

our mission:

cure desmoid tumors

ANNUAL REPORT 2023



Desmoid
Tumor
Research
Foundation

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2023 REFLECTIONS FROM JEANNE WHITING

Retiring Executive Director and the DTRF's Co-Founder

As a co-founder of The Desmoid Tumor Research Foundation, it is with very poignant emotions that I announce my retirement at the end of 2023. This foundation has been a life's work of passion and purpose for me. I'd like to take this occasion to reflect on DTRF's journey and accomplishments over the past 18 years.

When I was diagnosed with a retroperitoneal desmoid tumor over 20 years ago, there were no established treatment protocols, few existing treatments that were only sporadically effective, and very little research on these tumors. Under those circumstances, dealing with this rare disease was a terrifying prospect that led me and my co-founder, Marlene Portnoy, to start DTRF in 2005 with the goals of funding research and supporting patients and doctors with information.

How positively moving and inspirational it is to know that this year, in 2023, we obtained FDA approval of Osgiveo (nirogacestat) for the treatment of adults with progressing desmoid tumors. Having the first drug approved for this rare disease is a milestone worthy of cheers and celebration! It is a breakthrough that we could only have dreamed of when we started the DTRF!

We've seen great progress in awareness as well. The recognition of desmoid tumors as an important focus of research was made clear as desmoid tumors were highlighted as "Sarcoma of the Year" at the 2022 Connective Tissue Oncology Society conference. Awareness was also expanded when the DTRF was honored with two prestigious awards for leadership and advocacy in 2021 by the National Organization of Rare Disorders (NORD) and Global Genes.

I am thrilled with all of the milestones we've achieved to date as we have advanced research and expanded education and support for patients and medical professionals. Breakthroughs have included: the DTRF's annual International Research Workshops and Patient Meetings, the Global Consensus Paper and Virtual Tumor Board that help doctors and patients around the world, the development of publicly available desmoid cell lines and other models for research, the Patient Reported Outcomes (PRO) tool to reflect the patient's voice in clinical trials, the Patient Registry and Natural History Study, the approval of new ICD-10-CM diagnosis codes specific to desmoid tumors, and others too numerous to name.

I extend deep appreciation to our DTRF staff and Board of Directors, and all who have helped DTRF in our almost two decades of work. Our Medical and Scientific Advisory Boards are supportive at every turn. Industry colleagues and researchers have collaborated with us in bringing about new clinical trials toward new treatments. Donors and fundraisers have helped us fund over \$5,000,000 in research grants through the years.

After more than 18 years with the DTRF, I moved to emeritus status as of Nov 1, 2023, passing the Executive Director title and baton to Lynne Hernandez. I am excited for Lynne, who has worked with the Foundation for almost a decade as our Operations Director. A heartfelt dedication to the people of the desmoid tumor community is felt in every interaction with Lynne. We can think of no better person to be at the helm for the exciting things to come.

The future of the DTRF is extremely bright, and the possibilities for better outcomes for our patients have never been greater. Retirement will be the end of a very fulfilling era for me, but only the beginning of accelerated progress for the DTRF as we continue the undaunted quest for a cure for each and every desmoid tumor patient.

With deep gratitude to all, and unwavering hope for the future,

Jeanne Whiting

Co-founder and Executive Director Emeritus



NOTE FROM LYNNE HERNANDEZ

DTRF's New Executive Director

Since 2012, I have been humbled and inspired by the DTRF's work and the fearless resolve that has fueled our small, mighty team. I am deeply honored by this new opportunity, and I am excited to continue working with our partners to prioritize hope and progress for desmoid tumor patients everywhere.

Thank you for your interest in our accomplishments, and we invite you to support us by making a gift at dtrf.org. It's support like yours that makes our work possible.

We are excited for continued momentum in 2024!

A handwritten signature in black ink, appearing to read 'Lynne Hernandez'.

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.

OGSIVEO (nirogacestat) Approved!

The U.S. Food and Drug Administration (FDA) has approved OGSIVEO™ (nirogacestat) for the treatment of adults with progressing desmoid tumors!

Below is the DTRF press release with the details:

(Pittsburgh, PA) – November 27, 2023 – The U.S. Food and Drug Administration (FDA) announced approval today of OGSIVEO (nirogacestat) for the treatment of adults with progressing desmoid tumors. This is the first FDA-approved medical therapy for this rare disease. FDA approval follows positive results from the [SpringWorks Therapeutics, Inc.](#) (Nasdaq: SWTX) DeFi (NCT03785964) Phase 3 clinical trial, a global, randomized, double-blind, placebo-controlled trial evaluating nirogacestat in adult patients with desmoid tumors. Results from the DeFi trial were published on March 9, 2023, in The New England Journal of Medicine in the article, "[Nirogacesat, a \$\gamma\$ -Secretase Inhibitor for Desmoid Tumors](#)," by Drs. Gounder, Ratan, Kummar, Kasper et al.

OGSIVEO (nirogacestat) is an oral gamma secretase inhibitor. For more information, visit www.ogsiveo.com.

