

WE WILL FIND A CURE
TOGETHER.....

2019 ANNUAL REPORT



THE DESMOID TUMOR
RESEARCH FOUNDATION

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A LETTER FROM THE CO-FOUNDERS

Dear friends,

As 2019 comes to an end and a new decade approaches, we are entering a milestone year of serving the desmoid tumor patient community. In September 2020, we will celebrate the 15th anniversary of our founding. Looking back we can't help but feel overwhelmed by how far we have come with your help.

Today, better treatments are available to patients, multiple promising clinical trials are underway, more researchers are interested in studying desmoid tumors, and more physicians are aware of this disease and its serious and challenging nature.

As you'll see in the following pages, 2019 has been a great year for progress!

A cure is on the horizon. On behalf of all desmoid tumor patients fighting this disease, we look forward to getting there together as fast as we can!

With hope and gratitude,



Marlene Portnoy, Executive Director/Co-founder and Jeanne Whiting, President/Co-founder

Jeanne Whiting
Jeanne Whiting
President and Co-founder

Marlene Portnoy
Marlene Portnoy
Executive Director and Co-founder

DTRF'S MAJOR ACCOMPLISHMENTS IN 2019

DTRF-FUNDED RESEARCH

DTRF awarded 7 grants to support research priorities, including adding The Broad Institute of MIT and Harvard as DTRF-funded researchers. (See grants on page 7).

CONSENSUS PAPER

The first of its kind global consensus paper on desmoid tumor treatment was completed with DTRF support and has been submitted for publication. As there are varying treatments used for desmoid tumors and access to medical therapies and information varies greatly by country and location, many patients are treated based on the experience of a single physician, which may be limited. DTRF has made it a priority to improve this situation by making this collaborative paper available to physicians and patients worldwide. The paper was completed thanks to the hard work and collaboration of an international group of physicians and scientists, as well as patient advocates. It will be the first international evidence-based consensus of its kind on the treatment of desmoid tumors and answers critical questions regarding approach to treatment recommendations, types of treatments, and pain management.

PRO TOOL

Resulting from a project funded by DTRF, a paper entitled, "[Prospective development of a patient-reported outcomes instrument for desmoid tumors or aggressive fibromatosis.](#)" was published in *Cancer*.

The paper states that existing clinical trial endpoints such as the Response Evaluation Criteria in Solid Tumors (RECIST) and progression-free survival "are inadequate for capturing treatment efficacy" in desmoid tumors. "This study was designed to develop a novel clinical trial endpoint by capturing patient-reported outcomes (PROs)."

The study used concept elicitation (CE) interviews to explore desmoid patients' perspectives on key disease-related symptoms and impacts. Qualitative analysis was performed to determine the relative frequency and disturbance of symptoms and impacts. Draft and refined PRO scales were then developed and tested with additional interviewing. These resulted in a final 11-item Symptom Scale and a 17-item Impact Scale. The paper concludes, "This is the first disease-specific PRO instrument developed for desmoid tumors. The instrument is available as an exploratory endpoint in clinical trials. This study highlights the feasibility and challenges of developing PRO instruments for rare diseases."

DTRF DESMOID TUMOR PATIENT REGISTRY

This year, data and learnings from The DTRF Patient Registry were shared widely. The Registry had an abstract selected for publication by ASCO entitled, "Quality of life and tumor location in patients with desmoid tumors: Data from The Desmoid Tumor Research Foundation natural history study." At the DTRF Patient Meetings in South San Francisco (April) and Philadelphia (September), as well as the NORD Summit (October), registry posters were displayed to show data trends. In October, our registry PI, Dr. Kelly Mercier presented at both the NORD Summit and NORD Registry Community Meeting on best practices for patient registry design, launch, and data collection.

The DTRF Patient Registry, which launched in 2016, is an online system that securely collects and stores data for medical research. It is a dynamic participant-driven resource that can empower and unite the desmoid tumor community through shared knowledge. DTRF is committed to growing the registry to inform research efforts moving forward.

