor Natural History Study ✨
 Published two posters at ESMO 2025 Sarcoma and Rare Cancers Congress and ISPOR

21

Medical Institutions and Industry Partners
 Represented at DTRF Research Workshop

102

Registrants at the DTRF Annual Together We Will Weekend

29

Recorded Scientific/Educational Videos Featured on DTRF.org
 Created for patients, clinicians and researchers

15

Cases Presented at DTRF Int'l Virtual Tumor Boards

31

International Medical Advisory Board Members
 Guiding DTRF's research priorities

171

Attendees at DTRF Virtual Events
 Educating patients and caregivers

2,090

Participants in Desmoid-Specific CME Accredited Programs
 Educating clinicians



As we **uncover answers**, we work tirelessly to provide patients and caregivers with the resources, information, and opportunities needed to be **informed advocates** in their care.

I have never seen a group of people able to mobilize companies and the FDA like this!!

JEAN PATY, PHD
 VP, PATIENT CENTERED ENDPOINTS, IQVIA

We are undaunted.

Celebrating 20 years of Progress

In 2005, [Marlene Portnoy and Jeanne Whiting](#) co-founded the DTRF with the goal of facilitating and funding desmoid tumor research and providing patients with information and support.

In the years that followed, the co-founders fought for the [DTRF's mission](#) to find a cure for desmoid tumors by convening patients, caregivers, and leading desmoid tumor experts from around the world.

[Listen](#) to DTRF's Scientific Director, Dr. Mrinal Gounder talk about DTRF's impact over the years. We invite you to explore our Strategy and Impact page to learn more about our work since our founding.



[Explore DTRF Strategy and Impact](#)

DTRF Featured in Newsweek Article



In the Newsweek article titled [“Research Moves Slowly. Rare Diseases Don't—So Patients Aren't Waiting,”](#) rare disease advocates shared how systemic barriers delay progress, while patients face aggressive, life-altering conditions with limited treatment options.

The DTRF is the leading foundation in the world focused solely on desmoid tumors, advancing innovative research and uniting a global network of patients, clinicians, and scientists.

As the rare disease environment evolves, DTRF continues to build momentum. The Foundation invites patients, researchers, clinicians, and industry partners to join our [mission](#) and help close the gap between diagnosis and cure.

DTRF Site for International Pregnancy Study

The DTRF worked together with international partners to learn more about the decisions women make regarding pregnancy after a desmoid tumor diagnosis, as well as to understand how pregnancy may influence the behavior of a desmoid tumor. The following institutions and organizations in the study participated: Institut Curie, University of Toronto, Brigham and Women's Hospital, Fondazione Italiana Tumore Desmoide, and Fondazione IRCCS Istituto Nazionale dei Tumori di Milano.

In April 2025, the *European Journal of Cancer (EJC)* published an article on the study results:

“Impact and safety of pregnancy on desmoid fibromatosis management in the era of active surveillance. An international multicenter retrospective observational study.”
Fiore, Ljevar, Raut, et al.

[Read Full Article](#)

Cultivating Community



“This breakthrough represents the power of patient advocacy. The DTRF’s role in OGSIVEO’s path to approval represents collaboration at its finest. Were it not for their advocacy work to shepherd the drug through the trial phases, facilitate communication among stakeholders, and use their outreach to help fill the trial, we may not be here today.”

Mrinal Gounder, MD, DTRF Scientific Director and Medical Oncologist at Memorial Sloan Kettering Cancer Center



MRINAL GOUNDER, MD
Scientific Director

Notable Nirogacestat News & Articles

✦ **In August of 2025**, the European Commission approved Ogsiveo® (nirogacestat) as the first-ever treatment for adults with progressing desmoid tumors. We extend our gratitude to the SpringWorks Therapeutics team for their dedication and commitment to the desmoid tumor community. For more information about this significant milestone, please read [SpringWorks' press release](#).

✦ Read the published article, "[Nirogacestat—the pathway to approval of the first treatment for desmoid tumors, a rare disease,](#)" which chronicles the clinical development journey of nirogacestat from 2009 to its FDA approval in November of 2023. For roughly fifteen years, the DTRF advocated for this groundbreaking treatment in close collaboration with patients, clinical advisors and key stakeholders, including [SpringWorks Therapeutics](#).