The collaborative path to approval

The Desmoid Tumor Research Foundation (DTRF) has been instrumental in the nearly 15-year path to approval of OGSIVEO (nirogacestat). The drug was first studied in patients with a range of solid tumors including seven desmoid tumor patients. A poster presentation of the promising results of this early work in desmoid tumors caught the eye of members of the National Cancer Institute's (NCI) Rare Tumors Initiative, Shivaani Kummar, MD, and Abby Sandler, PhD. The pair were interested in a phase 2 trial, but due to the rare nature of the disease, concluded that to be successful they needed the support of a patient advocacy organization. A synergistic collaboration between the DTRF and NCI brought the phase 2 trial forward, and with the DTRF's outreach efforts, filled it in less than five months.

Despite promising results that were coming out of the phase 2 study, a business decision resulted in halting the development of the asset. Determined not to let this potential treatment stall, the DTRF once again galvanized its resources and continued discussions with Pfizer staff. Supportive clinicians, as well as encouraging staff at Pfizer, supported the effort to move the drug forward. Eventually, SpringWorks Therapeutics was created to license nirogacestat and other assets that showed potential in underserved patient populations.

Under newly-formed SpringWorks, the phase 3 DeFi trial for nirogacestat opened. During the conduct of the DeFi trial, and with the help of DTRF's patient outreach, the trial was fully enrolled in July 2020. In September 2022, trial data were presented in a Presidential Symposium during the ESMO Congress and at the annual DTRF International Desmoid Tumor Research Workshop. In December 2022, SpringWorks filed a New Drug Application for nirogacestat which was accepted for Priority Review on February 27, 2023. Today, FDA approval of OGSIVEO (nirogacestat), makes it the first FDA-approved drug for the treatment of adults with desmoid tumors.



“The significance of FDA approval of OGSIVEO (nirogacestat) to desmoid tumor patients cannot be overstated. This is an extraordinary victory in the area of rare diseases, and demonstrates the power of collaboration among patients, industry and researchers.”

Jeanne Whiting, Executive Director Emeritus, Desmoid Tumor Research Foundation

The DTRF congratulates SpringWorks Therapeutics on this breakthrough drug approval and extends our deepest gratitude to everyone involved. Desmoid tumor patients, researchers, clinicians, the team at SpringWorks, and the DTRF all collaborated on this benchmark example of bringing a drug to an underserved patient population.

An approval like this opens the door for continued research and interest in desmoid tumors. The DTRF will continue to aggressively fund research and collaborate with industry to accelerate the development of additional therapies toward a cure for each and every desmoid tumor patient.

The FDA and SpringWorks Therapeutics have also issued separate press releases about this important drug approval. Read more at these links:

[FDA Press Release](#)

[SpringWorks Therapeutics Press Release](#)



“SpringWorks is grateful to the Desmoid Tumor Research Foundation, as well as the patients and investigators who participated in our trials, whose enduring commitment and enthusiasm helped us get to this point. We are honored to provide the first FDA-approved therapy and committed to offering ongoing support to the desmoid tumor community throughout their treatment journey on OGSIVEO.”

Saqib Islam, Chief Executive Officer, SpringWorks Therapeutics

Featured in Times Square

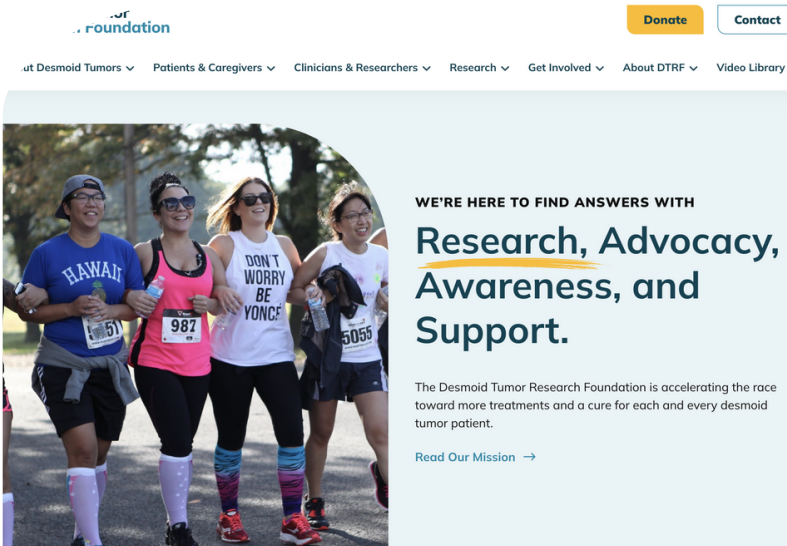
During September (Desmoid Tumor Awareness Month), the Times Square NASDAQ tower in New York City featured our awareness month logo which includes DTRF's logo and dtrf.org.

“Springworks thanks the Desmoid Tumor Research Foundation for their collaboration on finding answers for people living with desmoid tumors.”



“This breakthrough represents the power of patient advocacy. The Desmoid Tumor Research Foundation’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. I’m honored to be part of the process that brings the first-ever FDA-approved medical therapy to desmoid tumor patients.”

Mrinal Gounder, MD, Memorial Sloan Kettering Cancer Center



DTRF.org Reimagined

The DTRF has a bold new website! Thanks to more than a year of hard work by many, our website, DTRF.org, is a redesigned, powerhouse resource for desmoid tumor information.

