

# WE WILL FIND A CURE TOGETHER.....

2018 ANNUAL REPORT



THE DESMOID TUMOR  
RESEARCH FOUNDATION

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## A LETTER FROM THE CO-FOUNDERS

Dear Friends,

We are pleased to present our 2018 Annual Report. This year proved to be another banner year in our progress toward finding new treatments for desmoid tumors! With the support of the professional and the patient communities we're moving forward with accelerating speed.

Exciting developments in 2018 included:

**Research Grant Funding.** The funding of cutting-edge collaborative research continues to be our priority. Discoveries made through desmoid tumor research also may be applicable to many more common diseases such as colon, breast, lung, ovarian and pancreatic cancers.

This year we funded nine new or continuing multi-year grants, as described on page 6.

**Clinical Trials.** During the annual meeting of the American Society of Clinical Oncology (ASCO), the results of the pazopanib phase II clinical trial and the sorafenib phase III trial were shared. Both drugs are considered promising treatments for patients with desmoid tumors. In a landmark accomplishment, in December, the article setting forth the sorafenib trial results by DTRF Scientific Director Dr. Mrinal Gounder was published in the prestigious *New England Journal of Medicine*. Then the 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 is showcased with others showing "major breakthroughs in clinical cancer research and care." ([Read more](#) in the article entitled "Clinical Cancer Advances 2019: Annual Report on Progress Against Cancer From the American Society of Clinical Oncology"; and on [Conquer Cancer's website](#).)



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

In addition to the above trials, the Phase I trial in Tegavivint from Iterion therapeutics will open early next year. Iterion explains, "Tegavivint is a potent and specific inhibitor of nuclear beta-catenin activity and Wnt gene expression, both of which are implicated in a broad range of cancers including desmoid tumors. Beta-catenin also plays an important role in normal cell function. A unique characteristic of Tegavivint is that it has been shown in multiple non-clinical studies to inhibit beta-catenin's role in activating cancer genes without affecting its role in maintaining normal tissue function."

**DTRF Desmoid Tumor Patient Registry.** The DTRF Desmoid Tumor Patient Registry ([dtrf.iamrare.org](http://dtrf.iamrare.org)), which we set up in coordination with the National Organization of Rare Disorders (NORD) and the FDA, continues to glean important data regarding the natural history of the disease. With more patients participating every year, the data will become more and more valuable in aiding research.

**Facilitating tissue donation for research.** Two years ago, DTRF was selected as one of ten rare cancer groups to participate in a tissue donation project organized by the Rare Cancer Research Foundation in conjunction with the Broad Institute of MIT and Harvard. With patient participation via an online consent form at [pattern.org](http://pattern.org), desmoid samples were sent to the Broad's Cancer Cell Line Factory resulting in the development of multiple desmoid tumor cell lines. After further testing, these cell lines will be made available to researchers worldwide and will also facilitate future desmoid tumor research at The Broad Institute.

**PRO Tool.** The Patient Reported Outcome Tool created by a collaboration among DTRF, Dr. Mrinal Gounder of Memorial Sloan Kettering Cancer Center and IQVIA, is ready to be validated and will be used in new clinical trials opening next year.

**Researchers Collaborate.** In September, we held our Fifth International DTRF Desmoid Tumor Research Workshop in Philadelphia with another increase in attendance. Over 55 researchers from the United States, Europe and Asia participated. We are continuing to build worldwide collaborative networks for the advancement of the field.

**Virtual Tumor Board.** Working with our Scientific & Medical Advisory Boards we focused our efforts on launching the DTRF Virtual Tumor Board for clinicians to present their most challenging cases. In 2018 we hosted four quarterly tumor board calls, and physicians and patients have been very grateful for assistance from the experts from around the world who join the calls. We are encouraged by the direct impact that this tumor board has already had on the care received by desmoid tumor patients.