✦ This lay article features insights on the Phase 3 DeFi trial on nirogacesat, and incorporates advocate and patient voices: "[A study to learn if nirogacestat works and is safe for adult participants with desmoid tumors: a plain language summary of the DeFi study](#)" Bernd Kasper, Jeanne Whiting, Dana Lawson, Marlene Portnoy, Kathrin Schuster, Christina Baumgarten, Ravin Ratan, Allison Lim, Sunny Cho, Shivaani Kummar & Mrinal Gounder

2023 DTRF Press Release: FDA APPROVES OGSIVEO™ (NIROGACESTAT)

DTRF Virtual Tumor Board

Led by Dr. Aaron Weiss and Co-Moderated by Dr. Palma Dileo, the quarterly DTRF Virtual Tumor Board is an international video conference allowing physicians anywhere in the world to discuss their desmoid tumor cases with leading specialists in the field and receive input. During 2025, four boards were convened during which 15 cases from 10 different countries were presented.

DTRF Patient Registry

The DTRF Patient Registry and Natural History Study at DTRF.iamrare.org includes a powerful data collection tool that systematically collects, stores, and retrieves patient data for analysis. Patients answering online survey questions about their experience helps us find trends and disease characteristics that can lead to better understanding of desmoids. This de-identified data is invaluable to our community and to those working on improving patient care and advancing desmoid tumor research. Typically, the Registry team collaborates to submit scientific posters and abstracts characterizing our community to inform research efforts and clinical care.

This year the DTRF re-launched the Patient Registry after a short pause to migrate participant data to the National Organization for Rare Disorders' (NORD's) new IAMRARE 2.0 platform.

Enhancements of the new platform make the registry user-friendly and more efficient, which include:

- Mobile-friendly responsiveness
- Intuitive navigation for smoother interaction
- Click optimization and reduction to streamline tasks
- Visual and graphic improvements

DTRF's Partnership with Pattern.org for Tissue Donation

(until September 2025)

Since surgeries in desmoid tumors have become less frequent, there has been an increased need for fresh desmoid tissue samples for research. The DTRF continues to fund and collaborate in desmoid tumor research projects to learn more about the disease and potential treatments. To pilot new technologies in the disease, researchers need a continuing supply of fresh tissue samples. In partnership with Pattern.org (through Sept. 2025), and institutions like the Koch Institute at MIT, DTRF facilitated the collection of tissue samples via a simple online consent process. Before surgery, patients could consent at Pattern.org to a collection of a portion of excess tumor tissue that would then be sent to researchers.

The DTRF is committed to supporting the development of new treatments - and new treatment protocols - for the desmoid tumor patient community.

Among others, the following clinical trials were launched within the past few years:

[Phase II Study of Cryoablation and Nirogacestat for Desmoid Tumor at Stanford University](#)

- Phase 2 of this trial is recruiting desmoid tumor patients combining local treatment of cryoablation with the FDA-approved gamma secretase inhibitor, nirogacestat (OGSIVEO®).
- This trial is currently recruiting patients with desmoid tumors that cannot be completely cryoablated, with a target of 50-75% of the tumor volume for cryoablation.

[FOG-001 in Locally Advanced or Metastatic Solid Tumors](#)

- Phase 1/2 of this basket trial will determine if FOG-001 is safe and effective in participants with locally advanced or metastatic solid tumors. Desmoid tumors are included.
- This trial is currently recruiting patients in 18 sites around the United States.

Participation in clinical trials can contribute to research and provide access to a treatment still in development. However, the decision to participate in a trial should be carefully considered, and it is advised that you speak with your care team to learn more. If you and your care team think you may be a good fit for a clinical trial, your doctor can inform you of the next steps and help connect you with a representative of the trial.

[Explore Clinical Trials Page](#)



Conferences Featuring Desmoid Tumors

DTRF Leadership attends CTOS Annual Meeting



The DTRF's Incoming Executive Director, Katie Doyle Myers and Executive Director, Lynne Hernandez, were on-site at the CTOS Annual Meeting connecting with clinical experts and industry partners who are driving progress in desmoid tumor research.

These important conversations:

- Strengthen collaborations with leaders across the desmoid community
- Explore new opportunities to accelerate desmoid tumor research
- Ensure a smooth transition as Katie gets to know the researchers, clinicians, and partners who support DTRF's mission

One of several CTOS Annual Meeting posters:

["A phase 1/2 trial of FOG-001, a first-in-class direct \$\beta\$ -catenin:TCF inhibitor safety and preliminary antitumor activity in patients with desmoid tumors"](#)

A sample of desmoid-related posters at int'l conferences:

2025 SPAGN Annual Conference

["Desmoid Tumors: Systemic Therapies Beyond Nirogacestat and Management Challenges in Brazil"](#), Fernando Campos, MD, MsC Medical Oncologist Deputy Chair of the Sarcoma Reference Center, A.C.Camargo Cancer Center Sao Paulo, Brazil

2025 ASCO Annual Meeting

["Subgroup Analysis of the Phase 2 Part of the RINGSIDE Phase 2/3 Trial of Varegacestat for Treatment of Desmoid Tumors"](#), Rashmi Chugh, MD University of Michigan, Ann Arbor, MI

2025 ESMO Sarcoma and Rare Cancers Congress

["Long-term Nirogacestat Treatment in Adult Patients with Desmoid Tumors: Updated Efficacy and Safety From the Phase 3 DeFi Trial"](#)
Bernd Kasper, et al.