With our patients, caregivers, and their doctors in mind, we have included comprehensive information and resources related to desmoid tumors, supported with engaging and informative videos where possible.

You've Come to the Right Place

Whether you are a desmoid tumor patient, caregiver, researcher, or clinician, we can help you find answers.

How can we help you? ▾

New Diagnosis Codes Specific to Desmoid Tumors

The DTRF has worked for almost two years toward the implementation of new ICD-10-CM diagnosis codes specific to desmoid tumors, culminating in success this year. The DTRF formally requested the creation of new codes in March 2022 and successfully shepherded the request through each step of the process to approval by the CDC.

New ICD-10-CM diagnosis codes for desmoid tumors went into effect in the United States on October 1, 2023. ICD-10-CM codes are the administrative language of healthcare in the US, used by all physicians, hospitals, and health insurers to communicate with each other about billing, coverage, and payment. They are also used by researchers when accessing national medical databases.

Historically, desmoid tumors have been lumped into a vague diagnosis code with many other types of soft tissue "neoplasms of uncertain behavior." However, these newly-approved codes are specific to desmoid tumors and their location in the body.

By identifying desmoid tumors distinctly and by location, the new codes should help improve communication, reduce paperwork for physicians, and improve claims processing efficiency for insurers, all of which should result in reduced hassles for patients. The new codes will also greatly improve the ability of healthcare researchers to analyze "real world" data on desmoid tumors toward a better understanding of its course and effectiveness of treatments.



OCTOBER 1, 2023

Ten New ICD-10-CM Diagnosis Codes For Desmoid Tumors Go Into Effect on October 1, 2023, in the United States.

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 2023, four boards were convened.

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. By answering online survey questions about your experience, you can help 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.

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, 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.



RINGSIDE AL102 Phase 2/3

In 2023, Ayala Pharmaceuticals initiated recruitment for the Phase 3 part of the RINGSIDE trial of AL102 for the treatment of progressing desmoid tumors. This trial follows the positive results of the Phase 2 part of the trial. AL102 is a gamma secretase inhibitor (GSI) administered orally and once daily.

Phase 3 is Placebo-controlled and includes relapsed/refractory (tumor recurred or grew after treatment/did not respond to treatment) or treatment-naïve patients (patients who have not had any treatment) with tumor growth in the last 12 months. The trial is enrolling patients who are 12 years old and older and is currently enrolling in the US, Australia, Spain, Israel and other countries. Follow posted updates on [ClinicalTrials.gov](https://www.clinicaltrials.gov) website for additional locations as they open up.

Recursion Phase 2 TUPELO Trial

Recursion has initiated the TUPELO Trial, a Phase 2 trial of REC-4881, for the potential treatment of Familial Adenomatous Polyposis (FAP). The trial will include patients who have previously been diagnosed with classic Familial Adenomatous Polyposis (FAP) and have undergone colectomy or subtotal colectomy. FAP patients with desmoid tumors may qualify.

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

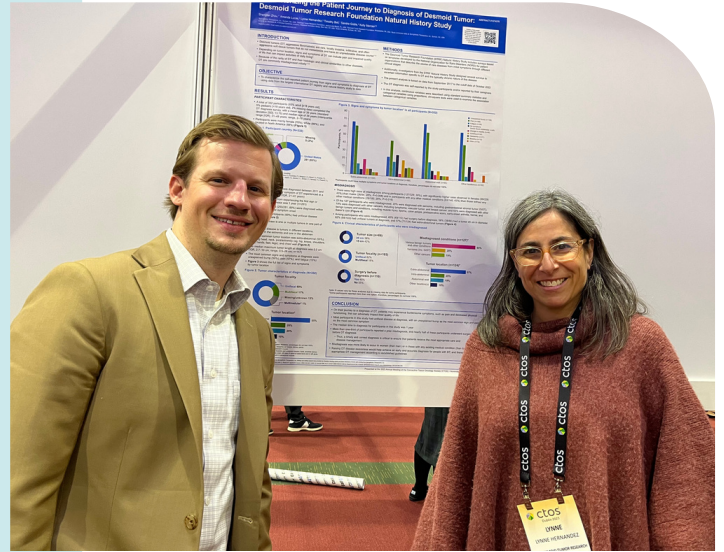


Conferences Feature Desmoid Tumors

DTRF's Patient Registry Poster Wins 1st Place Award at CTOS 2023

The DTRF Patient Registry poster titled, "Characterizing the Patient Journey To Diagnosis of Desmoid Tumor: Desmoid Tumor Research Foundation Natural History Study" was presented at CTOS 2023 by SpringWorks Therapeutics Medical Science Liaison, Mitchell Allen, PhD (pictured with Lynne Hernandez, DTRF Executive Director). It won first place in Category 1: Improving Sarcoma Care Globally.

This poster was created in partnership with SpringWorks Therapeutics, under the leadership of the DTRF's Principal Investigator for the Registry, Kelly Mercier, PhD, and the poster's first author Shengfan Zhou, MS (SpringWorks). Congratulations to the entire team from SpringWorks and the DTRF on this important accomplishment!



