

WE WILL FIND A CURE
TOGETHER

(VIRTUALLY IF NECESSARY!)

2020 ANNUAL REPORT



THE DESMOID TUMOR
RESEARCH FOUNDATION

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A LETTER FROM THE CO-FOUNDERS



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

Dear friends,

We thank everyone who has helped make this landmark year of 2020 a year of progress for DTRF. September of 2020 marked the 15th anniversary of DTRF's founding! Fifteen years is a major milestone. While half of rare diseases don't have a foundation or a research support group (source: Global Genes), we are grateful for the continued support that enables us to still be here fighting for you.

The year 2020 will go down in history as one of the most challenging for non-profits due to the worldwide COVID-19 pandemic. However, we are grateful for advisors, staff and volunteers who kept DTRF moving forward and thriving despite the year's challenges.

We pivoted to hold all of our meetings and September annual events virtually, and nearly tripled our participation in research meetings. Virtual communication and conferences have in many ways fostered even more effective collaboration and worldwide participation in our important initiatives like the DTRF Virtual Tumor Board and the annual DTRF International Research Workshop.

We've been gratified to hold interactive patient meetings and networking events to support and sustain our patient and caregiver community from all corners of the planet. And our community rallied around our Desmoid Tumor Awareness Month and Virtual Challenge fundraising event to keep the research funding going.

As always, our mission continues to be funding research toward a cure, and advocating for patients. We are grateful for the virtual technology that has brought us together this year, and we look forward to in-person meetings in the future.

Celebrating the 15th anniversary of our founding has been a poignant milestone. DTRF is grateful every day for our passionate community that has rallied to support us, and for our scientific and medical advisors and researchers. And we deeply appreciate our generous donors and fundraisers who have stayed with us for the long haul, and the new ones who join in the cause every year! Thank you all!

Sincerely,

DTRF Co-founders

Jeanne Whiting
President and Co-founder

Marlene Portnoy
Executive Director and Co-founder



WHAT WE DO AND WHY IT MATTERS

OUR MISSION

Founded in 2005, the mission of The Desmoid Tumor Research Foundation is to aggressively fund research to accelerate the development of improved therapies, and ultimately find a cure for desmoid tumors. We collaborate with dedicated researchers and clinicians worldwide to improve the lives of patients through education, awareness and support. 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 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 more common 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.**

2020 KEY EVENTS AND ACHIEVEMENTS

JANUARY 2020

DTRF's Partnership with The Broad. We continued our partnership with the Broad Institute of MIT & Harvard. **Their Rare Cancer Dependency Map Initiative has created patient models from living tissue and is using CRISPR/drug data** to help researchers map the best desmoid tumor drug targets. We're grateful to our patients who donated tissue which has been used to create cell lines that are ready for CRISPR technology. [Learn more about The Broad's Rare Cancer Dependency Map Initiative, which includes desmoid tumors.](#)

FEBRUARY 2020

The first of its kind Global Consensus Paper was published in the European Journal of Cancer. Supported by DTRF, this project came to fruition thanks to the hard work and collaboration of an international group of physicians and scientists, as well as patient advocates. By evaluating existing evidence from prior scientific publications, and incorporating the input of desmoid tumor experts worldwide, the paper is the first evidence-based consensus of its kind on the treatment of desmoid tumors. It answers critical questions regarding approach to treatment options, types of treatment, and pain management. There are varying treatments used for desmoid tumors, and access to medical therapies and expertise varies greatly by country. DTRF has made it a priority to improve this situation by making this collaborative paper available to physicians and patients worldwide. This paper is, in part, the result of a 2018 DTRF grant entitled *An evidence-based consensus on the treatment of desmoids/aggressive fibromatosis*.