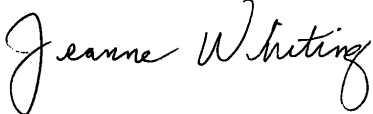
**Mouse Models.** Last year, we announced the beginning stages of the DTRF-funded transgenic mouse models project, a project that our DTRF Scientific Advisory Board identified as critical to the advancement in therapeutic drug development for desmoid tumors. Prior to the project's launch, there were no genetically modified mice that recapitulated the genetics of the disease involving the two most common beta catenin (CTNNB1) mutations found in desmoids. We are pleased to report that these mouse models have been created and we have now advanced to the next phase of this exciting project. The Principal Investigator, Ben Alman, MD, explains, "We will now proceed to test the mice to determine how well they mimic human desmoid tumors. If successful, the mice will be made generally available to researchers world-wide. By using a mouse which better reflects the genetics of desmoid tumors, we can substantially advance the work of scores of researchers throughout the world. These animals can be used to better understand how desmoid tumors grow, and to test new drugs or other therapeutic approaches."

**Collaboration with other desmoid tumor organizations worldwide.** We continue to network with desmoid tumor patient organizations in other countries such as: The Italian Desmoid Tumor Association (Associazione Italiana Tumore Desmoide); Sarcoma Patients EuroNet (SPAEN), Europe; sos-desmoid e.V. (Germany); and SOS Desmoide (France); Contactgroep Desmoid (The Netherlands); and The Desmoid Tumour Foundation of Canada. More information about these organizations and other social media entities here.

**Global Consensus Paper.** DTRF visited Milan, Italy in June for a meeting with 35 desmoid tumor specialists from North America, Europe and Asia who are initiating a global consensus paper on medical treatment for desmoid tumors. The paper, which DTRF helped fund, will eventually be available in two versions: (1) a long version presented in booklet form, and (2) a more concise version which they hope to publish in a top scientific journal. This global consensus paper will be an important resource and guide to doctors and patients around the world. It will also help clinicians in approaching their countries' regulatory agencies about receiving approval for medical therapies. DTRF is proud to help fund this important project with donations you have helped raise! You can read more about the grant for this paper at the link below by clicking on the project title: "An evidence based consensus on the treatment of desmoids/aggressive fibromatosis."

There are so many exciting developments on the horizon now! As we move forward with strategic partnerships, generous donations from small to large, and ongoing support from the patient and professional communities, we look forward to accelerated progress in the year ahead. Thank you for joining us to help propel our journey forward!

With warm regards,



**Jeanne Whiting**  
President and Co-founder



**Marlene Portnoy**  
Executive Director and Co-founder



# WHAT WE DO AND WHY IT MATTERS

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## 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 and Western Regional Patient Meeting provide 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.





2018 DTRF Research Workshop

## DTRF-FUNDED 2018 GRANTS

DTRF is pleased to note the following new or continuing projects supported by grants in 2018.

### New 2018 Grants

- » Gerlinde Wernig, MD, Assistant Professor of Pathology, Stanford University School of Medicine, “c-June-inducible mice, to study the pathomechanism of desmoid-type fibromatosis in vivo with particular attention to the role of b-catenin/wnt and Notch pathways.” (Jointly funded by The DTRF and The Desmoid Tumour Foundation of Canada).
- » **Raphael Pollock, MD, PhD**, The Ohio State University, “The role of the tumor microenvironment in S45F desmoid tumor chemotherapeutic resistance.”
- » **Benjamin Alman, MD**, Duke University and **Kelly Mercier, PhD**, RTI International, “Stable isotope resolved metabolomics to interrogate the interactions between stroma and desmoid tumors.
- » **Benjamin Alman, MD**, Duke University, “A genetically targeted mouse model of desmoid tumors.” (Jointly funded by The DTRF and The Desmoid Tumour Foundation of Canada)
- » **O. Hans Iwenofu, MD, FCAP**, Co-Principal Investigator, **Michael Freitas, PhD**, The Ohio State University, “Quantitative Proteomics Analysis of desmoid-type fibromatosis.” (*Recipient of The DTRF’s James R. Ryan Family Foundation Research Award*)
- » **Benjamin Wilke, MD**, Co-Principal Investigator, and **Steven Attia, DO**, The Mayo Clinic, “A pilot study of intralesional injection of triamcinolone acetonide for desmoid tumors.” (*Recipient of The DTRF’s Wong Family Research Award*)
- » **Peter Hohenberger, MD, PhD**, Medical Faculty, Mannheim, University of Heidelberg, Germany, “An evidence-based consensus on the treatment of desmoids/aggressive fibromatosis.” (*Recipient of The DTRF’s Matt Zechmann Research Award*)

