



our mission:

**cure desmoid
tumors**

ANNUAL REPORT 2024





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A Note From Lynne Hernandez, DTRF Executive Director

Dear Friends,

I cannot believe how quickly 2024 flew by! In November 2023, I began in the executive director role, which coincided with the first FDA-approved treatment for adults living with progressing desmoid tumors and the CDC's approval of a new set of ICD-10 codes for this rare disease. These shifts sparked a new trajectory for the field: more interest, more questions, and more discernment in our focus as a Foundation. It has been remarkable to watch the landscape shifting around us, and to see how the needs of patients are changing. We are committed to being curious, and to meeting patients where they are.

We experienced so many highlights this year that I want to share with you. Thanks to the collaborative Desmoid Tumor Working Group, the medical community received a revision to the Global Consensus Paper on the Management of Desmoid Tumors. These treatment guidelines are the leading resource for anyone working with a desmoid tumor patient. Just as essential, lay guidelines for patients will follow.

The DTRF was featured at two international conferences this year. The DTRF Natural History Study's PI, Dr. Kelly Mercier, and Registry Administrator, Amanda Lucas, led the publication and presentation of two posters at the ESMO Rare Cancers Congress. I was invited as faculty to speak at the ASCO Annual Meeting's Sarcoma Track on leveraging the relationship between patients and doctors to improve patient outcomes. It's an honor to share our learnings with the broader clinical and research communities.

This year, we hosted three virtual educational webinars for the patient community on the following topics: biomarkers when treating desmoid tumors, cryoablation as a treatment option, and an alongside webinar for adolescents and young adults. We also hosted our biannual Roundtable for Desmoid Tumor Groups in May and December to convene all nonprofits and social groups supporting desmoid tumors to learn about each other's work.

On the research front, along with our multi-year grants, we also funded a planning grant to learn about spontaneous tumor regression, at the guidance of our Medical and Scientific Advisory Boards. Our hope in 2025 is to fund a larger, collaborative, multi-institutional grant to learn more about this phenomenon.

In 2024, we hosted our *Together We Will* Weekend in a different location for the first time ever. Houston was home for the Annual Patient Meeting and International Research Workshop, and we hosted our signature fundraiser, the RFA Walk, at the Houston Zoo. Along with the Walk, our team was blown away by third-party fundraisers popping up in so many different places this year. In fact, this year, we reached our year-end giving campaign goal - what a remarkable achievement for the community!

At the DTRF, we are committed to evolving to new heights as we continue to learn more about the science behind desmoid tumors and the needs of the patient community. We are excited to continue partnering with those invested in solutions for patients who are still suffering and newly diagnosed.

Our team is humbled by your generosity and support this past year. **Our work is your work.** Together, we will continue working together to give real hope to the desmoid tumor patient community.

Looking forward,

Lynne Hernandez
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 Patient Meeting, we hold the annual 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 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.

Revised Global Consensus Paper

A revision to the [Global Consensus Paper on desmoid tumor management](#) has been published thanks to the hard work and collaboration of an international group of physicians, scientists, and patient advocates (collectively known as "The Desmoid Tumor Working Group"). Peter Hohenberger, MD, PhD, Bernd Kasper, MD, PhD, and Alessandro Gronchi, MD, also DTRF Advisory Board members, led the group on this project.

Essentially treatment guidelines, this paper answers critical questions regarding the approach to treatment recommendations, types of treatments, and pain management.

As there are varying treatments used for desmoid tumors and access to medical therapies, and information greatly varies by country, many patients are treated based on the experience and expertise of a single physician which may be limited. To address this, the DTRF supported the revision of this collaborative paper. The paper is, in part, the result of a 2023 DTRF grant, entitled [“An evidence-based 2nd consensus on the treatment for desmoid tumors.”](#)

Until mid-2025, the paper will only be accessible with a subscription through JAMA Oncology. After that, a full version will be publicly available. Patient guidelines are being developed and we're hopeful they will be published in 2025.

Building Community

Throughout 2024, patients, caregivers, and supporters around the world led the way with do-it-yourself fundraising benefitting the DTRF's mission. Their efforts raised crucial funds to support desmoid tumor research, raise awareness, and advocate for desmoid tumor patients.



DTRF Virtual Tumor Board

Led by Dr. Aaron Weiss, 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 2024, four boards were convened with 3-4 cases presented at each.