APRIL 2020

DTRF research funding and patient registry progress. This year, "rare cancers" was one of three new areas of medical research added to the Congressionally Directed Medical Research Programs (CDMRP), a Department of Defense (DoD) research funding program. Representing DTRF, Dr. Kelly Mercier presented at the CDMRP Stakeholders' meeting, which aimed to capture the important aspects that are needed to be considered in the rare cancer funding mechanism. The stakeholders included participants from the National Institutes of Health (NIH), the U.S. Food and Drug Administration (FDA), and patient advocacy groups who participate and fund rare cancer research. Dr. Mercier described the progress that DTRF has made in funding research in desmoid tumors and characterized the types of research (basic, translational, and clinical), as well as the need for increased data sharing and oversight.

MAY 2020

Timely Tumor Talks During the pandemic, we continued our community networking efforts virtually with a spring "Timely Tumor Talks" event. This virtual networking opportunity allowed patients and caregivers to connect from their own homes. Desmoid patients and caregivers are not alone in their desmoid journey!

AUGUST 2020

Podcast: The Behind-the-Scenes Story of the Breakthrough Sorafenib Clinical Trial. DTRF Co-founder, Marlene Portnoy, and DTRF Scientific Director, Dr. Mrinal Gounder of Memorial Sloan Kettering Cancer Center, recorded a conversation for the American Society of Clinical Oncology's (ASCO) Conquer Cancer Foundation's Annual "Your Stories" mini-podcast project. The conversation focused on the role of DTRF's patient advocacy in leading to the breakthrough clinical trial for sorafenib (Nexavar). [Listen to the podcast](#) by ASCO's ConquerCancer Foundation.

AUGUST 2020

Clinical Trial announcements this year: **SpringWorks Therapeutics Announced Full Enrollment of Phase 3 DeFi Trial Evaluating Nirogacestat in Adult Patients with Desmoid Tumors as follows:** “Nirogacestat has received Orphan Drug Designation from the U.S. Food and Drug Administration (FDA) for the treatment of desmoid tumors (June 2018) and from the European Commission for the treatment of soft tissue sarcoma (September 2019). The FDA also granted Fast Track and Breakthrough Therapy Designations for the treatment of adult patients with progressive, unresectable, recurrent or refractory desmoid tumors or deep fibromatosis (November 2018 and August 2019).”

Also, Iterion Therapeutics Initiated Enrollment of Phase 2a Dose Expansion Study of Tegavivint in Patients with Desmoid Tumors. Iterion’s press release explained: “The Phase 2a trial builds on a recently completed Phase 1 study that established safety and initial clinical efficacy of Tegavivint in patients with progressive desmoid tumors. It is expected to enroll up to 25 patients who will be treated with the recommended Phase 2 Dose (RP2D), which was established based on pharmacokinetic exposure levels and clinical responses in the recently completed Phase 1 study... ‘We are very pleased to advance the clinical development of Tegavivint in desmoid tumors as this disease target is greatly underserved and provides an optimal indication for demonstrating the drug’s safety and potential clinical utility in multiple cancer settings,’ said Rahul Aras, CEO of Iterion. ‘Our development plan for Tegavivint is to advance its development in desmoid tumors as a launching point for additional programs in acute myeloid leukemia, non-small cell lung cancer, and certain pediatric cancers for which nuclear β -catenin signaling has been identified as a potential therapeutic target.’”



SEPTEMBER 2020

DTRF's 15th Anniversary!

Fifteen years ago DTRF was co-founded by Jeanne Whiting and Marlene Portnoy. They met online when Jeanne was being treated for a desmoid tumor, as was Marlene’s husband. In their separate journeys they had quickly learned that the disease was very rare, there was little information available, few treatments that were only sporadically effective, no established treatment protocol, no FDA-approved treatment, and little research being done.

They decided to try to make a difference by creating a foundation in 2005. They’ve often referred to themselves as “two women at their kitchen tables” trying to make a difference. Fortunately, DTRF is still here and going strong 15 years after our founding! It has been a wonderful milestone to celebrate this year.



Swing for a Cure Event - Sept 28, 2020

SEPTEMBER 2020

DTRF's annual meetings were held virtually with great success. Keep reading for more details.