### Multi-year Grants continuing in 2018

- » **Benjamin Alman, MD**, and **Mushriq Al-Jazrawe, HBS, PhD Candidate**, The Hospital for Sick Children, Toronto, Ontario, Canada. “Single cell-derived clonal analysis of desmoid tumors to investigate tumor-stroma interactions.”
- » **Kris Vleminckx, PhD**, Ghent University, Belgium, “Identifying targets for therapy in a novel genetic *Xenopus* model for desmoid tumor formation.”





## FINANCIALS

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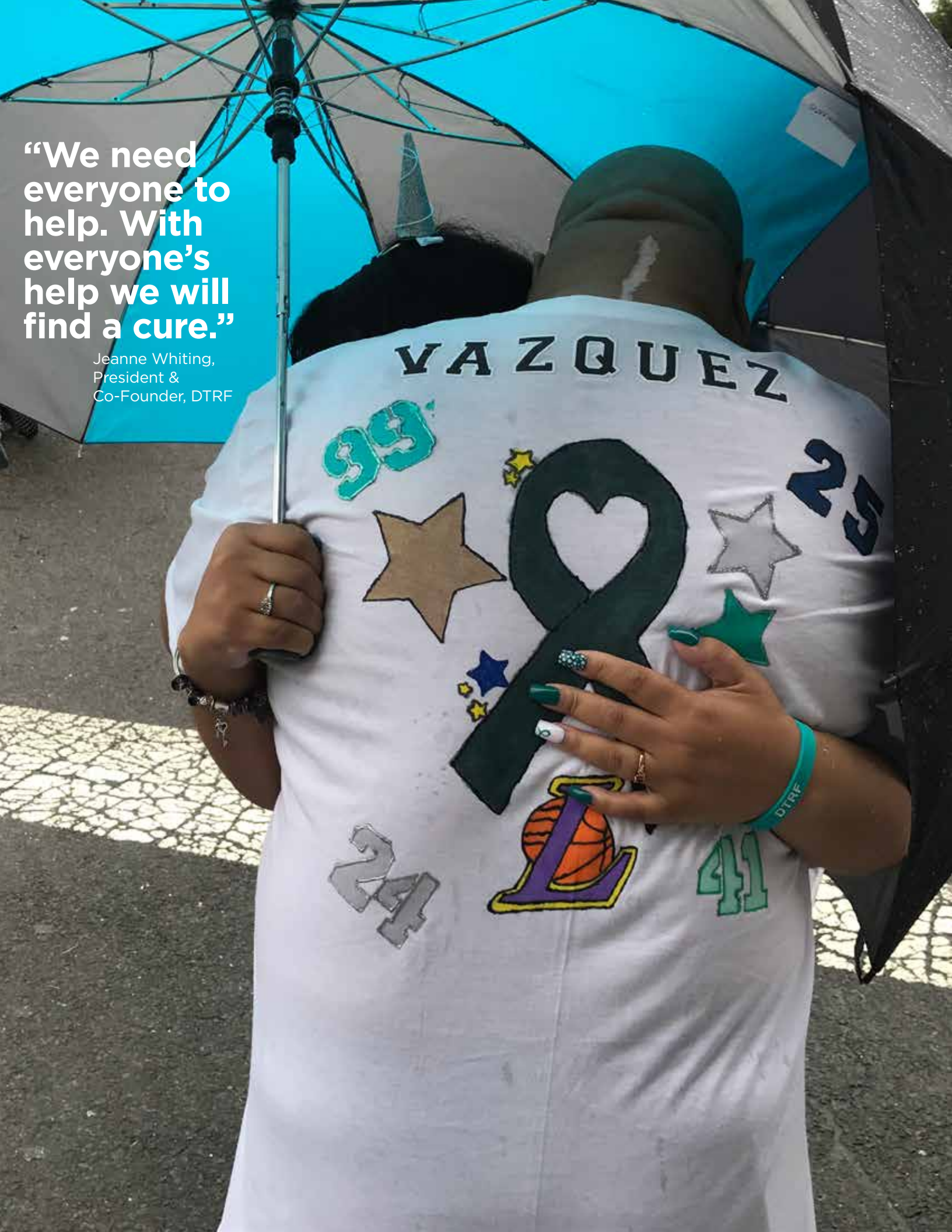
The Desmond Tumor Research Foundation depends on the generosity of donors to carry out its mission and we value every dollar received. DTRF is a 501(c)(3) tax-exempt organization and donations are tax deductible to the extent allowed by law.