CLINICAL TRIALS

We saw progress in important new clinical trials for new desmoid tumor treatments:

- **The SpringWorks Therapeutics Phase III DeFi trial** opened and received "Breakthrough Therapy Designation" from the FDA. DeFi is a study evaluating nirogacestat, a gamma-secretase inhibitor, in adults (18 years and older) with progressing desmoid tumors. This designation is in addition to the previously-granted "Orphan Drug" designation (June 2018) and "Fast Track" designation (Nov. 2018).
- **A pediatric clinical trial in nirogacestat** entered the design phase. It is anticipated to eventually be open at over 200 Children's Oncology Group study sites.

- **The Phase I clinical trial for Tegavivint** from Iterion Pharmaceuticals opened. Tegavivint is a new drug that directly interferes with beta-catenin stabilization that has shown promise in preclinical studies of desmoid tumors.
- In February, the recent **Phase III Sorafenib desmoid tumor study** was named by ASCO as one of the top breakthroughs in oncology in 2018. Named as an *“Advance of the Year,”* the desmoid study was showcased with others showing *“major breakthroughs in clinical cancer research and care.”*

ADVOCACY & AWARENESS

- DTRF became a member of the recently-established **Sarcoma Coalition**, an organization of sarcoma advocacy groups working together to support sarcoma patients, educate the public and medical community, and help fund research to find better treatments. While united in our commitment and efforts, each Sarcoma Coalition member organization offers its own unique areas of advocacy, resources, and services.
- DTRF met with pharmaceutical companies to advocate for desmoid tumor drug development, trials, and more.
- In September, we celebrated the first annual Desmoid Tumor Awareness Month to bring the importance of our cause to life. This worldwide annual campaign focuses on creating awareness for desmoid tumors and inspiring the patient and caregiver community. Patients from around the world participated by sharing their stories.
- DTRF was well-represented at important medical meetings. We were in Washington, DC in October for the **National Organization of Rare Disorders (NORD) Rare Diseases & Orphan Products Summit**. The DTRF Patient Registry Principal Investigator, Dr. Kelly Mercier, represented DTRF on NORD’s panel discussion discussing best practices for patient registry design, launch, and data collection. In addition, Dr. Mercier had an abstract about our patient registry accepted at the **2019 annual meeting of the American Society of Clinical Oncology (ASCO)**.

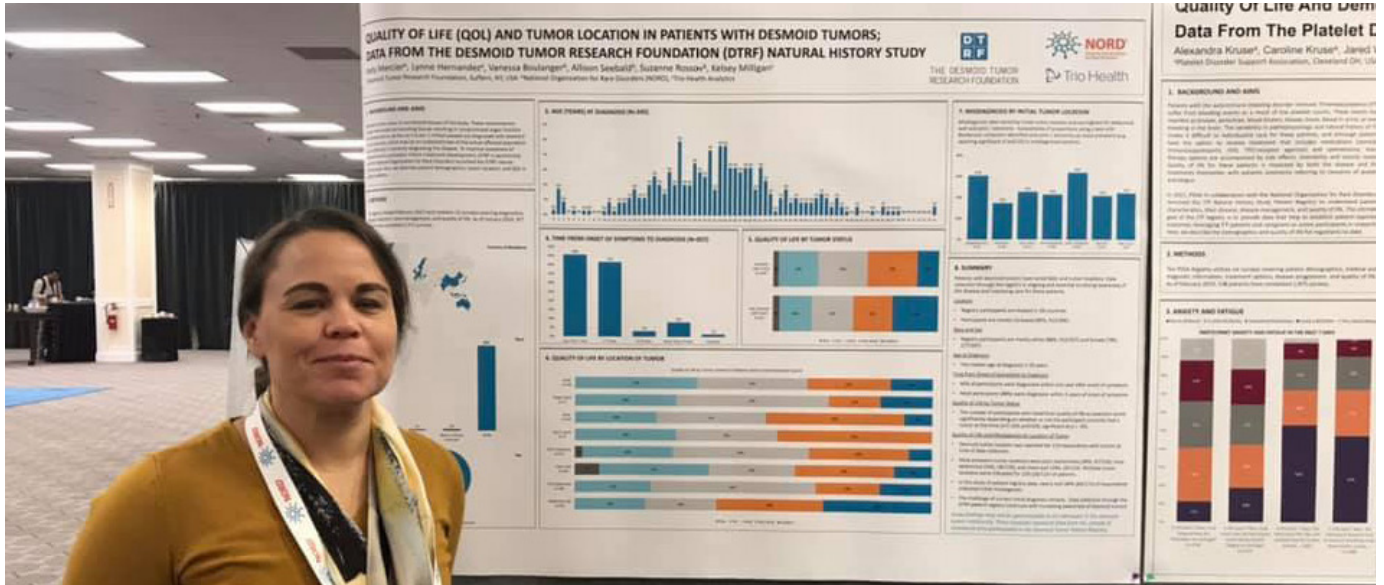
PATIENT SUPPORT AND RESEARCH COLLABORATION