NOVEMBER 2020

Initiating a New Investigator Research Grant. This year we initiated the Dr. Dina Lev New Investigator Memorial Research Grant named in honor of Dina Chelouche Lev, M.D., an early leader in desmoid tumor research. Dr. Lev was one of the original recipients of research support from the Desmoid Tumor Research Foundation in 2007, starting a reciprocal relationship that continued until her untimely passing in 2020 at the age of 55. The award embodies Dr. Lev's endless enthusiasm and tireless effort toward moving the science of desmoid tumors forward, as well as her commitment to the training of young surgeons and scientists interested in connective tissue tumor oncology, including desmoid disease. The Dr. Dina Lev New Investigator Memorial Research Grant is given to promising new investigators who are dedicated to advancing the science of desmoid tumors with an eye toward exerting a long-term influence in the field.

NOVEMBER 2020

The new DTRF Coordinating Center (DTRFCC). Collaborative research has always been the priority at the heart of the Foundation. However, this initiative will take those efforts to the next level, further accelerating our journey to a cure. The DTRFCC aims to connect researchers and their data, and to promote increased purposeful collaboration across various fields of study. We're thrilled to announce that this project is now underway! Kelly Mercier, PhD, was named as the new Chair of the DTRFCC, and a search began for a new research director to lead the center. (Maneesh Kumar, MD, PhD was named Research Director of the DTRFCC in early 2021.)



DTRF-FUNDED 2020 GRANTS

NOTE: The COVID-19 pandemic interrupted or delayed research at many institutions, impacting our grant applications, awards and renewals in 2020. However, the following grants were made.

MULTI-YEAR GRANTS CONTINUING IN 2020

- » **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,” Year 2 of 3.
- » **Kris Vleminckx, PhD**, Ghent University, “Identifying targets for therapy in a novel genetic Xenopus model for desmoid tumor formation,” Year 2 of 2.

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](#)
- » [2020 IRS Form 990](#)
- » [2020 Audited Financial Statement](#)



DTRF 2020 SIGNATURE EVENTS

TOGETHER WE WILL VIRTUAL WEEKEND, SEPT. 25-27, 2020

For over a decade, we've prioritized our annual fall weekend in Philadelphia as the time when our community comes together face-to-face. With the COVID-19 pandemic we pivoted to virtual Zoom meetings, seeing an opportunity to grow and to reach more people than ever.

This year's **Together We Will Virtual Weekend** convened our largest number to date of medical professionals, patients and caregivers, and fundraisers for a full weekend of setting research priorities, learning, networking and connecting.

TOGETHER WE WILL... ADVANCE RESEARCH

Seventh International DTRF Desmoid Tumor Research Workshop, Sept. 25, 2020

Every year, DTRF holds an annual research workshop to facilitate international scientific education and collaboration. In the 2020 virtual format, we were pleased to have 190 registered attendees from 72 institutions in 32 different countries!

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 and Industry represented at the Workshop included:

All India Institute of Medical Sciences (India)
Angel H. Roffo Institute of Oncology, Univ of Buenos Aires, Argentina
Anwer Khan Modern Medical College, Bangladesh
Aretaieio University Hospital, Athens, Greece
Ayala Pharmaceuticals
Bilaspur University, India
Boston University
Cancer Institute of Iran
Children's Mercy Hospital
Children's Hospital Los Angeles
Chris O'Brien Lifehouse, Australia
Contactgroep Desmoid, Netherlands
Dana Farber Cancer Institute
Dmitry Rogachev Nat'l Medical Research Center of Pediatric Hematology, Oncology, Immunology
Duke University
Emory University
Erasmus Medical Center, Rotterdam the Netherlands
Fondazione IRCCS Istituto Tumori di Milano, Italy
Ghent University, Belgium
Herlev Hospital, Denmark
Hôpital Maisonneuve-Rosemont, Canada
Hospital de Clinicas, Paraguay
Huntsman Cancer Institute, University of Utah
IHOPe-Leon Berard Center, France
Institute of Cancer Research, United Kingdom
Instituto Nacional de Cancerologia, Mexico
Istituto Tumori Milano, Italy
Johns Hopkins Hospital
Kyushu University, Japan
LaserCure, India
London Sarcoma Service, University College, United Kingdom
Louisiana State University
Maine Medical Center
Mannheim University Medical Center, University of Heidelberg, Germany
The Mayo Clinic
MD Anderson Cancer Center
Memorial Sloan Kettering Cancer Center
Military Hospital of Tunis, Tunisia
Moffitt Cancer Center
Mount Sinai Hospital, University of Toronto, Canada
N.N. Priorov Institute of Traumatology and Orthopedics, Russia
Nagoya University, Japan
Nat'l Institutes of Environmental Health Sciences
National Cancer Center, Japan
National Cancer Institute
Nemours Children's Specialty Care
Oxford University Hospitals
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Rabin Medical Center, Israel
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University of Miami, Sylvester Comprehensive Cancer Center
Rede DO'R, Brazil
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The Chinese University of Hong Kong
The Ohio State University
University Hospital, Zurich, Switzerland
University of Arkansas for Medical Sciences
University of California- San Diego, Rady Children's Hospital
University of Colorado- Anschutz Campus
University of Florida
Utah Cancer Specialists
Vanderbilt University Medical Center



Together We Will Virtual Weekend, Sept. 25-27, 2020

THE FOLLOWING PRESENTATIONS WERE GIVEN AT THE 2020 RESEARCH WORKSHOP:

Benjamin Alman, MD, Professor & Chair, Orthopedic Surgery, Duke University, *"Mouse models in 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, The Broad Institute of MIT and Harvard, *"The Desmoid Tumor Dependency Map."*

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

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

Kelly Mercier, PhD, Adjunct Associate, Duke University; Medical Science Liaison, Jazz Pharmaceuticals, Inc., *"Stable isotope resolved metabolomics to interrogate the interactions between stroma and desmoid tumors."*

Joanna Przybyl, PhD, Instructor, Department of Pathology, Stanford University, *"Genome-wide DNA methylation profiling of desmoid tumors."*

Gerlinde Wernig, MD, Assistant Professor, Department of Pathology, and Tristan Lerbs, PhD, Post doctoral Researcher, Stanford University School of Medicine, *"Jun and its Connections with Wnt and Notch."*

Anne-Rose W Schut, MD, PhD candidate, Surgical Oncology, Erasmus Medical Center Cancer Institute, *"The mechanism of Sorafenib in desmoid-type fibromatosis."*

Javier Martin Broto, MD, PhD, Instituto de Biomedicina de Sevilla (IBIS), *"Activity of taxanes in progressive or symptomatic desmoid tumors."*

Breelyn A. Wilky, MD, Associate Professor, University of Colorado Anschutz Medical Campus, *"Association of CTNNB1 mutation subtypes with responses to systemic therapy in patients with desmoid tumors."*

Christina Kosyla, Desmoid tumor patient and advocate.

Sameer Rastogi, MD, Medical Oncologist, All India Institute of Medical Sciences, *"Desmoid fibromatosis management in tertiary care center in India- Lessons learned."*

Aaron Weiss, DO, Associate Professor of Pediatrics, Maine Medical Center (Chair, DTRF Medical Advisory Board), *"The DTRF Virtual Tumor Board."*

Kelly Mercier, PhD, Adjunct Associate, Duke University; Medical Science Liaison, Jazz Pharmaceuticals, Inc., *"The DTRF Natural History Study."*

Chen Duksin, MD, MBA, Executive Medical Director, Ayala Pharmaceuticals, *"AL102, Oral Gamma-Secretase Inhibitor for the Treatment of Patients Living with Desmoid Tumors."*

Fariba Navid, MD, Associate Professor at the Keck School of Medicine and Medical Director of Clinical Research Support Office for the Cancer and Blood Disease Institute at Children's Hospital Los Angeles, *"ARST1921: A Safety Pharmacokinetic and Efficacy Study of a γ -Secretase Inhibitor, Nirogacestat (PF-03084014), in Children with Adolescents with Progressive, Unresectable Desmoid Tumors."*