View our:

- » [IRS 501\(c\)\(3\) determination letter](#)
- » [2018 IRS Form 990](#)
- » [2018 Audited Financial Statement](#)

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

Jeanne Whiting,  
President &  
Co-Founder, DTRF





# FIFTH INTERNATIONAL DESMOID TUMOR RESEARCH WORKSHOP

DTRF holds an annual research workshop to facilitate international scientific education and collaboration. This year we had 55 participants coming from around the world. Participants included those involved in 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)  
bioMerieux  
Children's Hospital, Los Angeles  
Contactgroup Desmoid  
Duke University Health System  
Erasmus Medical Center  
Focused Ultrasound Foundation  
Fondazione IRCCS Istituto Tumori di Milano  
Fox Chase Cancer Center  
Ghent University  
IQVIA  
Institut Bergonie  
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  
Northwell Cancer Institute  
Rabin Medical Center  
Sarcoma Alliance for Research Through Collaboration (SARC)  
Sarcoma Patients EuroNet (SPAEN)  
SpringWorks Therapeutics  
Stanford University  
Summit Therapeutics  
The Mayo Clinic  
The Ohio State University Comprehensive Cancer Center  
University of Miami Sylvester Comprehensive Cancer Center  
University of Minnesota  
University of Pennsylvania  
University of Toronto  
Virgen Del Rocio University Hospital

## The following presentations were given at the 2018 Research Workshop:

**Benjamin Alman, MD**, Professor and Chair, Department of Orthopedic Surgery, Duke University, "Collaborative research: A mouse model for desmoid tumors and collaboration for a cure."

**Gerlinde Wernig, MD**, Assistant Professor of Pathology, Stanford University, "To study the contribution of JUN to the pathomechanism of desmoid-type fibromatosis with a particular focus on the interaction with b-catenin/wnt and Notch pathways."

**O. Hans Iwenofu, MD, FCAP**, Associate Professor, Divisions of Head & Neck Pathology and Soft Tissue & Bone Pathology, Department of Pathology, The Ohio State University, "Quantitative Proteomics Analysis of Desmoid-Type Fibromatosis."

**Jesse Boehm, PhD**, Associate Director, Broad Cancer Program, Institute Scientist, Broad Institute, "Partnering with patients to create a desmoid tumor dependency map."

**Peter Hohenberger, MD, PhD**, Medical Faculty, Mannheim, University of Heidelberg, Germany, "The Management of Desmoid Tumors: A joint global evidence-based consensus approach for adult and pediatric patients."

**Chiara Colombo, MD**, Surgical Oncologist, Fondazione IRCCS Istituto Tumori Milano, "Can Wait and See be the standard of care for initial approach to primary sporadic desmoid tumors? Preliminary data from an Italian Sarcoma Group prospective study."

**Kris Vleminckx, PhD**, Professor, Animal Disease Modeling, Ghent University, Belgium, "Identifying targets for therapy in a novel genetic *Xenopus* model for desmoid tumor formation."

**Margaret von Mehren, MD**, Director of Sarcoma Oncology, Fox Chase Cancer Center, "NCCN guidelines for desmoid tumors."

**Yoshihiro Nishida, MD, PhD**, Rehabilitation & Orthopedic Oncology, Nagoya University Graduate School of Medicine, "Effects of uniaxial stretch forces and matrix stiffness on the cell behavior of desmoid-type fibromatosis."

**Eldad Elnekave, MD**, Director of Interventional Oncology Clinic, Rabin Medical Center, "Doxorubicin eluting intra-arterial therapy for pediatric extra-abdominal desmoid fibromatosis- a promising approach for a perplexing disease."