ASCO 2023

Desmoid tumors were the subject of several poster presentations and discussions during the Sarcoma Track of ASCO 2023, on Saturday, June 3rd. Below is a list of posters with links to their abstracts. The DTRF is grateful for all of the desmoid research that is taking place around the world.

Tumor volume and T2 hyperintensity changes from DeFi: A phase 3, randomized, controlled trial of nirogacestat in patients with desmoid tumors.

Thierry Alcindor, MD, MSc, McGill University Health Center, et. al.

Abstract: <https://meetings.asco.org/abstracts-presentations/218369>

Impact of nirogacestat on pain, a key symptom in patients with desmoid tumors (DT): Results from the phase 3 DeFi study.

Winette T.A. Van Der Graaf, Department of Medical Oncology, Netherlands Cancer Institute, Amsterdam, Netherlands, et. al.

Abstract: <https://meetings.asco.org/abstracts-presentations/220655>

RINGSIDE phase 2/3 trial of AL102 for treatment of desmoid tumors (DT): Phase 2 results.

Mrinal M. Gounder, MD, Memorial Sloan Kettering Cancer Center, et. al.

Abstract: <https://meetings.asco.org/abstracts-presentations/218382>

ASCO 2023 (cont.)

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>

International Patient Advocacy Group Meeting

Desmoid patient advocacy groups from around the world were hosted by the Italian group, Desmoid Foundation ONLUS Associazione Italiana Tumore Desmoide, at the end of June. DTRF Executive Director, Jeanne Whiting, participated in discussions with and presented to this inspiring workgroup.

Together we're stronger! *DTRF holds an annual Desmoid Tumor Global Roundtable with international patient advocacy groups as we all work together to advocate for patients around the world.*

DTRF Leadership Team Attends CTOS 2023

Lynne Hernandez, DTRF Executive Director, and Jeanne Whiting, DTRF Executive Director Emeritus and attended CTOS 2023 in Dublin, Ireland, November 1-4.

The team was honored to connect and collaborate with other patient advocacy groups, researchers and industry professionals. The conference was filled with energy and the promise of accelerating science toward more treatment options for desmoid tumor and all sarcoma patients.

Last year's 2022 designation of desmoid tumors as "Sarcoma of the Year" reflected a year of groundbreaking research in our rare disease. Researchers from varied backgrounds presented multiple scientific posters about desmoid tumors.

2023 DTRF-funded Research Grants

Each year, with the guidance of our Grant Review Board, 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 2023:

- **Manon Braat, N.G.J.A., MD**, University Medical Center Utrecht (UMCU), *Magnetic resonance image-guided high intensity focused ultrasound for patients with desmoid type fibromatosis: the MAGNIFIED trial*. Year 2 of 2.
- **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 2 of 2.
- **Eldad Elnekave, MD**, Shaare Zedek Medical Center, *Doxorubicin Eluting Embolization for Desmoid Fibromatosis, clinical trial*. Year 1 of 3. Jointly funded by the DTRF and Desmoid Tumour Foundation of Canada (DFC).
- **Peter Hohenberger, MD**, University of Heidelberg, Germany, *An evidence-based 2nd consensus on the treatment for desmoid tumors*. Year 1 of 1.
- **Joanna Przybyl, PhD**, Research Institute – McGill University Health Centre, Canada, *Targeting hexosamine biosynthesis pathway for the treatment of desmoid tumors*. Year 2 of 2. Jointly funded by the DTRF and Desmoid Tumour Foundation of Canada (DFC)
- **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 1 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 10th Annual International Desmoid Tumor Research Workshop was held on Friday, September 23rd, in conjunction with our Patient Meeting webinars 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:

Memorial Sloan Kettering Cancer Center
SpringWorks Therapeutics
Ayala Pharmaceuticals
EcoR1
Dana-Farber Cancer Institute/Harvard Medical School
Thomas Jefferson University Hospital
Hillel-Yaffe Medical Center
Massachusetts Institute of Technology; Break Through Cancer
EMD Serono
University of Michigan
Yale University
Stanford University
University College Hospital London
Shaare Tzedek Medical Center
Fondazione IRCCS Istituto Nazionale dei Tumori
Memorial Sloan Kettering Cancer Center
Clarity Coding
Institute of Cancer Research
Mannheim University Medical Center
University of Colorado - Anschutz
Johns Hopkins University
Nagoya University Hospital
Maisonneuve-Rosemont Hospital
Northwestern University
Cincinnati Children's Hospital Medical Center
McGill University
The University of Texas MD Anderson Cancer Center
Ghent University
Maine Medical Center
Duke University



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

RESEARCH WORKSHOP ATTENDEE

[Watch Workshop Videos](#)

2023 Research Workshop Presentations

Jonathan Noujaim, MD, Assistant Clinical Professor of Medicine, Universite de Montreal (Canada) - “Tyrosine kinase inhibitors in desmoid type fibromatosis - a Canadian multicenter retrospective CanSaRCC study.”

Bernd Kasper, MD, PhD, Professor, University of Heidelberg, Mannheim University Medical Center, Mannheim Cancer Center, Sarcoma Unit (Germany) - “Global consensus paper on desmoid tumor management.”