TOGETHER WE WILL.... CONNECT

DTRF Virtual Community Networking Event, Sept. 25, 2020

In the spirit of our previous “Speed Desmoidian-ing” in-person event, and our virtual “Timely Tumor Talks” event in the spring, this September virtual networking event provided a structured conversation allowing patients and caregivers to share their journeys and experiences. To ensure a more personal setting in our virtual Zoom environment, there were multiple breakout groups and interactive engagement tools. Kudos go to Patient Advocate and FAP survivor Dakota Fisher-Vance who imagined and moderated the event.

TOGETHER WE WILL... EMPOWER OURSELVES WITH INFORMATION

DTRF Virtual Patient Meeting Webinars, Sept. 26, 2020

Our virtual Patient Meeting consisted of two separate one-hour webinars, focusing on topics important to the patient community. Roughly 170 community members joined us internationally. Patients submitted questions via the written Q&A as well as live after each panelist presentation.

Our patient meeting webinars included the following presentations:

Webinar #1: Desmoid Tumors 101 featured topics:

- » Collaborations with patient advocacy groups by Dr. Mrinal Gounder, Memorial Sloan Kettering Cancer Center (Scientific Director, DTRF)
- » An overview of desmoid tumors by Dr. Breelyn A. Wilky, University of Colorado
- » Pediatrics by Dr. Aaron Weiss, Maine Medical Center (Chair, DTRF Medical Advisory Board)
- » Pregnancy by Dr. Chandrajit Raut, Brigham and Women’s Hospital and Dana-Farber Cancer Institute

Webinar #2: Therapies and Clinical Trials for Desmoid Tumors featured topics:

- » High Intensity Focused Ultrasound (HiFU) by Dr. Matthew Bucknor, University of California- San Francisco
- » Intra-arterial doxorubicin drug-eluting embolization (DEE) by Dr. Eldad Elnekave, Rabin Medical Center
- » Nirogacestat Phase 3 Trial by Dr. L. Mary Smith, SpringWorks Therapeutics
- » Tegavivint Phase 2a Trial by Dr. Casey Cunningham, Iterion Therapeutics

Special thanks goes to SpringWorks Therapeutics for its generous sponsorship of the Patient Meeting.

TOGETHER WE WILL... FUND A CURE!

RFA Virtual Challenge, July - Sept., 2020

The DTRF is principally funded by grass-roots private donations raised through signature DTRF events and 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 this support and are always here to help!



With the pandemic, most in-person fundraisers were cancelled so we had to get creative and expand our virtual fundraising. The patient-caregiver community rallied around our **RFA Virtual Challenge**. Patients participated from all over the world, feeling connected to each other while helping us achieve our collective fundraising goal. “Challengers” were invited to create their own personal challenges, match them with a fundraising goal, document their successes and share them with the community. We were so inspired by the ideas, support and drive to achieve these goals. There were opportunities for virtual check-ins and virtual celebrations daily around personal achievements and fundraising milestones.

