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Dear Friends,

2014 was a year of great progress, recognition and growth for The Desmoid Tumor Research Foundation (DTRF). We were honored to be asked to participate on a panel at the Rare Tumors Initiative Symposium at the National Cancer Institute in Washington DC in June. We presented DTRF’s perspective on the subject: Strategies to develop therapies for rare tumors: small numbers, but big opportunities.

We held our First International DTRF Desmoid Tumor Research Workshop which drew experts from U.S. and Europe together for collaboration on how to move the science of desmoid tumors forward toward a cure. We’re thrilled to have three projects that came out of the workshop already underway.

We’re always so grateful for the grass-roots fundraising efforts that keep us going strong. Patients, family members and friends helped raise funds that supported nine grants this year. Our thanks also go out to generous sponsors and donors who continue to support the cause.

It is DTRF’s primary mission to provide hope to patients through funding research and doing all we can to expedite the discovery, development and approval of new effective treatment options. We are now entering our tenth year in this cause! We have funded dozens of research projects in both basic science and clinical trials over the years. We’re currently funding ten grants at the following institutions: Brigham and Women’s Hospital; Duke University, Mt. Sinai, MD Anderson collaboration; Fondazione IRCCS Istituto Nazionale dei Tumori; Maine Medical Center; Mauro Baschirotto Institute for Rare Diseases, Vincenza, Italy; Memorial Sloan Kettering Cancer Center; The Ohio State University; Stanford University; and, Vanderbilt University Medical Center. See project details below on page 3.

We also played an important role in supporting the Phase II trial in desmoid tumors by the Rare Tumors Initiative of the National Cancer Institute. They contacted us saying, “We want to study desmoid tumors, but could DTRF help make that happen by partnering with us in the outreach to patients?” Of course, we were thrilled to participate and we were able to help them fill the trial in a matter of weeks instead of what could have taken months or years. The trial will be winding up next year.

We continue to develop accelerating momentum in our search for a cure! We welcome all to be part of this extraordinary, hopeful journey.

With warm regards,

Jeanne Whiting
President and Co-founder

Marlene Portnoy
Executive Director and Co-founder
OUR MISSION

Founded in 2005, The Desmoid Tumor Research Foundation (DTRF) is dedicated to 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 dedicated to funding desmoid tumor research and finding a cure for this rare disease. We fund research projects at the world’s top 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 be applied to many other kinds of cancers such as breast, colon, ovarian and other sarcoma cancers.

Patients are no longer fighting this disease alone. Our website provides information and helps direct them to other sources for information and support. 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 with your continued support.

EDUCATION AND COLLABORATION

DTRF has established a very successful annual fall patient symposium that brings patients, physicians and researchers together for education, support and collaboration. Our 2014 eighth annual DTRF Patient Meeting held in Philadelphia, brought new information, new connections and hope.

Our 2014 weekend in Philadelphia included the first International Desmoid Tumor Research Workshop described below. This annual 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.
DTRF supports research that will have the greatest potential to lead to new effective treatments. We are happy to note the new or continuing projects below funded in 2014.

• Benjamin Alman, MD, Duke University, with collaborators Robert Maki, MD, PhD, Mt. Sinai Medical Center; Alexander Lazar, MD Anderson Cancer Center; and Alessandro Datti, PhD, Samuel Lunenfeld Research Institute, *Collaboration for a Cure: Identifying new therapeutic targets for desmoid tumors*. This project is screening libraries of over 100,000 available drug agents to identify those which inhibit desmoid tumor cell growth but do not affect normal fibroblast cells.

• Matt van de Rijn, MD, PhD, Stanford University, *Next generation sequencing approach to desmoid tumors*. Dr. van de Rijn is collaborating with Dr. Cates at Vanderbilt.

• Justin M. Cates, MD, PhD, Vanderbilt University, *Genetic determinants of local recurrence in desmoid-type fibromatosis*.