Gerlinde Wernig, MD, Assistant Professor, Department of Pathology, Stanford University School of Medicine - “Studying CD47 blockade as an immunotherapy for desmoid-type fibromatosis.”

Kris Vleminckx, PhD, Full Professor, Department of Biomedical Molecular Biology, Ghent University (Belgium) - “Investigating EZH2 as a druggable mediator of immune cell exclusion in desmoid tumors.”

Jesse Boehm, PhD, Principal Investigator, Koch Institute, MIT - “Progress towards creating a prototype desmoid tumor dependency map.”

Gabe Augdahl, Desmoid Tumor Patient

Cristabelle De Souza, PhD, Postdoctoral Fellow, Cancer Biology, Stanford University - “Activation of c-JUN modulates the transcriptional activity of CD63 serving as a novel target for the treatment of desmoid type fibromatosis.”

Paul Huang, PhD, Head, Molecular and Systems Oncology Laboratory Division of Molecular Pathology, Institute of Cancer Research (UK) - “What has proteomics taught us about desmoid tumours?”

Linda Holtzman, MHA, RHIA, CCS, CCS-P, CPC, COC, President, Clarity Coding - “New desmoid tumor ICD-10-CM codes.”



2023 Research Workshop Presentations (cont.)

Joanna Przybyl, PhD, Assistant Professor, McGill University (Canada) - “Expression of the hexosamine biosynthesis pathway components in desmoid tumors.”

Yoshihiro Nishida, MD, Department of Rehabilitation Medicine and Orthopaedic Surgery, Nagoya University Hospital - “Treatment for upper limb desmoid causing pain and joint contracture: the importance of medication and rehabilitation.”

Joseph Pressey, MD, Professor of Pediatrics, University of Cincinnati College of Medicine and Cincinnati Children’s Hospital Medical Center - “Percutaneous Cryoablation with and without VEGF-Tyrosine Kinase Inhibitor Therapy for Pediatric and Adult Patients with Desmoid Tumors.”

Aaron Weiss, DO, Associate Professor, Department of Pediatrics, Division Chief, Pediatric Hematology-Oncology, Maine Medical Center - “A Pilot Study Evaluating the Use of Sirolimus in Children and Young Adults with Desmoid-type Fibromatosis.”

Jacob Bickels, MD, Orthopedic Oncologist, Hillel-Yaffe Medical Center - “Microbiome of desmoid tumor and its impact on the clinical course of disease.”

Ravin Ratan, MD, Associate Professor, Sarcoma Medical Oncology, MD Anderson Cancer Center - “Impact of nirogacestat on pain, a key symptom in patients with desmoid tumors (DT): Results from the phase 3 DeFi study.”

Thierry Alcindor, MD, MSc, Senior Physician, Dana-Farber Cancer Institute/Harvard Medical School - “Tumor volume and T2 hyperintensity changes from DeFi: a phase 3, randomized, controlled trial of nirogacestat in patients with desmoid tumors.”

Rashmi Chugh, MD, Professor, Division of Hematology/Oncology, University of Michigan Rogel Comprehensive Cancer Center - “RINGSIDE Phase 2/3 Trial of AL102 for Treatment of Desmoid Tumors (DT): Phase 2 Results.”



Researchers, clinicians, and industry professionals at DTRF Research Workshop in Philadelphia, PA

DTRF Patient Registry & Natural History Study

The DTRF Patient Registry is a powerful way for desmoid tumor patients and their family members to contribute directly to research that will improve our understanding of desmoid tumors. This important DTRF initiative collects de-identified survey data inputted by patients about their desmoid tumor patient experience. The data is aggregated and analyzed to create a natural history study of the disease, accessible to researchers.

Patients and caregivers can join the registry here: [DTRF.iamrare.org](https://dtrf.iamrare.org). WATCH an informative video: "DTRF Patient Registry & Natural History Study 101" at <https://vimeo.com/849314076>. Dr. Kelly Mercier provides an overview of these important research tools. Learn more about the DTRF Patient Registry and Natural History Study at <https://dtrf.org/patient-registry/>.

Living Cell Line Now Publicly Available for Desmoid Tumor Research

We are thrilled that through our research at The Broad Institute and partnership with Pattern.org, the first publicly available desmoid tumor living model, called a cell line, has been generated and is now available for researchers to purchase at ATCC, a renowned public bio-repository.

Cell lines are critical for researchers to learn more about the disease and in testing new therapeutic options. The availability of this cell line is an initial, but very significant milestone as we work to provide verified and standardized resources to our research community.

We thank all of our desmoid patients who have consented to donate tissue through Pattern.org, as you are instrumental in helping expedite the development of improved therapies. If you have an upcoming surgery and would like to donate tissue, all you need to do is fill in an online consent form prior to surgery at Pattern.org and they will handle all the arrangements, working with your surgical institution. There is no cost or any additional effort on your part to participate!



Jeanne Whiting and Barbara Van Hare (Rare Cancer Research Foundation) meet at ATCC.

Updated NCCN Guidelines for Desmoid Tumors

The National Comprehensive Cancer Network (NCCN) has recently updated the NCCN Clinical Practice Guidelines for Soft Tissue Sarcomas, of which desmoid tumors are listed as a sub-type. The NCCN guidelines are often the first resource that medical providers consult to understand desmoid tumors.