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 help us better understand 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.

DTRF's Partnership with Pattern.org for Tissue Donation

Since surgeries in desmoid tumors have become less frequent, there is 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, and institutions like the Koch Institute at MIT, DTRF facilitates the collection of tissue samples via a simple online consent process. Before surgery, patients can consent at Pattern.org to a collection of a portion of excess tumor tissue that is then sent to researchers.



The DTRF is committed to supporting the development of new treatments - and new treatment protocols - for the desmoid tumor patient community. These clinical trials were launched in 2023/2024.

[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.
- Patients must have United States medical insurance and have the ability to travel to Stanford monthly for treatment. All patients must also have their MRIs evaluated by Stanford interventional radiologists to determine if they are suitable for trial enrollment.

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

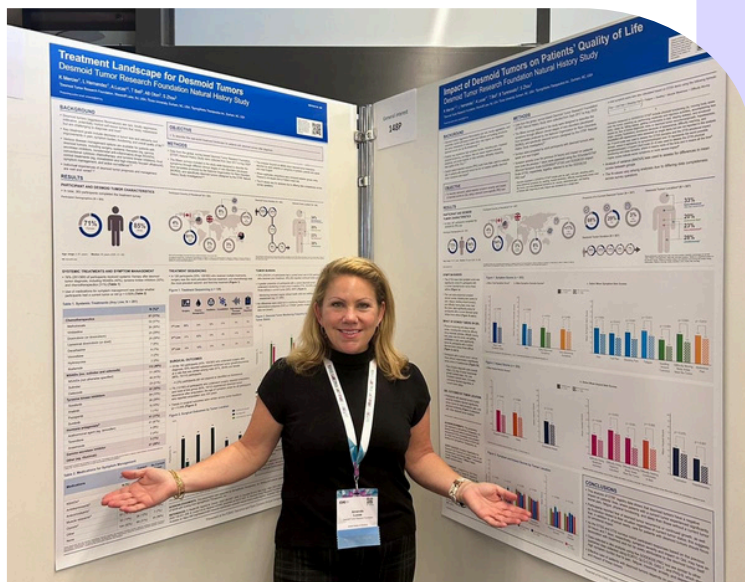
- Phase 1/2 of this basket trial will determine if FOG-001 is safe and effective in participants with locally advanced or metastatic solid tumors. Desmoid tumors are included.
- This trial is currently recruiting patients in Arizona, Connecticut, Massachusetts, Missouri, New York, Oregon, Tennessee and Texas.

See other ongoing trials, which include desmoid tumors, at [ClinicalTrials.gov](https://clinicaltrials.gov).



Conferences Featuring Desmoid Tumors

DTRF Natural History Study Featured at 2024 ESMO Sarcoma and Rare Cancers Congress



The DTRF was honored to present two posters in Lugano, Switzerland on Friday, March 15th.

Amanda Lucas, Registry Administrator of The DTRF Patient Registry & Natural History Study, presented posters entitled "Impact of Desmoid Tumors on Patients' Quality of Life: Desmoid Tumor Research Foundation Natural History Study" and "Treatment Landscape for Desmoid Tumors: Desmoid Tumor Research Foundation Natural History Study."

Led by the DTRF Natural History Study Principal Investigator, Dr. Kelly Mercier, these two projects were conducted in collaboration with SpringWorks Therapeutics.

Desmoid tumors were the subject of several posters, presentations, and abstracts during ESMO. Below we've listed a few.

Selected Sample of 2024 ESMO Desmoid Research Topics:

Treatment Landscape for Desmoid Tumors: Desmoid Tumor Research Foundation Natural History Study

Kelly Mercier, PhD, Duke University, Durham, NC, et. al.

Poster: https://dtrf.org/wp-content/uploads/2024/03/Treatment_ESMO-DTRF-DXTX-Poster.pdf

"The Patient Voices: Revealing the Challenges Faced by Persons with Desmoid Tumors in a Middle-Income Country"

Carolina Maria de Menezes Chaves, Desmoid Tumor Brazilian Association

Desmoide Brasil, São Paulo, SP, Brazil, et. al.