DTRF Natural History Study & Patient Registry



Kelly Mercier, PhD, DTRF Principal Investigator of the Natural History Study and Patient Registry, presented: *"The Association of Pain With Function for Adult Patients With Desmoid Tumor: Findings From the Desmoid Tumor Research Foundation Natural History Study"* at the 2025 DTRF Int'l Desmoid Tumors Research Workshop.

Watch her [presentation](#) to learn more.

DTRF Natural History Study posters featured at international conferences:

ISPOR 2025

["An Assessment of Financial Burden and Its Association With Desmoid Tumor Specific Symptoms and Impact in Adult Patients With Desmoid Tumors: Desmoid Tumor Research Foundation Natural History Study"](#)

ESMO Sarcoma and Rare Cancers Congress

["The Association of Pain With Function for Adult Patients With Desmoid Tumor: Findings From the Desmoid Tumor Research Foundation Natural History Study"](#)

In collaboration with SpringWorks Therapeutics, Shengfan (Sophia) Zhou, MS, Senior Manager of RWD Outcomes Research, SpringWorks Therapeutics, Inc., presented: *"The Financial Burden of Desmoid Tumors in Adult Patients: Desmoid Tumor Research Foundation Natural History Study"* at the 2025 DTRF Annual Patient Meeting.

Watch her [presentation](#) to learn more.



2025 DTRF-Funded Research Grants

Each year, with the guidance of our grant reviewers and Grants Committee, the DTRF awards grants for promising desmoid tumor research projects. These are 1 to 3-year grants and include early-career and more advanced investigators. The DTRF funds research that will advance current scientific knowledge about desmoid tumors, moving toward the development of new treatment options and bringing us closer to our ultimate goal of a cure for each and every patient.

The Foundation is particularly interested in innovative and translational research projects and will consider applications across the spectrum of research from basic science to clinical trials and correlative studies.

The DTRF is pleased to list our new or continuing research grants awarded in 2025:

- **Sameer Rastogi, MD**, All India Institute of Medical Sciences, “*To see the early effect of sorafenib on cognition, cardiovascular and reproductive functions in patients with aggressive fibromatosis.*” Year 3 of 3.
- **Eldad Enekave, MD**, Shaare Zedek Medical Center, Israel “*Doxorubicin Eluting Embolization (DEE) for Desmoid Fibromatosis.*” Year 1 of 3.
- **Noujaim, Jonathan, MD**, McGill University Health Center, Canada, “*Development of a Multimodal Deep Learning Model to Predict Disease Evolution in Newly Diagnosed Desmoid Tumors.*” New 2025 award, 1 year.
- **Alman, Benjamin, MD and Mushriq Al-Jazrawe, PhD**, Duke University, “*Modeling Regression and Progression in Desmoid Tumors via Transcriptional and Cellular Programs.*” New 2025 award, 3 years.
- **Colombo, Chiara, MD**, Istituto Nazionale dei Tumori, Italy, “*Investigating immune mechanisms mediating tumor regression in patients with desmoid fibromatosis.*” New 2025 award, 3 years.

[Click the button below to learn more about these important research projects:](#)

DTRF-Funded Grants



Research Events and Initiatives

2025 DTRF International Research Workshop

The annual International Desmoid Tumor Research Workshop was held in Chicago, IL, on Friday, September 12th, in conjunction with our Annual Patient Meeting the following day.

The Workshop featured a forum to share research findings, develop new collaborations, bring new scientists into the research field, and discuss innovations that will lead to new treatments. Group discussions focused on gaps in desmoid tumor science and how best to address them through high impact collaborative research.

Research Workshop Presentations

DATA FROM PATIENTS

Peter Hohenberger, MD, PhD, Professor of Surgical Oncology, Mannheim University Medical Center, University of Heidelberg (Germany), “Disease Burden in Desmoid Tumor Patients.”

Kelly Mercier, PhD, Principal Investigator, DTRF Patient Registry & Natural History Study, The Desmoid Tumor Research Foundation, “The Association of Pain With Function for Adult Patients With Desmoid Tumor: Findings From the Desmoid Tumor Research Foundation Natural History Study.”