**Fariba Navid, MD**, Associate Professor, Children's Hospital Los Angeles, "Pediatric gamma secretase inhibitor study."

**Jessica Foley, PhD**, Chief Scientific Officer, Focused Ultrasound Foundation, "Focused Ultrasound: State of the field and potential for treating desmoid tumors."

**Antoio Italiano, MD, PhD**, Medical Oncologist and Head of Early Phase Trials and Sarcoma Units, Institut Bergonié, "Pazopanib versus IV methotrexate/vinblastine in adult patients with progressive desmoid tumors."

**Kelly Mercier, PhD**, Adjunct Associate, Duke University and Sr. Clinical Scientist at bioMerieux, "An update on the DTRF Patient Registry and National History Study."

**Mrinal Gounder, MD**, Assistant Professor and Medical oncologist, Memorial Sloan Kettering Cancer Center, "Phase III, randomized, double blind, placebo-controlled trial of sorafenib in desmoid tumors."

**Raphael Pollock, MD, PhD, FACS**, Professor and Director, Division of Surgical Oncology, Surgeon in Chief, James Comprehensive Cancer Center, The Ohio State University Wexner Medical Center, "RUNX3 can abrogate CTNNB1 S45F mutation impaired apoptotic responses in desmoid tumors."

**Mushriq Al-Jazrawe, HBSc, PhD Candidate**, University of Toronto, Laboratory Medicine & Pathobiology, "Stroma-derived secreted factors increase desmoid tumor cell proliferation."

**Milea Timmergen, MD, PhD candidate**, Surgical Oncology/Medical Oncology, Erasmus MC, "Mutation stratification of desmoid tumors using a radiogenomics approach."

**Aaron Weiss, DO**, Pediatric oncologist, Maine Medical Center, "Feasibility of pre-operative mTOR inhibitor sirolimus in children and young adults with desmoid tumor."

**Joanna Przybyl, PhD**, Postdoctoral Research Fellow, Department of Pathology, Stanford University, "Gene expression profiling of desmoid tumors."



2017 Tucking for Tumors Fundraiser

## 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:

### **Fundraising & Networking Event**

May 3, 2018 in Toronto, Canada  
Organizer: Desmoid Tumour Foundation of Canada

### **Join Us in Finding a Cure for Isaac**

May 4, 2018 in Alameda, CA  
Organizer: Yating Wong

### **5th Desmoid Dash**

May 12, 2018 in Mendota Heights, MN  
Organizers: The Zechmann Family

### **Voorhees Middle School Walk-a-thon**

May 25, 2018 in Voorhees, NJ  
Organizers: Christina Kosyla

### **A Lemonade Stand in Support of DTRF**

May 27, 2018 in Burlington, Ontario  
Organizer: Jennifer Stubbs

### **Clothing Drive & Chicken Dinner**

June 2018 in Lyons, PA  
Organizers: Corinne Conrad and Rochelle Miller

### **10th Annual Lap4Life**

June 16, 2018 in Newburgh, NY  
Organizer: Maddalena Casabianca Reade and Lap4Life

### **Beer, Bags and Boards Fundraiser Benefiting DTRF**

September 22, 2018  
Organizer: Char Leeson

### **3rd Annual JoeStrong Volleyball Tournament**

October 27, 2018 in Austin, Texas  
Organizer: Joe Erickson

### **Halloween Party to Support DTRF**

October 27, 2018  
Organizer: Cordero

### **Lap4Life Brewery Fundraiser**

November 18, 2018 in Newburgh, NY  
Organizer: Maddalena Casabianca Reade & Lap4Life

### **2018 Tucking for Tumors**

November 27, 2018 in Cary, NC  
Organizer: Dr. Kelly Mercier





2018 Running for Answers 5K

## SIGNATURE DTRF EVENT

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### **Ninth Annual Running for Answers 5K & Kids' Fun Run, September 23, 2018**

The day after the Patient Meeting, on Sunday, September 23rd, we celebrated RFA's 9th year! We ran our 5K at the Please Touch Museum once again, and although it rained, our runners and walkers shined all morning.

Approximately 400 race participants joined us with over 35 teams. Largest teams included Team Rachel, Kate's Krewe, the Unicorn Squad, Robin's Runners, and Team Margie which had teammates from Ecuador once again!