In addition to our fall Annual Patient Meeting in Philadelphia, DTRF jointly hosted a spring 2019 Regional Patient Meeting in South San Francisco with Stanford University Sarcoma Team. Our patient meetings provide a supportive atmosphere where patients are able to interact with each other and medical professionals, learn the latest information about desmoid tumor treatments and research, and ask the experts their questions. Along with our annual fall Research Workshop, our meetings continue to encourage worldwide scientific collaboration and patient-physician interaction.



Jeanne Whiting makes a presentation about the needs of desmoid tumor patients at the SpringWorks Therapeutics annual meeting, July 2019.

WHAT WE DO AND WHY IT MATTERS



DTRF Patient Registry Principal Investigator Dr. Kelly Mercier at 2019 NORD Summit

OUR MISSION

Founded in 2005, The Desmoid Tumor Research Foundation (DTRF) is dedicated to aggressively funding research for a cure for desmoid tumors and supporting patients with information. The founders have a deep sense of urgency in this cause motivated by a personal connection to the disease. We press forward to fund cutting-edge research that will develop new effective therapies for desmoid tumors, leading to the ultimate goal, *a cure!*

RESEARCH FUNDING

DTRF is the only foundation in the country solely dedicated to funding desmoid tumor research and finding a cure 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 medical and surgical options work best, and what existing drugs or potential new drugs could provide effective treatments. DTRF facilitates collaboration between researchers from different institutions to expedite the development of a cure. DTRF-funded research has already made significant advancements in our understanding of the disease. Discoveries made through desmoid tumor research can also potentially have a significant impact on many other kinds of cancers such as breast, colon, ovarian and other cancers.

EDUCATION AND COLLABORATION

DTRF has established a very successful annual fall 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 moving the field forward toward a cure. 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.

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 provides a supportive environment for patient interaction and informative lectures by clinicians and researchers. Most of all, we seek to support patients by giving them hope through funding research for a cure. 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 a cure. We know that our goal of a cure is within reach...*and we will get there together.*



DTRF Co-founders Marlene Portnoy and Jeanne Whiting with The Broad Institute's Dr. Jesse Boehm

DTRF-FUNDED 2019 GRANTS

DTRF is pleased to note the following new or continuing projects supported by grants in 2019.

Multi-year Grants continuing in 2019

- » **Gerlinde Wernig, MD**, Stanford School of Medicine, Year 2 of “*c-Jun-inducible mice, to study the pathomechanism of desmoid-type fibromatosis in vivo with particular attention to the role of β -catenin/wnt and Notch pathways.*”
Jointly funded by The DTRF and The Desmoid Tumour Foundation of Canada (DFC)
- » **Kris Vleminckx, PhD**, Ghent University, Year 3 of “*Identifying targets for therapy in a novel genetic Xenopus model for desmoid tumor formation.*”
Jointly funded by The DTRF and The Desmoid Tumour Foundation of Canada (DFC)