Desmoid Tumor Patient Panel on Lived Experience

DATA FROM CLINICAL TRIALS AND STUDIES

Nicole Hardy, MS, Medical Student, University of Connecticut, “Treatment discontinuation in desmoid tumors: Factors associated with better outcomes after sorafenib discontinuation.”

Sameer Rastogi, MD, Additional Professor, Medical Oncology, All India Institute of Medical Sciences (India), “To see the early effect of Sorafenib on cognition, cardiovascular and reproductive functions in patients with fibromatosis.”

Mrinal Gounder, MD, Medical Oncologist, Memorial Sloan Kettering Cancer Center, “Analysis of Changes in T2-Weighted Signal Intensity and Tumor Volume and Exposure-Response in the Ringside Phase 2 Study of Voregacestat in Patients with Desmoid Tumors.”

Andrea Penrose, BA, Research Assistant, and Pedro Hermida de Viveiros, MD, Northwestern Medicine, “Real-World Data from a Single Institution on Nirogacestat for Refractory, Symptomatic Desmoid Tumor: Dosing, Adverse Event Management and Symptom Improvement from Medical Record Review.”

[Watch Workshop Videos](#)

2025 Research Workshop Presentations (cont.)

DATA FROM BASIC AND TRANSLATIONAL SCIENCE

Gary Schwartz, MD, FASCO, Director, Case Comprehensive Cancer Center and Vice Dean for Oncology, CWRU School of Medicine, "Exploring the mechanism of action in FOG-001."

Cristabelle De Souza, PhD, Instructor, Stanford University School of Medicine, "Multiomic profiling uncovers integral immune molecules that drive the pathogenic fibroblast milieu in desmoid tumors."

Mushriq Al-Jazrawe, PhD, Scientific Director, High Throughput Sciences, Koch Institute at MIT, "Concurrent genotyping and transcriptomics of Desmoid Tumor single cells and nuclei to study disease trajectory and therapeutic vulnerability: DTRF planning project update."

Joanna Przybyl, PhD, Assistant Professor, McGill University (Canada), "Genomic, epigenomic, and transcriptomic inter- and intra-tumor heterogeneity in desmoid tumors."

Kris Vleminckx, PhD, Group Leader, Unit of Developmental Biology, Ghent University (Belgium), "Modeling desmoid tumors in Xenopus: Improvement and expansion of the CRISPR-based pipeline and use of lightsheet microscopy for 3D-spatial mapping of the tumor microenvironment."

[Watch Workshop Videos](#)



Past and present DTRF grantees gather together at the 2025 DTRF Int'l Desmoid Tumor Research Workshop

Published Research Articles

Dozens of recently published articles have been posted on the Published Research page of our website. This increasing volume of research is yet another indicator of increased awareness of desmoid tumors within the medical research community. With more interest in desmoid research comes advancements that bring us even closer to new treatments.

Topics include nirogacestat, pain, sorafenib, and many case reports. These, and hundreds of other articles, have been organized for patients, researchers, and physicians to peruse on the DTRF website. Readers can use the keyword search bar at the top of the page to quickly and easily find articles related to their area of interest.

Here are just three papers that were published this year on desmoid tumors:

[“Surgical Management of Desmoid Tumors-Patient Selection, Timing, and Approach.”](#)

Authors: Lazano & Gronchi

[“Evolving Concepts in the Management of Desmoid Tumors.”](#)

Authors: Bonvalot, Miah & Kasper

[“Active Surveillance in Patients with Extra-abdominal Desmoid-Type Fibromatosis: A Pooled Analysis of Three Prospective Observational Studies.”](#)

Authors: Colombo, Hakkesteegt, Le Cesne, et. al

Access Publish Research Articles



Education, Advocacy and Awareness



DTRF Together We Will Weekend September 12-13, 2025

Chicago, Illinois was the ideal place to host the **DTRF Together We Will Weekend**. The event included a welcome reception for patients, clinicians and industry professionals, the **International Desmoid Tumor Research Workshop** featuring participants from around the world and across many disciplines, a community networking event and “Meet the Doctors” patient-doctor networking brunch, and the **Annual Patient Meeting**, our signature patient support event that includes educational lectures by leading clinicians, researchers, and other stakeholders.

All of the Weekend's content is curated with topics of interest to our patient, caregiver and medical community.

Patient Education

A key part of our mission is empowering patients in their journey by providing a variety of educational programs and opportunities for involvement.