Opening ceremonies included our notable survivor photo and super-fast, superhero-themed Kids' Fun Run! Race attendees lined the short out and back course cheering as little feet dashed. It was a great way to get our day started!

Race day speakers included Christina Kosyla, who expressed her gratitude for the community and for DTRF and reminded us that "we are the answers". Kevin Reilly echoed her sentiments reminding us how far we've come in so little time. As always, this hometown hero finished by leading us in an EAGLES cheer.

Chris Allegra warmed us up with some pre-race Zumba, then we were off to do our 5K!

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 celebrate 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, Altoonian Photography, PHILADELPHIA RUNNER, 6abc, ADH Communications and Philadelphia Parks & Recreation.





## DTRF PATIENT MEETINGS

### Western Regional Patient Meeting, April 28, 2018, Salt Lake City, Utah

In an effort to convene and educate the patient/caregiver community on the west coast, DTRF hosted 50 attendees at its First Western Regional Patient Meeting in Salt Lake City on April 28, 2019.

We were excited to get updates on trials in two potential new desmoid tumor treatments: a Phase III trial in the GSI inhibitor Nirogacestat (a gamma secretase inhibitor) by SpringWorks planned for early 2019, and a Phase I study of Tegavivint (a beta catenin inhibitor) by Iterion Therapeutics (formerly Beta Cat Pharmaceuticals) that has already begun dosing patients.

We received updates about the DTRF Patient Registry, learned about HIFU and received a broad overview of desmoid tumors.

Yating Wong expressed her gratitude toward the community and shared her experience as the caregiver of a pediatric desmoid patient.

Special thank you to our sponsors, event photographer Farrell Lafferty and videographer Trenton Brown.

Our patient meeting presentations included:

**R. Lor Randall, MD, FACS**, *Director of Sarcoma Services, Huntsman Cancer Institute, University of Utah*, “Desmoid tumors: The nonmalignant malignancy.”

**Raffi S. Avedian, MD**, *Assistant Professor of Orthopaedic Surgery, Stanford University*, “Magnetic Resonance Guided Focused Ultrasound Treatment for desmoid tumors.”

**Jon Northrup**, *CEO & Co-Founder, Iterion Therapeutics (formerly Beta Cat Pharmaceuticals, Inc.)*, “Tegavivint (BC-2059), an emerging potential treatment for desmoid tumors.”

**Yating Wong**, *Mother of pediatric desmoid tumor patient*

**Victor Villalobos, MD, PhD**, *Assistant Professor, Director of Sarcoma and T3 (Target-based Therapeutics Team), University of Colorado, Denver*, “Nirogacestat (a gamma secretase inhibitor) in desmoid tumors.”

**Mary Smith, PhD**, *Vice President of Clinical Research & Development, SpringWorks Therapeutics*, “Phase 3 Nirogacestat clinical study update.”

**Kelly Mercier, PhD**, *Adjunct Associate, Duke University*, “The Natural History of Desmoid Tumors: What we are learning from the DTRF Patient Registry and Natural History Study.”

## Annual Patient Meeting, September 22, 2018, Philadelphia, Pennsylvania

DTRF welcomed roughly 200 attendees to our annual Patient Meeting in Philadelphia, September 22nd. Many physicians attended this year, offering great opportunities for physician-patient interaction.

We were excited to get updates from SpringWorks planned for early 2019, and Iterion Therapeutics (formerly Beta Cat Pharmaceuticals). We also had reports on past desmoid tumor trials in sorafenib and pazopanib that showed encouraging results for patients.

Presentations also enlightened us about minimally invasive MR-guided HIFU and needle ablation treatments in children, and about an important new resource for physicians handling difficult cases called the DTRF Virtual Tumor Board. Other talks informed us in general about the disease and treatments and answered frequently asked questions (FAQ) in desmoids. We also learned more about how to understand MRI imaging of desmoids, and how patients can deal with the psychological impacts of desmoid tumors.

One presentation highlighted how much progress we've seen with researchers around the world collaborating as teams, and patients working together with researchers. For example, patients can help contribute to research by participating in the tissue donation program (by consenting prior to surgery at Pattern.org), as well as in the DTRF Desmoid Tumor Patient Registry (at dtrf.iamrare.org). Patient participation is key to the success of these important initiatives.