Poster: https://dtrf.org/wp-content/uploads/2024/04/BANNER_Brazil.pdf

Impact of Nirogacestat on Patient-Reported Outcomes in Adults with Desmoid Tumor with a Best Overall Response of Stable Disease: Post Hoc Analysis from The DeFi Study

Sylvia Stacchiotti, MD, Fondazione IRCCS Istituto Nazionale dei Tumori, et. al.

Presentation: https://dtrf.org/wp-content/uploads/2024/03/2024_Stacchiotti_ESMO-conference-Lugano-Desmoidi-Nirogacestat-DeFI_SD_PRO_MiniOral_FINAL-1.pdf

Desmoid tumors and the DTRF made the spotlight at the 2024 Annual Meeting for the American Society of Clinical Oncology (ASCO) in Chicago. DTRF Executive Director Lynne Hernandez served as a faculty member this year at an educational session entitled “Leveraging Successful Partnerships to Improve Global Health Outcomes.”

Her talk focused on the critical role of patient advocacy organizations in building relationships between patients and physicians. The Foundation is grateful to our community of stakeholders—especially patients and doctors—for trusting us to serve as advocates in the space.

We thank ASCO, along with session chair Dr. Matias Chacon from IAF (Instituto Alexander Fleming) and SELNET and Denisse Evans from The Life Raft Group for their collaboration on this important session.

DTRF Presents at ASCO Annual Meeting



Desmoid tumors were the subject of several posters, presentations, and abstracts during the Sarcoma Track of ASCO 2024. Below we've listed a few.

Selected Sample of 2024 ASCO Desmoid Research Topics:

A phase II basket trial of dual anti-CTLA-4 and anti-PD-1 blockade in rare tumors (DART) SWOG S1609: The desmoid tumors (cohort 27).

Young Kwang Chae, Northwestern University, Chicago, IL, et. al.

Abstract: <https://meetings.asco.org/abstracts-presentations/220010>

Impact of pregnancy in women with desmoid fibromatosis: An international retrospective observational study.

Marco Fiore, MD, FACS, Sarcoma Service, Fondazione IRCCS Istituto Nazionale dei Tumori, et. al.

Abstract: <https://meetings.asco.org/abstracts-presentations/218386>

**Famitinib for familial adenomatous polyposis-associated aggressive desmoid tumors:
A single-center exploratory study.**

Sai Ge, Department of Gastrointestinal Oncology, Key laboratory of Carcinogenesis and Translational Research (Ministry of Education), Peking University Cancer Hospital & Institute, Beijing, China, et. al.

Abstract: <https://meetings.asco.org/abstracts-presentations/218434>

DTRF Attends CTOS Annual Meeting

In mid-November, CTOS hosted their Annual Meeting in San Diego. Lynne Hernandez, DTRF Executive Director, represented the Foundation at this special event, where she connected with the leadership of other patient advocacy groups, pharmaceutical companies working with desmoid tumors, clinicians treating our patients, and researchers publishing in the space.

The DTRF is so grateful to be part of a collaborative effort driving improved outcomes for the patient community.



Desmoid tumors were the subject of several posters, presentations, and abstracts during CTOS. Below we've listed a few.

Selected Sample of 2024 CTOS Desmoid Research Topics:

Multi-omic and Multi-region profiling of desmoid tumors reveals intra- and inter-tumor heterogeneity

Chelsea De Bellis, Department of Surgery, McGill University, Montreal, QC, Canada

Poster: https://dtrf.org/wp-content/uploads/2024/11/CTOS_2024_3.pdf

Nirogacestat Treatment in Adult Patients with Desmoid Tumors: Long-Term Efficacy and Safety From the Phase 3 DeFi Trial

Ravin Ratan, MD, MEd, University of Texas, MD Anderson Cancer Center, Department of Sarcoma Medical Oncology, Division of Cancer Medicine, Houston, TX, USA, et. al.

Presentation: https://dtrf.org/wp-content/uploads/2024/11/Ratan-CTOS-2024-DeFi-Landmark-Oral_FINAL.pdf

Pegylated liposomal doxorubicin in symptomatic desmoid tumor

Kjetil Boye, Department of Oncology, Oslo University Hospital, Oslo, Norway, et. al.

Poster: https://dtrf.org/wp-content/uploads/2024/11/CTOS_2024_6.pdf

Utilization of Mental Health and Supportive Care Resources Among Patients with Desmoid Tumors

Victoria Wytiaz, MD, University of Michigan, Department of Oncology, et. al.