Here are the 2025 Patient Meeting presentations:

The DTRF Annual Patient Meeting

Candace L. Haddox, MD, Physician, Dana-Farber Cancer Institute,
“Introduction to desmoid tumors & Understanding the mechanisms of spontaneous tumor regression.”

Bernd Kasper, MD, PhD, Professor, University of Heidelberg, Mannheim University Medical Center, Mannheim Cancer Center, Sarcoma Unit (Germany)
“Latest Edition of the Global Management Consensus from The Desmoid Tumor Working Group.”

Eldad Elnkave, MD, Interventional Radiology, Sha'are Tzedek Medical Center (Israel), “Treating Desmoid Tumors with Interventional Radiology: Histotripsy (High Intensity Focused Ultrasound or HiFU)/ Cryoablation/ Doxorubicin Eluting Embolization (DEE).”

The DTRF Annual Patient Meeting (cont.)

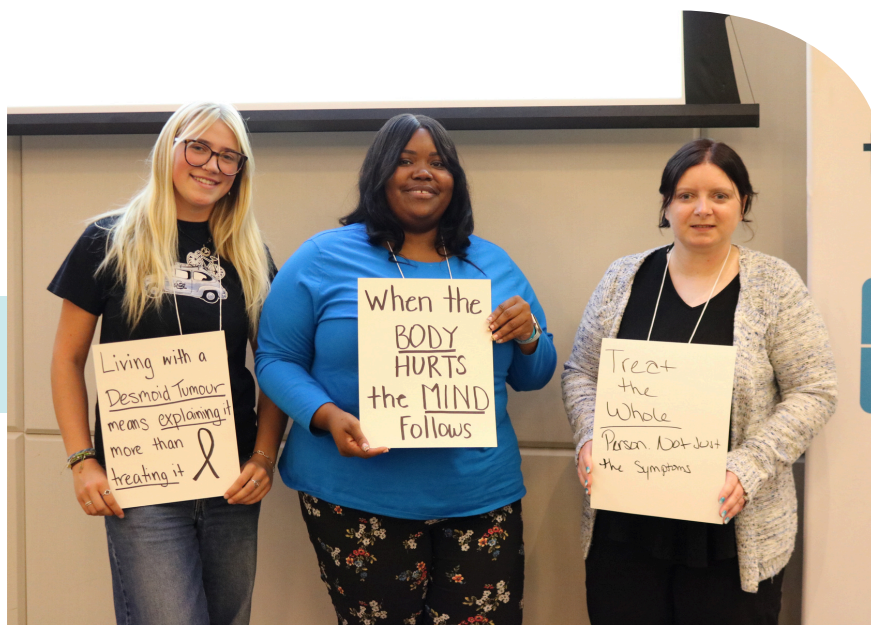
Jason Ortwerth, DTRF Board Member and Desmoid Tumor Patient, “We won’t stop until there is a cure.”

MaryEllen Pavone, MD, MSCI, Professor, Department of Obstetrics and Gynecology, Division of Reproductive Endocrinology and Infertility, Northwestern Medicine, “Fertility Preservation in Patients with Desmoid Tumors.”

Samman (Sam) Shahpar, MD, Associate Professor, Physical Medicine and Rehabilitation, Northwestern University Feinberg School of Medicine, Lead Physician, Cancer Rehabilitation Program, Shirley Ryan Ability Lab and Senior Residents, Drs. Lydia Henderson and Ryan Kelly, “Rehabilitation and Physiatry – A Functional Focus for Life.”

Bernd Kasper, MD, PhD, Professor, University of Heidelberg, Mannheim University Medical Center, Mannheim Cancer Center, Sarcoma Unit (Germany), “Long-Term Nirogacestat Treatment in Adult Patients With Desmoid Tumors: Updated Efficacy and Safety From the DeFi Trial.”

Shengfan (Sophia) Zhou, MS, Senior Manager of RWD Outcomes Research, SpringWorks Therapeutics, Inc., “The Financial Burden of Desmoid Tumors in Adult Patients: Desmoid Tumor Research Foundation Natural History Study.”



Patients create impactful messages together at the Community Networking Event during the DTRF Annual Patient Meeting in Chicago

The DTRF Annual Patient Meeting (cont.)