Patients can access a patient version here:

[NCCN Guidelines](#)

Ideally, desmoid tumor patients are treated by a robust multidisciplinary team of doctors, familiar with both the updated NCCN guidelines and the Global Consensus Paper for the management of desmoid tumors. The consensus paper is a powerful, desmoid-specific resource for patients, caregivers, and medical professionals that answers critical questions regarding approach to treatment recommendations, types of treatments, and pain management.

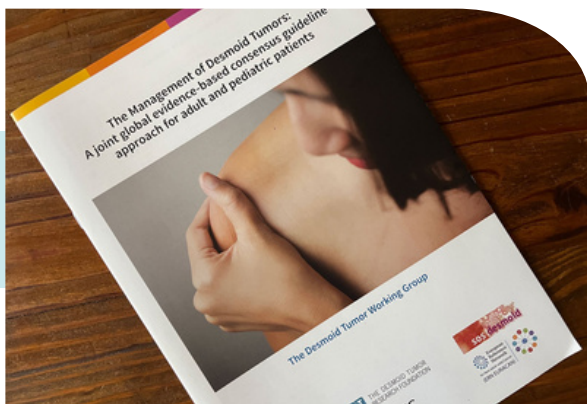
Workgroup Updates Global Consensus Paper

A group of nearly 60 desmoid tumor experts including DTRF's Executive Director, Jeanne Whiting, convened at Milan's Fondazione IRCCS Istituto Nazionale dei Tumori in late June to review and update the Global Consensus Paper on the management of desmoid tumors. We look forward to sharing the revised version as soon as it is available. Publication is expected in early 2024.

GODDESS© is the First Validated PRO Instrument in Desmoid Tumors

Funded by the DTRF, an important milestone in desmoid tumor research was achieved years ago with the successful development of the GODDESS© Patient Reported Outcome (PRO) tool, by collaboration among DTRF, Mrinal Gounder, MD. of Memorial Sloan Kettering Cancer Center and IQVIA, a leader in PRO development. A PRO tool, which consists of a series of surveys which patients fill out, is an important way to have the patient voice heard in determining the efficacy of new treatments. A PRO tool is then validated through use in the clinical trial process.

The GODDESS© tool was developed to assess desmoid tumor symptom severity and its impact on patients' lives. The results of the analysis of patient-reported outcomes in the clinical trial of nirogacestat, found GODDESS© to be "dependable, valid, responsive, and interpretable as a means of examining the effect of treatment on patient-reported outcomes." This is a huge step forward in facilitating and honoring the desmoid patient voice in clinical trials.



IQVIA Features DTRF in Report on Collaboration Among Patient Advocacy Groups and Life Sciences Companies

The IQVIA Institute for Human Data Science, a leader in developing Patient Reported Outcome (PRO) tools, published a new report titled, Supporting Patients through Research Collaboration: Interactions between patient organizations and life sciences organizations. The report examines the different types of patient organizations, the dynamics affecting them and the activities they conduct, exploring:

- Where collaborations with life sciences companies are occurring
- Where they have been successful and
- Where patient organizations have indicated there is room for improvement

The DTRF is discussed on page 44, where the development of the GODDESS® Patient Reported Outcome (PRO) tool, is described in detail. The collaboration among the DTRF, Mrinal Gounder, MD of Memorial Sloan Kettering Cancer Center, and IQVIA shows how the synergy between stakeholders resulted in a milestone for desmoid tumor research.

Click the button below to learn more:

IQVIA:
*Supporting Patients Through
Research Collaboration*



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 nirogacesat, 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.

Education, Advocacy and Awareness



DTRF Together We Will Weekend Sept 22th - 24th

Old City Philadelphia 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 2023 highlights in this area:

The DTRF Annual Patient Meeting

Candace Haddox, MD, Medical oncologist, Dana-Farber Cancer Center -
“Desmoid tumors 101 / Getting the most from your consultation and treatment plan.”

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’”

Bernd Kasper, MD, PhD, Professor, University of Heidelberg, Mannheim University Medical Center, Mannheim Cancer Center, Sarcoma Unit (Germany) - “DeFi: A phase 3 study of nirogacestat in adults with desmoid tumors.”

Alessandro Gronchi, MD, Chair, Sarcoma Service, Department of Surgery, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano (Italy) - “Active surveillance as a desmoid tumor treatment.”

The DTRF Annual Patient Meeting (cont.)

Ryan Brunsing, MD, PhD, Clinical Assistant Professor of Radiology, Director of MRI, Stanford University - “MRI-guided cryoablation and HIFU in the treatment of desmoid tumors.”

Eldad Elnkave, MD, Director, Kahn Unit for Interventional Oncology, Shaare Tzedek Medical Center (Israel) - “Arterial doxorubicin eluting embolization (DEE) as a desmoid tumor treatment.”

Mrinal Gounder, MD, Associate Professor, Sarcoma Medical Oncologist and Early Phase Drug Development, Memorial Sloan Kettering Cancer Center - “RINGSIDE Phase 2/3 trial of AL102 for treatment of desmoid tumors: updated Phase 2 results.”