Poster: https://dtrf.org/wp-content/uploads/2024/11/CTOS_2024_1.pdf

[View External Conferences Posters and Abstracts](#)

2024 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 2024:

- **Mushriq Al-Jazrawe, PhD**, Koch Institute for Integrative Cancer Research at MIT, *“Concurrent genotyping and transcriptomics of Desmoid Tumor single cells and nuclei to study spontaneous regression and therapeutic vulnerability.”*
- **Cristabelle DeSouza, PhD**, Stanford University, *“Activation of c-JUN modulates the transcriptional activity of CD63 serving as a novel target for the treatment of Desmoid Type Fibromatosis.”* Year 3 of 3.
- **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 2 of 3.

Click the button below to learn more about these important research projects:

DTRF-Funded Grants



Research Events and Initiatives

DTRF International Research Workshop

The annual International Desmoid Tumor Research Workshop was held in Houston, TX on Friday, September 20th, in conjunction with our 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.

List of Institution & Industry Represented at the Workshop:

FOG Pharma
SpringWorks Therapeutics
Immunome
Eversana
Johns Hopkins Hospital
Children's Hospital Los Angeles
Institute of Health
Edinburgh Cancer Centre
Koch Institute of MIT
Mayo Clinic
Moffit Cancer Center
University of Michigan
Stanford University
Shaare Tzedek Medical Center
Fondazione IRCCS Istituto Nazionale dei Tumori
Institute of Cancer Research
Mannheim University Medical Center
Nagoya University Hospital
Northwestern University
McGill University
Dana-Farber Cancer Institute
Cleveland Clinic
Erasmus Medical Center
All India Institute of Medical Sciences
The University of Texas MD Anderson Cancer Center
Maine Medical Center
Duke University

[Watch Workshop Videos](#)



"This was my first DTRF [Research Workshop] and I was extremely impressed by the content and the enthusiasm of everyone there."

RESEARCH WORKSHOP ATTENDEE

2024 Research Workshop Presentations

Ben Alman, MD, Department Chair, Orthopedic Surgery, Duke University

"Cellular heterogeneity."

Chiara Colombo, MD, Surgical Oncology, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano (Italy)

"Spontaneous regression in desmoid tumors."

Yoshihiro Nishida, MD, Department of Rehabilitation Medicine, Orthopaedic Surgery, Nagoya University Hospital (Japan)

"Efficacy and safety of auranofin for progressive desmoid-type fibromatosis: an open-label phase II trial."

Cristabelle De Souza, PhD, Instructor, Stanford University

"Multiomic profiling uncovers integral immune molecules that drive the pathogenic fibroblast milieu in desmoid tumors."

Chiara Colombo, MD, Surgical Oncology, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano (Italy)

"Immune modulation."

Jesse Boehm, PhD, Principal Investigator, Koch Institute, MIT

"Update on Progress Towards Creating a Prototype Desmoid Tumor Dependency Map."

Nirogacestat (Ogsiveo™) Presentations

Ravin Ratan, MD, Medical Oncologist, MD Anderson Cancer Center

- *"Impact of Pain on Physical and Role Functioning in Adult Patients with Desmoid Tumors Treated with Nirogacestat."*
- *"Impact of nirogacestat on patient-reported outcomes in adults with desmoid tumor with a best overall response of stable disease: post hoc analysis from the DeFi study." (Encore of ESMO Sarcoma 2024 mini-oral presentation)*

Bernd Kasper, MD, PhD, Professor, University of Heidelberg, Mannheim University Medical Center, Mannheim Cancer Center, Sarcoma Unit (Germany)

"Efficacy of nirogacestat in patients with poor prognostic factors for desmoid tumors: Analyses from the randomized phase 3 DeFi study." (Encore of ASCO 2024 poster)



Duke University's Dr. Alman sparks discussion during DTRF Research Workshop in Houston, TX

2024 Research Workshop Presentations (cont.)

Joanna Przybyl, PhD, Assistant Professor, and **Richard Miallot, PhD**, Postdoctoral Research Fellow, McGill University (Canada)

"Therapeutic targeting of the hexosamine biosynthesis pathway in desmoid tumors."

Amanda Lucas, Registry Administrator, The DTRF Patient Registry & Natural History Study, Desmoid Tumor Research Foundation

"DTRF Natural History Study Updates."