“How does a Multidisciplinary Tumor Board work?”

featuring Northwestern Medicine

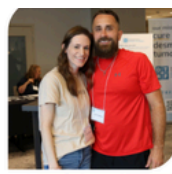
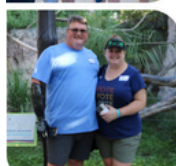
- **Seth Pollack, MD** (Medical oncology)
- **Pedro A. Hermida de Viveiros, MD** (Medical oncology)
- **Borislav Alexiev, MD** (Pathology)
- **Shishir K. Maithel, MD** (Surgical oncology)
- **Eldad Elnkave, MD** (Interventional radiology, Sha'are Zedek Medical Center, Israel)

Watch Annual Patient Meeting Videos



Patients and caregivers gather together at the DTRF Annual Patient Meeting in Chicago

A Brand New Awareness and Educational Campaign



In conjunction with Rare Disease Day, the [2025 DTRF Spread the Word Campaign](#) launched in early February. The DTRF witnessed a ripple effect of connection and conversation around the [WHO classification of desmoid tumors](#).

The medical community, research publications, and other sources often use differing terms when describing desmoid tumors; one of those terms is the word “benign.” Over the years, we’ve heard countless stories that this is confusing to patients as well as clinicians. This confusion can lead to misunderstandings about treatment and minimizes the potentially serious consequences of this rare disease.

The campaign messaging was amplified by generating more conversations with key stakeholders in the desmoid tumor community and the strategic landscape of this campaign evolved throughout the year. The scope of the campaign expanded as it built momentum within the patient, caregiver, and clinical target audiences.

Campaign Highlights:

- Watch the [Spread the Word Facebook Live](#) conversation with desmoid tumor patient, Amy Beitz.
- Watch the Spread the Word Webinar, [“Understanding the Classification of Desmoid Tumors.”](#)
- View and follow the campaign posts on [Facebook](#).

The Next Era of In-Person Patient Education Events

In collaboration with esteemed institutions and with the support of generous partners, the DTRF hosted two in-person patient education events entitled, *“Navigating Your Desmoid Tumor Diagnosis: A 1/2 day patient education and networking opportunity,”* in February and December of 2025.



On February 8th, desmoid patients, caregivers, and Penn Medicine clinicians gathered together at our recent patient education event presented by the DTRF in partnership with Penn Medicine.

Attendees enjoyed a half-day of presentations on a variety of desmoid tumor educational topics along with a patient panel that shared lived experiences related to their desmoid tumor journeys.

"It was so amazing connecting with people. I'm newly diagnosed, and I learned so much from just talking to other patients. It was really incredible, and I will absolutely participate in future sessions and try to get my caregiver to join as well."

- Anonymous Desmoid Tumor Patient Attendee

On December 6th, desmoid patients, caregivers, and the Stanford School of Medicine clinicians came together to learn, connect, and strengthen the bonds that move our mission forward.

The conversations, insights, and support exchanged in the room underscored the value of gathering face-to-face as a community. Two highlights from this special event were the Mock Tumor Board and the Q&A with a panel of clinicians.



Educational Webinars for Patients & Caregivers

Educational webinars are a vital part of DTRF's efforts to equip the patient and caregiver community with trusted knowledge that empowers informed decisions. By breaking down complex science and sharing real-world expertise, these webinars extend our impact by creating meaningful, everyday support for the desmoid tumor community, no matter where community members are located.

January

DTRF Desmoid Tumor Research Foundation

"REPRODUCTIVE CONSIDERATIONS FOR DESMOID TUMOR PATIENTS"
2025 LUNCH N' LEARN

SPONSORED BY: SpringWorks

Laurie J. MCKENZIE, MD
Associate Professor
MD Anderson Cancer Center
Oncofertility/Reproductive Endocrinology and Infertility/Gynecologic Oncology and Reproductive Medicine

During our first webinar of the year, our special guest, Laurie J. McKenzie, MD, Associate Professor at MD Anderson Cancer Center, presented information about reproductive considerations for desmoid tumor patients and closed with a Q&A.

May

DTRF Desmoid Tumor Research Foundation

"A NEW CLINICAL TRIAL FOR DESMOID TUMOR PATIENTS: FOG-001"
2025 EDUCATIONAL WEBINAR

SPONSORED BY: Parabilis MEDICINES

GREGORY COTE, MD, PHD
Physician at Massachusetts General Hospital and Associate Professor at Harvard Medical School

Special guest, Gregory Cote, MD, PhD focused on the challenges of developing drugs, the basics of clinical trials, and a new clinical trial for adults living with desmoid tumors: ["FOG-001 in Locally Advanced or Metastatic Solid Tumors"](#).

May

DTRF Desmoid Tumor Research Foundation

Spread the Word
DESMOID TUMORS ARE NOT BENIGN.
EDUCATIONAL WEBINAR

FEATURING SPECIAL GUESTS:

Ravin Ratan, MD
Associate Professor, Sarcoma, MD Anderson Cancer Center

DeAnn Sorenson
Administrator, The Desmoidian Facebook Group

Alexander Omeygyn, DSc
Desmoid Tumor Patient and Patient Advocate

During this virtual conversation, our special guests discussed the challenges in communication faced by both patients and doctors and what the desmoid community can do in the future to help alleviate misunderstandings about this rare disease.