Gabe Augdahl, Desmoid Tumor Patient



Dr. Alessandro Gronchi presents to patients, caregivers and clinicians at the DTRF Annual Patient Meeting in Philadelphia

The DTRF Annual Patient Meeting (cont.)

DTRF Mock Tumor Board Featuring:

CO-MODERATORS

- **Palma Dileo, MD**, Consultant Medical Oncologist, London Sarcoma Service, University College London Hospitals (England)
- **Aaron Weiss, DO**, Associate Professor, Department of Pediatrics, Division Chief, Pediatric Hematology-Oncology, Maine Medical Center

PANELISTS

- **Ravin Ratan, MD**, Associate Professor, Sarcoma Medical Oncology, MD Anderson Cancer Center
- **Alessandro Gronchi, MD**, Chair, Sarcoma Service, Department of Surgery, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano (Italy)
- **Eldad Elnekave, MD**, Director, Kahn Unit for Interventional Oncology, Shaare Tzedek Medical Center (Israel)

Robert Lefkowitz, MD, Attending radiologist, Memorial Sloan Kettering Cancer Center - “Imaging of desmoid tumors.”

Kelly Mercier, PhD, Principal Investigator, DTRF Patient Registry, Desmoid Tumor Research Foundation - “An update on the dtrf patient registry - September 2023.”

Marco Fiore, MD, FACS, Sarcoma Service, Department of Surgery, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano (Italy) - “What we’ve learned from the international pregnancy study.”



Webinars for Patients & Caregivers

“**Dealing with Desmoids: Mental Health Tools for the Desmoid Patient**” is a virtual educational program series hosted by the DTRF and facilitated by Ashley Williams, a Licensed Clinical Social Worker (LCSW) and desmoid tumor patient. This series, which is still available on our website, explores the unique experience of a desmoid patient and provides mental health education, tools, and strategies for coping with the emotional challenges of this diagnosis.

Sessions this year included “**Survivor’s Guilt & Toxic Positivity,**” where we discussed the impact of other’s responses on a patient’s mental health and identified strategies in dealing with these responses. We also discussed the impact of survivor guilt and strategies to overcome it.

We also hosted a webinar titled, “**An Integrative Approach to Health and Well-Being**” with desmoid tumor patient, Jessica Clark, RN, BSN. Using Duke University Health System’s Wheel of Health, Jessica explored how viewing health through an integrative, holistic lens can improve a person’s overall well-being.

Facebook Lives in September included a session on “**Fundraising for Answers**” by our new Development Director, Debbie Nathan, and a session with patient John MacKinnon featuring “**One Desmoid Tumor Patient’s Journey**” where John shared how his perspective changed once he realized how rare desmoid tumors are.

Watch Virtual Series

DEALING WITH DESMOIDS: Mental Health Tools for the Desmoid Patient

A Virtual Series Hosted by



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



CME Program “On the Cusp of Change: Modernizing the Treatment of Desmoid Tumors with Novel Gamma Secretase Inhibitors”

This CME-certified PeerView onDemand activity, which is available on our website, features a panel of leading experts in managing patients with desmoid tumors, including Bernd Kasper, MD, PhD from the Mannheim Cancer Center (MCC) in Mannheim, Germany, Mrinal Gounder, MD from the Memorial Sloan Kettering Cancer Center in New York, New York and Alessandro Gronchi, MD from the Fondazione IRCCS Istituto Nazionale dei Tumori in Milan, Italy.

The faculty provide expert insights and practical guidance for navigating the latest treatment advances for desmoid tumors, including GSIs. In addition, illustrative cases and clinical scenarios are discussed to demonstrate the emerging role and integration of novel GSIs in real-world patient care settings.

CME Program “Addressing Key Questions about the Latest Diagnostic and Therapeutic Advances in Desmoid Tumors”

Featuring experts Ravin Ratan, MD, M.Ed, and Christina L. Roland, MD, MS, FACS, both of MD Anderson Cancer Center, as well as patient Kathleen Hodgkins, this CME program provides an update on the evolving evidence base for new and emerging therapies. It offers practical, case-based guidance for the multidisciplinary care team to help facilitate the application of recent advances with the goal of improving patient care and outcomes. Patient perspectives and experiences are also integrated into the activity to highlight the importance of their education and engagement in care decisions. This event was produced with PeerView Institute for Medical Education.

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.

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

Community fundraisers like these make a big impact, not just by the donations they generate, but by spreading awareness to people unaffected by the disease. We are a rare disease, so every person we reach outside of our own desmoid community is significant. 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.

Below are some of the fundraisers that took place in 2023:

RFA (Running for Answers) and our Champions Virtual Awards Ceremony

Our September 2023 in-person Running for Answers RFA event in Philadelphia unfortunately had to be canceled due to an ill-timed hurricane in the area. However, RFA participants raised funds virtually and the outcome was a big success!

We were LIVE on Facebook Thursday, 11/2, to celebrate our community and their fundraising efforts. We first spoke to Katie Doyle Myers about her recent diagnosis and successful fundraiser in Colorado. Then we chatted with Tiffany Black and her team, The Spenguis. They are perennial RFA Champions, and it was so exciting to have most of them on screen with us.