David Liska, MD, MA, FACS, FASCRS, Chair, Department of Colorectal Surgery, Sanford R. Weiss Center for Hereditary Colorectal Neoplasia, Digestive Disease Institute, Cleveland Clinic

"The Role of Surgery in FAP associated Desmoid Disease: From Prevention to Intestinal Transplant."

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."

Eldad Elnekave, MD, Interventional Radiologist, Sha'are Tzedek Medical Center (Israel), *"Trans-arterial Doxorubicin Eluting Embolotherapy for Desmoids: a prospective, multicenter study design."*

Stefanie Hakkesteegt, MD, PhD candidate, Erasmus University Medical Center Rotterdam (Netherlands) *"Magnetic resonance image-guided high intensity focused ultrasound for patients with desmoid-type fibromatosis: the MAGNIFIED trial."*

Watch Workshop Videos



Researchers, clinicians, and industry professionals at
DTRF Research Workshop in Houston, TX

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.

View one article of note below. This project was supported by multi-year grants from the DTRF and Desmoid Tumour Foundation of Canada (DFC):

[“Genomic, epigenomic and transcriptomic inter- and intra-tumor heterogeneity in desmoid tumors”](#)
by Joanna Przybyl, Chelsea De Bellis, Sujay Vennam, et al.

Access Publish Research Articles



Education, Advocacy and Awareness



DTRF Together We Will Weekend

Sept 20th - 22nd

Houston, Texas was the perfect place to host the **DTRF Together We Will Weekend**. The event included a welcome reception for patients, clinicians and industry professionals; a patient networking event and “Meet the Doctors” patient-doctor networking brunch; the DTRF International Research Workshop featuring participants from around the world and across many disciplines; and the DTRF Patient Meeting, our signature patient support event that includes educational lectures by leading clinicians, researchers, and other stakeholders. Content is geared toward 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 2024 highlights in this area:

The DTRF Annual Patient Meeting

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

“Reproductive/ Fertility Considerations: Important things to know.”

Thierry Alcindor, MD, MSc, Senior Physician, Sarcoma Center, Dana-Farber Cancer Institute, Brigham and Women's Hospital, Harvard Medical School

“Learning in the basics: Desmoid Tumors 101.”

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’.”

The DTRF Annual Patient Meeting (cont.)

Kelly Mercier, PhD, Principal Investigator, The DTRF Patient Registry & Natural History Study, Desmoid Tumor Research Foundation

“An Update on the DTRF Natural History Study- September 2024.”

Chiara Colombo, MD, Surgical Oncology, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano (Italy)

“Active Surveillance: An accepted first-line treatment in most desmoid tumor cases.”

Ravin Ratan, MD, Medical Oncologist, MD Anderson Cancer Center

“Impact of pain on physical and role functioning in adult patients with desmoid tumors treated with nirogacestat/ Impact of nirogacestat on patient-reported outcomes in adults with desmoid tumor with a best overall response of stable disease: post hoc analysis from the DeFi study.”

Andrea Vanzulli, MD, Diagnostic and Interventional Radiology, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano (Italy)

“Cryoablation as a desmoid tumor treatment option.”

Megan Barrell on her Desmoid Tumor Journey

Aaron Weiss, DO, Associate Professor, Department of Pediatrics, Division Chief, Pediatric Hematology-Oncology, Maine Medical Center

“Short and long term side effect considerations of current therapies in the pediatric population.”



Patients, caregivers and clinicians gather together at the DTRF Annual Patient Meeting in Houston

The DTRF Annual Patient Meeting (cont.)

DTRF Multi-Disciplinary Mock Tumor Board featuring MD Anderson Cancer Center

Ravin Ratan, MD (Medical Oncology)
Emily Keung, MD, FACS (Surgical Oncology)
Raul Valenzuela, MD (Radiology)
Ahsan Farooqi, MD (Radiation Oncology)
Eldad Elnekave, MD (Interventional Radiology) Sha'are Tzedek Medical Center, Israel

Survivorship with a focus on AYA (Adolescents and Young Adults)

Panel: “What happens next?” featuring MD Anderson Cancer Center

Haleigh Mistry, PA-C, Physician Assistant
Heather M DeRousse, LCSW, OSW-C, Adolescent and Young Adult Vocational Counselor
Jessica Blanc, LCSW, Social Work Counselor, Adolescent and Young Adult (AYA) Clinic