New 2019 Grants

- » **Jesse Boehm, PhD**, Associate Director of the Cancer Program, Director of the Cancer Cell Line Factory, Principal Investigator in the Cancer Model Development Center, Institute Scientist, The Broad Institute of MIT and Harvard, “*Using genome-scale CRISPR screening to create a Desmoid Tumor Dependency Map.*”
- » **Paul Huang, PhD**, The Institute of Cancer Research, London, UK, “*Characterising the desmoid tumour matrisome for biomarker and drug target discovery.*”
- » **Fariba Navid, MD**, and **Aaron Weiss, DO**, Children’s Hospital Los Angeles, “*Patient Reported Outcomes (PROs) in Pediatric Patients with Desmoid Tumor Treated on ARST1921: A Children’s Oncology Group Study Evaluating the Safety, Pharmacokinetic and Efficacy of a Gamma-Secretase Inhibitor, Nirogacestat (PF-03084014).*”
- » **Fariba Navid, MD** and **Aaron Weiss, DO**, Children’s Hospital Los Angeles, “*Comprehensive Genomic Analysis of Desmoid tumors in Pediatric Patients Treated on ARST1921: A Children’s Oncology Group Study Evaluating the Safety, Pharmacokinetic and Efficacy of a Gamma-Secretase Inhibitor, Nirogacestat (PF-03084014).*”
- » **Daniela Segat, PhD**, “Mauro Baschiroto” Institute for Rare Diseases - B.I.R.D. Foundation, “*CRISPR/Cas9 approach for creating a simplified cellular model to study the Desmoid cells phenotype in response to external stimuli.*”



Patients mingle at the 2019 Regional Patient Meeting in South San Francisco

FINANCIALS

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.

View our:

- » [IRS 501\(c\)\(3\) determination letter](#)
- » [2019 IRS Form 990](#)
- » [2019 Audited Financial Statement](#)



**“We need everyone
to help. With
everyone’s help we
will find a cure.”**

Jeanne Whiting, President &
Co-Founder, DTRF

SIXTH INTERNATIONAL DESMOID TUMOR RESEARCH WORKSHOP

DTRF holds an annual research workshop to facilitate international scientific education and collaboration. This year's attendees included roughly 50 participants from around the world representing fields of desmoid tumor research, human genetics, drug development and related fields. In addition to short scientific presentations, significant time was dedicated to discussions around the important questions: What are the gaps in the science that we need to address next? How can we collaborate to move the science forward most efficiently? Institutions represented at the Workshop included:

The Broad Institute of MIT & Harvard
Iterion Therapeutics (formerly Beta Cat
Pharmaceuticals)
Inivata, Ltd.
Children's Hospital, Los Angeles
Contactgroep Desmoid
Duke University Health System
Erasmus Medical Center
Fondazione IRCCS Istituto Tumori di Milano
Ghent University
Johns Hopkins Medicine
London Sarcoma Service/University College
London Hospitals
Maine Medical Center
Mannheim University Medical Center/University of
Heidelberg
MD Anderson Cancer Center

Memorial Sloan Kettering Cancer Center
Nagoya University Graduate School of Medicine
Rabin Medical Center
Sarcoma Patients EuroNet (SPAEN)
SpringWorks Therapeutics
Stanford University
The Ohio State University Comprehensive Cancer Center
University of Miami Sylvester Comprehensive Cancer Center
University of Toronto
University of Michigan Health System
Yale University
University of Colorado
The Institute of Cancer Research
IHOPE-Leon Berard Center
SOS Desmoide France
Cincinnati Children's Hospital Medical Center

The following presentations were given at the 2019 Research Workshop:

Mushriq Al-Jazrawe, PhD, Postdoctoral Associate, Cancer Program/Rare Tumors, The Broad Institute of MIT and Harvard, "Cellular heterogeneity and the Desmoid Tumor Dependency Map."

Benjamin Alman, MD, Professor & Chair, Orthopaedic Surgery, Duke University, Introduction/ "A genetically targeted mouse model of desmoid tumors."

Jesse Boehm, PhD, Scientific Director of the Cancer Dependency Map, Associate Director of the Cancer Program, Director of the Broad Cancer Model Development Center, Institute Scientist, The Broad Institute of MIT and Harvard, "The Desmoid Tumor Dependency Map."

Danielle Braggio, PhD, Post-doctoral sarcoma researcher, The Ohio State University, "The role of the tumor microenvironment in desmoid tumor progression and therapeutic resistance."