We wrapped up with an encouraging toast from desmoid tumor patient, former Philadelphia Eagles linebacker, and motivational speaker, Kevin Reilly.

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



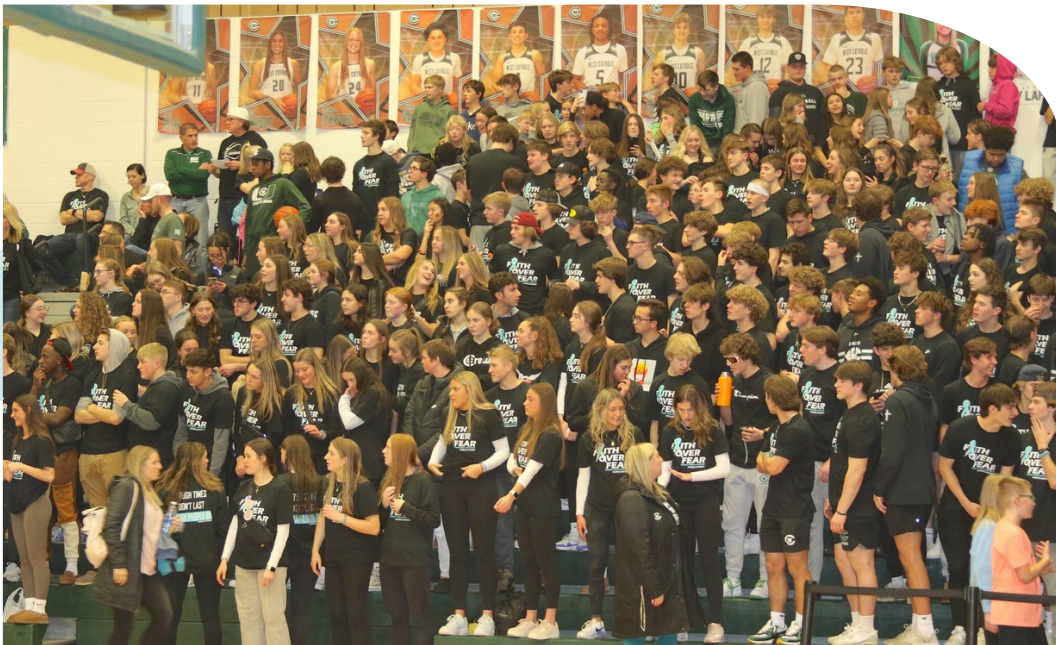
The Spenguis organized a 5K in Virginia to celebrate RFA. Even Mister Softee joined them!

Faith Over Fear Community Event

Many thanks to desmoid warrior Gabe Augdahl and his family for hosting an extraordinary fundraiser to benefit the DTRF.

On Fri., Feb. 17th, the West Catholic High School Girls and Boys varsity basketball games were dedicated to Gabe, as the culmination of their "Faith Over Fear" fundraising campaign. Roughly \$18,000 was raised!

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



JoeStrong Volleyball Tourney

In early November, Joe Erickson came through once again with his 7th Annual JoeStrong Volleyball Tournament in Texas. Joe's supporters came out for some friendly competition and raised more than \$5,000 for desmoid tumor research! This is right on the heels of Joe raising nearly \$2,500 through RFA/Running for Answers.

With heartfelt gratitude for the Ericksons' fundraising work, we applaud their unwavering commitment to supporting our mission.



JoeStrong Tourney participants gather for their annual photo at the event

Swing for a Cure - St. Louis

Jason Ortwerth and his wife Katie did it again. The 5th Annual Swing for a Cure - St. Louis, held in September, was a fantastic success raising over \$44,000 for desmoid tumor research!

We are inspired by and so thankful for Jason's loved ones for “driving” our efforts to support our efforts on behalf of the patient community.



Swing For a Cure participants are greeted at the golf event

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](#)

[2023 Financials \(To be posted when available\)](#)

[2023 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 Development Director & Operations Manager

This July, DTRF proudly introduces Debbie Nathan as our new Development Director. Debbie's extensive experience in disease-specific, non-profit development with the Parkinson's Foundation and Lupus Foundation reinforces our commitment to aggressively fund desmoid tumor research.

We had another new addition in December! DTRF is excited to onboard Shannon Shoop as our new Operations Manager. Shannon encompasses her areas of strength with a passion for organization. She has worked in various industries from startups to growing nonprofits.

Leadership, Volunteers and Staff

JEANNE WHITING

Executive Director and Co-founder; as of Nov., Executive Director Emeritus

LYNNE HERNANDEZ

Director of Operations; as of Nov., Executive Director

DEBBIE NATHAN

Development Director

KELLY MERCIER, PhD

Principal Investigator, The DTRF Patient Registry & Natural History Study

AMANDA LUCAS

Associate, The DTRF Patient Registry & Natural History Study

MRINAL GOUNDER, MD

Scientific Director

MAGGIE CAMERON

Communications Manager

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Operations Manager

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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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KEILA TORRES, MD, PhD

Assistant Professor, Department of Surgical Oncology, Division of Surgery, MD Anderson Cancer Center



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