[Watch Annual Patient Meeting Videos](#)



Patients and caregivers gather together at the annual DTRF Patient Meeting

Webinars and Facebook Lives for Patients & Caregivers

"**Times Are A-Changin': Heading into Young Adulthood with a Desmoid Tumor**" was a two-part webinar series led by Dakota Fisher-Vance, a patient advocate and young adult living with a desmoid tumor. In part one, attendees learned tips and tricks for navigating the unique challenges and milestones young adults face like dating, moving out, and starting a career while taking ownership over your medical care. Part two was a special "Speed Desmoidian-ing" virtual networking event just for young adults with desmoid tumors.

In October, we hosted an educational webinar on **Cryoablation** with special guests, Jean-Emmanuel Kurtz, MD, PhD, Professor of Medical Oncology, Strasbourg University- Hôpitaux Universitaires de Strasbourg in France will discuss how cryoablation is performed and how it works. Dr. Kurtz covered what we do and don't know about this targeted treatment option for desmoid tumors. Bernd Kasper, MD, PhD, Professor at the University of Heidelberg, Mannheim University Medical Center in Germany, discussed systemic treatments.

Desmoid Tumor Awareness Month

During Desmoid Tumor Awareness Month (DTAM), we featured three virtual events. Our first event was an educational webinar entitled "**Biomarkers: Predicting tumor behavior and choosing therapies,**" with Dr. Dale Shepard, Medical Oncologist at the Cleveland Clinic.

Our second virtual event was a Facebook Live entitled, "**One Desmoid Tumor Patient's Journey,**" featuring Megan Barrell, where she shared her perspective as an adolescent and young adult (AYA) desmoid patient.

Our third virtual event was another Facebook Live entitled, "**One Desmoid Tumor Caregiver's Journey,**" with Amanda MacKinnon. Featured was Amanda's personal experience as a mom of an adolescent desmoid tumor patient.

Watch Webinar Recordings

Watch Facebook Live Recordings



DTRF Desmoid Tumor Research Foundation

BERND KASPER, MD, PHD
Professor, University of Heidelberg,
Mannheim University Medical Center

JEAN-EMMANUEL KURTZ, MD, PHD
Professor of Medical Oncology from Strasbourg
University- Hôpitaux Universitaires de Strasbourg

CRYOABLATION:
"What We Do and Don't Know"
2024 PATIENT EDUCATION WEBINAR



September is
DESMOID TUMOR awareness month
DTAM 2024

"One Desmoid Tumor Patient's Journey"
2024 DTAM FACEBOOK LIVE

Virtual Event Sponsor: Recursion

MEGAN BARRELL
Desmoid Tumor Patient

Advocacy & Awareness

2024 Patient Advocacy Committee

To continue having the DTRF's work informed by the patient voice, the DTRF Patient Advocacy Committee (PAC) was formed to include patient and caregiver voices and encourage direct collaboration with the Foundation. PAC members work with The DTRF in the following areas according to their interest:

- Connecting the patient voice in ad-hoc requests to engage with industry groups
- Guiding The DTRF on the needs of patients and caregivers by providing insights on their journeys from the patient and caregiver perspective
- Assisting with fundraising
- Shaping and expanding patient and caregiver engagement
- Advising on topics of interest for patient meetings and networking events



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 are two CME programs that we featured throughout 2024:

CME for new Desmoid Tumor ICD-10-CM Diagnosis Codes

DTRF partnered with PeerView on a CME event for the new ICD-10-CM Diagnostic Codes for Desmoid Tumors which includes learning how to implement these codes into clinical practice and understanding their implications for patient care and research. Featuring Mrinal Gounder, MD, and Linda Holtzman, MHA, RHIA, CCS, CCS-P, CPC, COC, this program was developed together with our partner, PeerView Institute for Medical Education.

PlatformQ CME

DTRF partnered with PlatformQ Health on this CME program on relevant strategies to address timely diagnosis in patients with Desmoid Tumors. In this free CME, Mrinal Gounder, MD, and a panel of experts discuss the best strategies to improve timely diagnoses of patients. They review the recent shift away from extensive surgery to active surveillance and explore emerging treatments that have demonstrated promising results for patients with progressive disease. Panelists also discuss the need for multidisciplinary review to determine if treatment is warranted and examine which patients are eligible for treatment with emerging options.