Maddalena Casabianca Reade, Caregiver and Advocate

Eldad Elnekave, MD, Director of Interventional Oncology Clinic, Rabin Medical Center, "Selective intra-arterial doxorubicin eluting emboli-therapy for aggressive desmoid fibromatosis: anatomically targeted chemotherapy."

Abha Gupta, MD, MSc, FRCPC, Associate Professor, Department of Pediatrics, University of Toronto; Staff Oncologist, Solid Tumour Program, The Hospital for Sick Children; Staff Oncologist, Sarcoma Program, Princess Margaret Cancer Centre; Medical Director, Adolescent and Young Adult Program, PMCC, "Clinical benefit with methotrexate plus vinorelbine chemotherapy for desmoid fibromatosis (DF) and correlation of treatment response with MRI" and "High prevalence of persistent emotional distress in aggressive fibromatosis."

Peter Hohenberger, MD, PhD, Professor of Surgical Oncology, Mannheim University Medical Center, University of Heidelberg, "An evidence-based consensus on the treatment of desmoid/aggressive fibromatosis."

Paul Huang, PhD, Head, Molecular and Systems Oncology Laboratory, Division of Molecular Pathology, The Institute of Cancer Research, "Deconstructing the desmoid tumour matrisome."

Hans Iwenofu, MD, FCAP, Associate Professor, The Ohio State University Wexner Medical Center, "Quantitative Proteomics Analysis of desmoid-type fibromatosis."

Elena Palassini, MD, Medical Oncologist, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, Italy, "Low dose chemotherapy in FAP-related Desmoid Tumor (DT): results from a multi-institutional case-series."

Milea JM Timbergen, MD, PhD candidate, Surgical Oncology, Erasmus Medical Center Cancer Institute, "Health-related quality of life issues of patients affected by desmoid-type fibromatosis; experiences from two countries."

Kris Vleminckx, PhD, Professor of Developmental Biology, Ghent University, "Identifying and characterizing dependency factors in a genetic *Xenopus tropicalis* desmoid tumor model."

Tristan Lerbs, Postdoctoral research scholar, Laboratory of Professor Gerlinde Wernig, Stanford University, "Unraveling the interactions between β -catenin/wnt and possible therapeutic implications."

Breelyn Wilky, MD, Associate Professor & Director of Sarcoma Translational Research, University of Colorado School of Medicine, final results of the desmoid mutation sequencing project. "Beta- catenin mutations as predictors of systemic therapy response."



2019 Lap4Life Fundraiser in Newburgh, NY

OUR COMMUNITY

The DTRF is funded solely by private donations, often through patient-organized fundraising events. Volunteers, including patients, caregivers and supporters, are encouraged to plan and host fundraisers around the country. We cannot accomplish our mission without you and are always here to help you!

Our heartfelt thanks go out to the following volunteers who helped fund research this year:

4th Annual DTRF Beer Pong Tournament

April 13, 2019 in New York, NY
Organizers: Brittany Longenbach and Danielle Portnoy

Fundraising & Networking Event

May 2, 2019 in Toronto, Canada
Organizer: Desmoid Tumour Foundation of Canada

Desmoid Tumor T-shirt Virtual Campaign

September 1, 2019
Organizer: Natalie Lauerman

Swing for a Cure- St. Louis

September 9, 2019 in St. Louis, MO
Organizers: Katie and Jason Ortwerth

6th Annual Desmoid Dash

September 29, 2019 in Mendota Heights, MN
Organizers: The Zechmann Family

Parents' Night OUT

May 2019 in Lakewood, Ohio
Organizers: Emerson Elementary Service Club

2019 Golf Classic

June 3, 2019 in Tuxedo Park, NY
Organizers: Nan and Richie Klein

11th Annual Lap4Life

June 15, 2019 in Newburgh, NY
Organizer: Maddalena Casabianca Reade and Lap4Life

4th Annual JoeStrong Volleyball Tournament

November 2, 2019 in Austin, Texas
Organizer: Joe Erickson

2019 Tour de Blax

November 16, 2019 in Warrenton, VA
Organizer: Tiffany Black & Family

Lap4Life Brewery Fundraiser

November 24, 2019 in Newburgh, NY
Organizer: Maddalena Casabianca Reade & Lap4Life Foundation

Facebook fundraisers

Many Facebook users have set up fundraisers on the social media platform. By sharing their experiences with desmoid tumors, they have garnered support for DTRF.