October

DTRF Desmoid Tumor Research Foundation

"PREGNANCY AND DESMOID TUMORS"
2025 EDUCATIONAL WEBINAR

Featuring special guests:
From Dana-Farber Cancer Institute and The Brigham and Women's Hospital

Katherine E. Economy, MD

Elizabeth Sarah Ginsburg, MD

Chandrojit P. Rout, MD, M.Sc., FACS, FSSO

Suzanne George, MD

During our final webinar of 2025, our special guests from Dana-Farber Cancer Institute and The Brigham and Women's Hospital discussed the management of desmoids during pregnancy, the current literature around the topic, and their approach to treating desmoid tumors during pregnancy.

Watch Webinar Recordings

Facebook Lives with Desmoid Tumor Patients

Facebook Live events give patients a platform to openly share their stories, transforming personal experiences into collective strength for the desmoid tumor community. By elevating patient voices and real-time connection, these events deepen understanding, inspire resilience, and reinforce that no one faces desmoid alone.



AMY BEITZ
Desmoid Tumor Patient

2025 RARE DISEASE DAY
Spread the Word:
Facebook Live

Virtual Event Sponsor:
SpringWorks
THERAPEUTICS

DTRF Desmoid Tumor Research Foundation

February

Rare Disease Day



JASON ORTWERTH
Desmoid Tumor Patient
DTRF Board Member

2025 SARCOMA AWARENESS MONTH
"One Desmoid Tumor Patient's Journey"

Virtual Event Sponsor:
SpringWorks
THERAPEUTICS

DTRF Desmoid Tumor Research Foundation

July

Sarcoma Awareness Month



TIFFANUY BRASWELL
Desmoid Tumor Patient

2025 DESMOID TUMOR AWARENESS MONTH
"One Desmoid Tumor Patient's Journey"

Virtual Event Sponsor:
SpringWorks
THERAPEUTICS

DTRF Desmoid Tumor Research Foundation

September

Desmoid Tumor Awareness Month

[Explore Facebook Live Recordings](#)

[Click on each video tile to watch the Facebook Live recording.](#)

Desmoid Tumor Awareness Month (DTAM)

Every September, the DTRF and the global patient and caregiver community share stories and facts, and rally support to advance desmoid tumor research. Wherever you are, we encourage you to participate and help us raise **#DesmoidAwareness!**

In 2025, we launched our first-ever **DTAM logo design contest** with the help of our **DTRF Marketing Intern and desmoid patient, Sara Keller**. During the month of August, we collected submissions from desmoid patients and caregivers, and the winner was anonymously voted on by the DTRF Board of Directors and staff.

Desmoid tumor patient, Cassandra Hernandez, was our logo contest winner. Her artistic design (below) was chosen because it beautifully captures both the reality of desmoid tumors and the resilience of those who live with them.

We are grateful to Cassandra, and all of the patients and caregivers who took the time and energy to participate and share their stories during this special awareness month.



The butterfly bush reminded me of desmoid tumors. It grows deep and invades nearby spaces, but its beauty above ground symbolizes hope and resilience of the desmoid community.

This contest means a lot to me because it's about taking back my power and finding pride in the challenges I've faced. My wish is that every patient and caregiver finds a part of themselves that continues to bloom and show their beauty, even in the hardest times."

[Learn more about DTAM](#)

Advocacy & Awareness

2025 DTRF Ambassadors Program

The DTRF launched a new Ambassador Program in 2025 in order to find passionate volunteers to help support and strengthen the desmoid tumor community across the U.S.

As a DTRF Ambassador, volunteers use their experiences to offer empathy and guidance to patients and caregivers, share educational resources, and help connect their local community to the desmoid tumor resources they need.

Whether they are interested in peer support, medical outreach, or community-building, the DTRF guides each Ambassador to find a meaningful way to get involved.

Those interested in learning more about the Ambassador program are welcome to email us at info@dtrf.org.



Medical Education and CME Opportunities

The DTRF forms partnerships with entities that specialize in creating authorized Continuing Medical Education (CME) credit courses for medical professionals, providing the opportunity and incentive to increase their understanding of this rare tumor type and its treatment.

Here is a CME program that we featured throughout 2025:

Patient-Centric Frameworks in Desmoid Tumors: Integrating Emerging Science on Gamma-Secretase Inhibitors for Progressive Disease."