We are here to support your fundraisers both big and small. Fundraising is easy when you're having a good time!

Community fundraisers make a big impact, not just by the donations they generate, but by spreading awareness to people unaffected by the disease. Desmoid tumors are a rare disease, so every person we reach outside of the desmoid community makes a difference.

For more information about fundraising for DTRF, visit our website. There is no limit to the creative ways you can make an impact on desmoid research.

We're always here to help and support you.

RFA (Running for Answers) 5K Walk

The first-ever RFA Walk (formerly RFA 5K and Fun Run) was a big success at the Houston Zoo and virtually by supporters around the world. Attendees enjoyed a beautiful morning at the zoo (the bald eagles were a hit!) while following the walk route with fellow patients, caregivers, and DTRF supporters.



We wrapped up the walk with a patient and caregiver networking session to help participants connect and share stories

The RFA community raised more than \$63,000 for desmoid tumor research.



Scenes from the 2024 RFA Walk at the Houston Zoo

Faith Over Fear Community Events

Many thanks to desmoid warrior Gabe Augdahl and his family for hosting two extraordinary fundraisers to benefit the DTRF in 2024. The Augdahls organized the 2nd Annual Faith Over Fear basketball game in February raising over \$8,000.

Due to the success of the basketball game, the Augdahls decided to organize a Golf for a Cure, golf tournament benefiting the DTRF in September. The golf tournament raised over \$20,000 for desmoid tumor research!

DTRF is profoundly grateful for their efforts to spread awareness about this rare disease.



Gabe Augdahl's high school supported him and DTRF at the Faith Over Fear fundraiser



Gabe's community gathered together again in September for the first-ever Golf for a Cure fundraiser

JoeStrong Volleyball Tourney

Joe Erickson, supported by his family and friends, held the 8th Annual JoeStrong Volleyball Tournament in Austin, TX. This fun DIY fundraising event raised over \$6,500 for desmoid tumor research!

We are so grateful for the Ericksons' fundraising efforts. Thank you to everyone who came out to spread awareness and support our the DTRF's mission!



Several JoeStrong Tourney participants pose for a team photo at the event

Swing for a Cure - St. Louis

On the day after Jason Ortwerth's first daughter was born, he was diagnosed with a large abdominal desmoid tumor. Ever since his diagnosis, he and his wife have hosted an annual golf tournament to fund a cure for desmoid tumors.

At the end of September, the 6th Annual Swing for a Cure golf tournament in St. Louis raised \$24,000 to support the DTRF's mission. We are incredibly grateful to the Ortwerth family and their community for their yearly support and generosity at this special event.



Swing For a Cure attendees enjoy a round of golf at this annual event

Strings of Hope

In September, Lisa Gray gathered friends, family, and community members in Michigan to raise over \$5,000 at the first-ever Strings of Hope fundraiser to support the DTRF's mission.

We are thankful for this beautiful musical event and the generosity of Lisa's community!



Attendees listen to musical guests at Strings of Hope

WMK Lacrosse Classic

In early May 2024, William, a desmoid tumor patient advocate, was joined by his parents, family, and friends for the 1st Annual WMK Classic fundraiser benefiting the DTRF.

The 3-on-3 small ball, lacrosse tournament raised over \$14,000 to support the DTRF's mission to CURE desmoid tumors! The DTRF is honored and grateful for everyone who supported William and made this fun event a huge success.



Lacrosse players surround William in support of the DTRF's mission

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](#)

[2024 Financials \(To be posted when available\)](#)

[2024 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!

Early this year, DTRF proudly welcomed Chaney Pope as our new Communications Manager. She brings an arsenal of experience from her Master's in Public Health, to professional photography and videography background. Chaney has a wealth of experience with nonprofits and is passionate about service. She is eager to support our mission to serve the patient community.

Throughout the year, we continued to expand our board, by adding three new board members. Tom Allen, DJ Conner and Yating Wong, all invested in the DTRF's mission by stepping onto the board to aid us in fundraising, finance and strategy. We are honored to have them join us.

Leadership, Volunteers and Staff

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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

SHANNON SHOOP

Operations Manager

MANNESH KUMAR, PhD

Published Research Advisor

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Co-Founder, DTRF

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