DFC- Desmoid Tumour Foundation of Canada 3rd Annual Patient Networking & Fundraising Event

May 2, 2019 in Toronto, Canada
Organizers: Nancy Croitoru & The Smith Family



Patients celebrate Running for Answers' 10th anniversary in Philadelphia!

SIGNATURE DTRF EVENT

TENTH ANNUAL RUNNING FOR ANSWERS 5K & KIDS' FUN RUN, SEPTEMBER 22, 2019

Year 10 of Running for Answers 5K is in the books, and what a wonderful celebration it was!

625 people joined us on race day for a beautiful race course, free ice cream and cheesesteaks, yoga, Zumba... and, most importantly, to raise funds for desmoid tumor research!

Our Kids' Fun Run kicked off the beautiful fall morning with lots of tiny, fast feet, loud cheers and fans lining the out-and-back course. Afterwards, we were inspired by the welcome speeches of board members and desmoid tumor survivors Rachel Sitta and Kevin Reilly. Our #DesmoidSurvivor photo featured lots of color and we sang "Happy Birthday" on behalf of RFA's 10th year, such a big milestone for our community. Then, Nicole Pelullo led us in Zumba to get warmed up for the 5K and Jill Cummings cooled us down with post-race yoga.

Thank you to all attendees, fundraisers and donors for rallying around this patient-founded event for the past decade and helping us *SURPASS* our fundraising goal this year!! We are so grateful to the 26 RFA teams who brought so much energy to the event with their colorful attire and commitment to fundraising!

We would also like to take a moment to express our gratitude to our dedicated RFA Race Committee members, the race day volunteers, Don and Jeanne Conner and the Conner Catering team who make this event a wonderful experience for all who attend each year!

Upon returning, race attendees were encouraged to enjoy free cheesesteaks and ice cream. Yogi Jill Cummings welcomed runners to join her for a post-race stretch.

Steve Portnoy managed our award ceremony which recognizes community members that we have lost to desmoid tumors, and we celebrated our award winners who continue to drive us toward a cure by creating awareness and raising funds for research.

Free cheesesteaks and ice cream cones along with other race snacks and coffee were provided by our event sponsor, Conner Catering. Other generous sponsors included Fox Chase Cancer Center, PHILADELPHIA RUNNER, 6abc, ADH Communications and Philadelphia Parks & Recreation.



2019 Annual Patient Meeting in Philadelphia

DTRF PATIENT MEETINGS

REGIONAL PATIENT MEETING, APRIL 13, 2019, SAN FRANCISCO, CALIFORNIA

In an effort to convene and educate the patient/caregiver community on the west coast, DTRF hosted 50 attendees at a Regional Patient Meeting in South San Francisco, CA, on April 13th.

Presentations included updates on new treatments and clinical trials. The Stanford Sarcoma Team formed a mock tumor board onstage and discussed how they collaborate to determine the best course of treatment for patients. Attendees also learned about desmoid tumor pathology and targeted treatment options.

Chris Barry, a local patient, shared his journey as an FAP patient.

Special thank you to our sponsors, event photographer Petal & Pear, Co. and videographer Maya Curry at Virtual Ground.

Presentations at the meeting included:

Chris Barry, Desmoid Tumor Patient.

Casey Cunningham, MD, Chief Medical Officer, Iterion Therapeutics (formerly Beta Cat Pharmaceuticals, Inc.), “Update on the recent launch of Phase I trial for Tegavivint.”

Kristen Ganjoo, MD, Associate Professor of Medicine (Oncology) & Director, Stanford Sarcoma Program, Stanford University Medical Center, “The Stanford Desmoid Tumor Board.”

Pejman Ghanouni, MD, PhD, Assistant Professor of Radiology, Stanford School of Medicine, “Treatment of desmoid tumors with magnetic resonance imaging guided High Intensity Focused Ultrasound (HIFU) and cryoablation.”

Shivaani Kummar, MD, FACP, Director of the Translational Oncology and Phase I Clinical Research Programs, Stanford University, “Targeted treatments for desmoid tumors.”