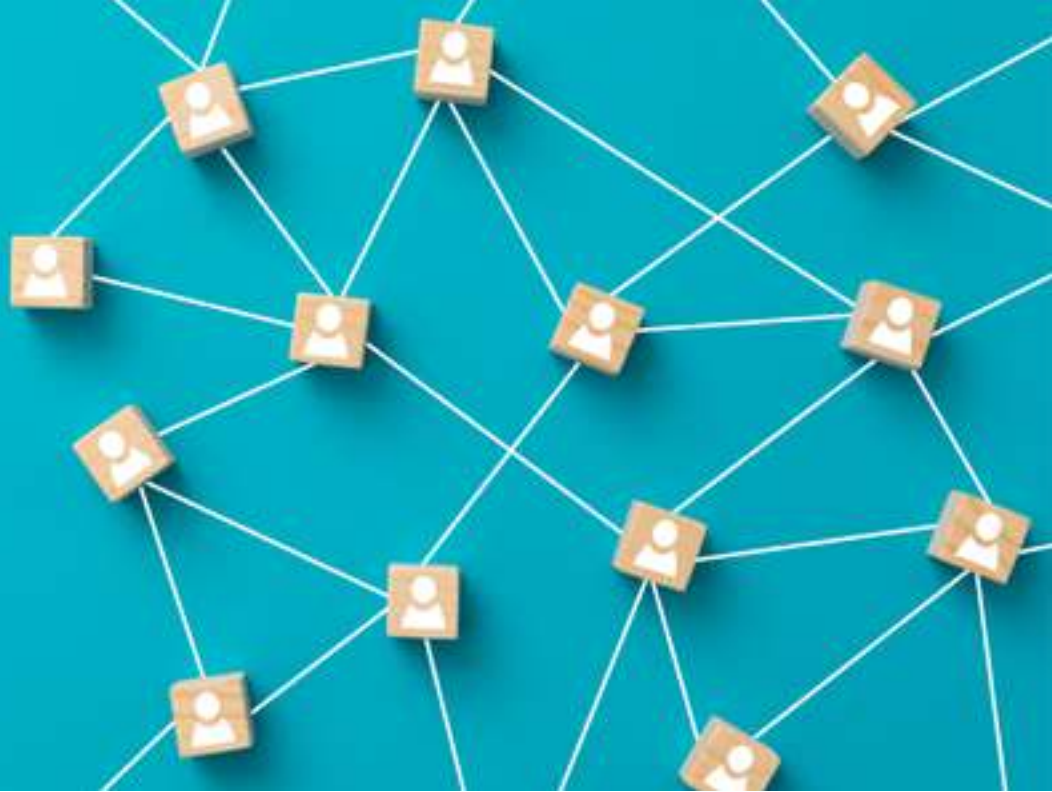




For her RFA Virtual Challenge, Jackie recruited donors online by promising lip sync videos

Here are just a few of the goals set by our Challengers:

- » **Bri** walked 1 mile for every \$100 she raised. She invited family and friends to join her as she walked toward her fundraising goal!
- » **Dana** hiked over 16,000 feet in elevation and wove that magical number into her fundraising ask!
- » **DeAnn** rode 2,100+ miles to Philly virtually, on her stationary bike, recruiting donors as her team members. They gave, did the mileage, and some did both!
- » Two challengers walked virtually from their home towns to Philly. **DeeDee** walked from Maryland and **Rachel** from Virginia. They asked friends and family for pledges and shared their progress and photos every few days.
- » **Jackie** created a wacky lip sync video for every \$200 she raised for DTRF. Family and friends got involved and kept her busy creating videos.
- » **Lisa** created a fundraising page for Desmoid United UK, and worked with her community to hit their fundraising goal!
- » **Lynne** would get a buzz cut if she reached her goal.
- » **Natalie** did a 5K for every \$200 she raised.
- » **Jeanne** and her husband Steve rowed 100,000 meters on the Great Salt Lake.



OUR TEAM

LEADERSHIP, VOLUNTEERS AND STAFF

MARLENE PORTNOY

Executive Director and Co-founder

JEANNE WHITING

President and Co-founder

LYNNE HERNANDEZ

Director of Events, Operations and Outreach

MRINAL GOUNDER, MD.

Scientific Director
Memorial Sloan Kettering Cancer Center

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MATTHEW VAN DE RIJN, MD, PhD

Professor, Department of Pathology, Stanford University Medical Center

BREELYN WILKY, MD

Associate Professor & Director of Sarcoma Translational Research, University of Colorado School of Medicine



"I have challenged myself to climb a cumulative 16,404 ft in elevation... and also to raise that same amount in donations for DTRF... Together, we are increasing awareness about this disease and helping others to find the cure!"

Dana L.

Dana's RFA Virtual Challenge: Hikes 50K in cumulative elevation change: 16,404 feet!



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