This CME program was developed in collaboration with Sarcoma Alliance for Research through Collaboration (SARC) and PeerView Institute and presented at the 2025 ASCO Annual Meeting with the purposes of:

- Advancing understanding of the latest guidance and evidence for using gamma-secretase inhibitors in patients with desmoid tumors
- Developing personalized treatment plans that include systemic treatment options for desmoid tumors using the latest data and practice guidelines
- Gaining comprehensive insights into the latest strategies for optimizing patient care, focusing on practical aspects such as dosing, scheduling, and adverse event management

[Explore CME Opportunities](#)



Fundraising

Community fundraisers are a powerful force for progress.

From small gatherings to large events, each one brings people together, raises critical support, and shows how meaningful impact can grow from shared moments of connection and creativity.

Beyond funding critical desmoid research, these efforts expand awareness of desmoid tumors to people who may never have encountered the disease before. For a rare disease, every new voice and every new supporter makes a difference.

There's no limit to how you can make an impact—and we're here to support you every step of the way.

Get Involved Today



The Desmoid Tumor Research Foundation depends on the generosity of donors to carry out its mission, and we value every dollar received.

DTRF is a 501(c)(3) tax-exempt organization and donations are tax deductible to the extent allowed by law.

Click on the buttons below to view the following DTRF documents:

[IRS 501\(c\)\(3\) Determination Letter](#)

[2025 Financials \(To be posted when available\)](#)

[2025 990 \(To be posted when available\)](#)

[Past Annual Reports](#)



Together We Will
LEARN.

Together We Will
COLLABORATE.

Together We Will
FUND A CURE.

DTRF Welcomes New Staff and Board Members!

In May, we welcomed **Pearlvernine Eslava** to the DTRF team as *Operations Manager*, strengthening the backbone of our day-to-day work. In November, **Katie Doyle Myers** joined us as *Incoming Executive Director*, marking an exciting new chapter for the Foundation. We are deeply grateful for their leadership, passion, and commitment to advancing our mission.

Throughout the year, we continued to expand our Board of Directors, by welcoming **John MacKinnon, Sally Augdahl, Christina Kosyla, Lisa Marie Gray, and Jason Ortwerth**. Each member brings valuable expertise and a shared dedication to DTRF's work, supporting our efforts in fundraising, financial stewardship, and long-term strategy. We are honored to have their partnership as we continue building momentum toward a future without desmoid tumors.

Leadership, Volunteers and Staff

LYNNE HERNANDEZ

Executive Director

KATIE DOYLE MYERS

Incoming Executive Director

JEANNE WHITING

Co-founder/Grant Advisor

DEBBIE NATHAN

Development Director

KELLY MERCIER, PhD

Principal Investigator, The DTRF Patient Registry & Natural History Study

AMANDA LUCAS

Associate & Registry Administrator, The DTRF Patient Registry & Natural History Study

MRINAL GOUNDER, MD

Scientific Director

CHANEY POPE

Communications Manager

PEARLVERNINE ESLAVA

Operations Manager

MANNESH KUMAR, PhD

Published Research Advisor

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Senior Director of Marketing, The Clorox Company

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Board of Directors, The Desmoid Tumor Research Foundation

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STEVEN WHITING

Financial Services Executive and Consultant

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Assistant Attending Surgeon, Memorial Sloan Kettering Cancer Center

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Department Chair, Orthopedic Surgery, Duke University

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Chief Science Officer, Break Through Cancer Principal Investigator, MIT and Broad Institute

MRINAL GOUNDER, MD

Associate Professor and Medical Oncologist, Memorial Sloan Kettering Cancer Center

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Chief of Sarcoma Service, Chair of the Department of Surgery, Fondazione IRCCS Istituto Nazionale dei Tumori (National Cancer Institute) Milan, Italy

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Director, Department of Pathology, The University of Texas - MD Anderson Cancer Center Selective (Soft Tissue) Pathology Fellowship Training Program

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PI of the DTRF Desmoid Tumor Patient Registry, adjunct associate professor at Duke University and Diagnostics Regional Medical Lead for Daiichi Sankyo

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Vice President, Patient Centered Endpoints, IQVIA

MATT VAN DE RIJN, MD, PhD

Professor, Department of Pathology, Stanford University Medical Center

Medical Advisory Board

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Assistant Professor, Medical Oncology, Department of Internal Medicine, University of Michigan Health System

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Consultant Medical Oncologist

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Professor of Surgical Oncology, University of Heidelberg

MRINAL GOUNDER, MD

Associate Professor and Medical Oncologist, Memorial Sloan Kettering Cancer Center

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Lynne Hernandez
Executive Director

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