L. Mary Smith, PhD, VP of Clinical Research & Development, SpringWorks Therapeutics, “An update on Phase 3 trial of nirogacestat.”

Matthew van de Rijn, MD, PhD, Professor, Department of Pathology, Stanford University Medical Center, “The pathology of desmoid tumors.”

Jeanne Whiting, President and Co-Founder of DTRF, “The DTRF’s accomplishments.”

ANNUAL PATIENT MEETING, SEPTEMBER 21, 2019, PHILADELPHIA, PENNSYLVANIA

The DTRF welcomed roughly 200 attendees to our Annual Patient Meeting in Philadelphia on Saturday, September 21st.

Many physicians attended, offering great opportunities for physician-patient interaction. The meeting provided invaluable information and we made wonderful connections.

The day began with our Speed Desmoidian-ing Networking Event facilitated by Patient Advocate Dakota Fisher-Vance. The event convened a group of 25 for powerful one-on-one discussions about the patient and caregiver experience.

During the meeting, we heard updates on two current clinical trials for desmoid patients: SpringWorks Therapeutics' Phase 3 trial for nirogacestat and Iterion Therapeutics' Phase 1 trial for Tegavivint. We also heard a preliminary presentation on the findings of the global consensus paper (to be published soon), a live example of the DTRF Virtual Tumor Board, an update on research regarding the S45F desmoid tumor mutation, and more.

Also, we were inspired hearing Joe Erickson talk about his patient experience and his dedication to helping fund research for a cure.

Special thanks go to ADH Communications for videography, and SpringWorks Therapeutics for a generous Silver Sponsorship of the meeting.

Our patient meeting presentations included:

Robert Benjamin, MD, Clinical Professor, Sarcoma, The University of Texas- MD Anderson Cancer Center, "*Overview of desmoid tumors.*"

Jesse Boehm, PhD, Scientific Director of the Cancer Dependency Map, The Broad Institute of MIT and Harvard, "*Using genome-scale CRISPR screening to create a Desmoid Tumor Dependency Map.*"

Casey Cunningham, MD, Chief Medical Officer, Iterion Pharmaceuticals, "*Update on the recent launch of Phase 1 trial of Tegavivint.*"

Joe Erickson, Desmoid Tumor Patient.

Joseph Erinjeri, MD, PhD, Interventional Radiologist, Memorial Sloan Kettering Cancer Center, "*Cryoablation as a desmoid tumor treatment.*"

Bernd Kasper, MD, PhD, Professor, Interdisciplinary Tumor Center, Sarcoma Unit, Mannheim University Medical Center, "*The management of desmoid tumors: a joint global evidence-based consensus guideline approach for adult and pediatric patients.*"

Alexander Lazar, MD, PhD, Director, Department of Pathology, The University of Texas- MD Anderson Cancer Center, "*The pathology of desmoid tumors.*"

Raphael Pollock, MD, PhD, FACS, Director, The Ohio State University Comprehensive Cancer Center, "*The S45F Desmoid Story: Worth revisiting?*"

Mary Smith, PhD, Senior Vice President of Clinical Research & Development, SpringWorks Therapeutics, "*Discussion of the phase 3 study design and brief update.*"

Kim van der Zande, Co-Founder, Contactgroup Desmoid and **Christina Baumgarten**, Co-Founder, Sarcoma Patients EuroNet (SPAEN) and Founder, sos-desmoid e.V. Germany, "*International patient advocacy collaboration.*"

Aaron Weiss, DO, Associate Professor of Pediatrics, Maine Medical Center, "*The tumor board: A behind-the-scenes look.*"

Breelyn A. Wilky, MD, Associate Professor, University of Colorado Anschutz Medical Campus and **Martin McCarter, MD**, Professor of Surgery, Surgical Oncology, University of Colorado Anschutz Medical Campus, "*If in doubt, should we cut it out? Unique challenges of intra-abdominal desmoid tumors.*"



OUR TEAM

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**“Live,
Breathe,
Beat Desmoid
Tumors!”**

Motto of Brianna Jackson, RFA
Captain of Team Bri





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