We were inspired hearing patients Kevin Reilly and David Croitoru talk about their patient experiences and their dedication to helping fund research for a cure.

Special thanks go to Altoonian Photography for event photos, Bryan Schaefer for videography, and SpringWorks Therapeutics for a generous Gold Sponsorship of the meeting.

Our patient meeting presentations included:

**Casey Cunningham, MD**, *Chief Medical Officer, Beta Cat Pharmaceuticals*, "Phase I study to evaluate safety of Tegavivint in subjects with progressive desmoid tumors."

**Benjamin Alman, MD**, *Professor and Chair, Department of Orthopedic Surgery, Duke University*, "What we can do together in research."

Remarks by **David Croitoru**, Desmoid tumor patient and advocate.

**Mrinal Gounder, MD**, *Assistant Professor and Medical Oncologist, Principal Investigator of phase III trial of sorafenib, Memorial Sloan Kettering Cancer Center*, "Phase III, randomized, double blind, placebo-controlled trial of sorafenib in desmoid tumors."

**Antoine Italiano, MD, PhD**, *Medical oncologist and Head of Early Phase Trials and Sarcoma Units, Institut Bergonié, France*, "Pazopanib versus IV methotrexate/vinblastine in adult patients with progressive desmoid tumors."

**Carol Kessler, MD**, *MDiv, Child, Adolescent & Adult Psychiatrist*, "Desmoid tumors: The story of a rare disease as told by its sufferers."

**Robert Lefkowitz, MD**, *Associate Professor, Radiology, Weill Cornell Medical College/Memorial Sloan-Kettering Cancer Center*, "MR Imaging in desmoid tumors."

**Karun Sharma, MD, PhD, FSIR**, *Director, Interventional Radiology, Principal Investigator, Bioengineering Initiative, SZI, Children's National Medical Center*, "Non-invasive and minimally-invasive image-guided treatment options for desmoid tumors: MR-HIFU and needle ablation."

**L. Mary Smith, PhD**, *Vice President of Clinical Research & Development, SpringWorks Therapeutics*, "Brief update on the planned Phase III study for nirogacestat."

**Aaron Weiss, DO**, *Associate Professor of Pediatrics, Maine Medical Center*, "A new platform for discussion of challenging desmoid tumor cases: DTRF Virtual Tumor Board."

**Breelyn Wilky, MD**, *Assistant Professor in Hematology/Oncology, University of Miami Sylvester Comprehensive Cancer Center*, "FAQs in desmoid tumors."



## OUR TEAM

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### Leadership, Volunteers and Staff

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MARLENE PORTNOY  
Executive Director and Co-founder

JEANNE WHITING  
President and Co-Founder

LYNNE HERNANDEZ  
Director of Events, Operations and Outreach

MRINAL GOUNDER, MD, Memorial Sloan Kettering  
Cancer Center  
Scientific Director

AMANDA HOFFMAN  
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KATE WENC  
Published Research Advisor

PHILIP GRAND  
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NICOLE ZECHMANN  
Human Resources Leader, Ecolab, Inc.

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University Of Michigan Health System

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RICK HAAS, MD, PhD  
Netherlands Cancer Institute

PETER HOHENBERGER, MD, PhD  
University of Heidelberg

MRINAL GOUNDER, MD  
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Ohio State University Comprehensive Cancer Center

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Harvard Medical School

VINOD RAVI, MD  
MD Anderson Cancer Center

VICTOR VILLALOBOS, MD, PhD  
University of Colorado-Denver

SYLVIA STACCHIOTTI, MD  
Fondazione IRCCS Istituto Nazionale Dei Tumori

KEILA TORRES, MD, PhD  
MD Anderson Cancer Center

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Memorial Sloan Kettering Cancer Center

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Stanford University School of Medicine

JEAN PATY, PhD  
IQVIA

MATTHEW VAN DE RIJN, MD, PhD  
Stanford University Medical Center



**“We had a fantastic weekend. Met some great people, talked to the doctors. It really meant a lot to us to be there.”**

Jeni P., Mother of desmoid tumor patient, Zeppi, about Patient Meeting and RFA weekend





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