• Mrinal Gounder, MD, Memorial Sloan Kettering Cancer Center, *A Phase III, double blind, randomized, placebo-controlled trial of sorafenib in desmoid tumors*. DTRF is funding the research on the correlative specimens from biopsies in the trial.

• Raphael Pollock, MD, Ohio State University Comprehensive Cancer Center, *A rational search for anti-desmoid therapies, investigating the molecular driving forces behind the development and progression of desmoid tumors*.

• Aaron Weiss, DO, Maine Medical Center, *Deregulated mTOR in desmoid-type fibromatosis, a pilot study examining the role of sirolimus in the treatment of children and young adults with desmoid tumor that is deemed likely to recur following resection*.

• Chiara Colombo, MD, Fondazione IRCCS Instituto Nazionale dei Tumori, *A high throughput genome study to identify predictors of aggressiveness in patients with sporadic desmoid tumor who undergo a wait and see approach*.

• Nancy L. Cho, MD, Brigham and Women’s Hospital, *Targeting Hyaluronic Acid in Desmoid Tumors*.

• Daniela Segat, PhD, "Mauro Baschirotto" Institute for Rare Diseases - B.I.R.D. Foundation, Vicenza, Italy, *In vitro studies of the microenvironmental factors responsible for the proliferation and aggressiveness of desmoid tumor cells*.

• Raphael E. Pollock, MD, PhD, Ohio State Comprehensive Cancer Center, *Reactivating of apoptosis: a potential therapeutic target for desmoid tumors with CTNNB1 S45S mutation*.
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; 2014 IRS Form 990; and, 2014 Audited Financial Statement.

*Please note that substantial funds were kept in reserve in our grants budget in order to fund a large project in 2015.
This year we took a leap forward in our progress toward developing international scientific education and collaboration. We held the First International DTRF Desmoid Tumor Research Workshop in connection with our annual Patient Meeting. Participants included a diverse group of scientists from US and Europe, including those involved in desmoid tumor research, human genetics, drug development and related fields. We devoted several hours to discussions asking 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? The Workshop identified several important initiatives for follow-up and we are thrilled to see projects progressing that came out of the workshop.
The Desmoid Tumor Research Foundation’s work is funded solely through individual donations and fundraisers. The Foundation is fortunate to have volunteers who organize events all over the world. These fundraisers are essential for the Foundation to continue its work! Thanks go to the organizers of this year’s events listed below.

2014 THIRD PARTY FUNDRAISERS

THE DESMOID DASH
October 11, 2014 in Mendota Heights, MN
Organizers: Zechmann Family

KUTZTOWN FALL FESTIVAL
September 20, 2014 in Kutztown, PA
Organizers: Corinne Conrad and Rochelle Miller

FUNDRAISING DINNER
September 20, 2014 in Breyate, Switzerland
Organizer: Ciara Barrell
2014 THIRD PARTY FUNDRAISERS CONTINUED...

BEEF N’ BEER FOR RFA TEAM DESMOID DESTROYERS
September 6, 2014 in Norristown, PA
Organizer: Daniela Wexler

SOPHIE’S WALK FOR REED
August 20, 2014 in Mission Hills, KS
Organizers: Anne and Sophie Hickok

I LOVE SOMEONE RARE: A CELEBRATION OF WARRIORS
August 9, 2014 in Spanish Fork, UT
Organizers: DeAnn Sorenson & Mechelle Cebrowski

BOWL FOR A CURE
July 26, 2014 in Prescott, AZ
Organizer: Karen Sidebottom

LAP4LIFE
June 21, 2014 in Newburgh, NY
Organizer: Maddalena Casabianca Reade

CHILI COOKOFF
June 21, 2013 in San Leandro, CA
Organizer: Jeni Pisani

CLOTHING DRIVE AND CHICKEN DINNER
June 14, 2014 in Lyons, PA
Organizers: Rochelle Miller and Corinne Conrad

BAKE SALE SUPPORTING RFA TEAM, MIGHTY MAX’S ANGELS
May 3, 2014 in Phoenixville, PA
Organizers: Kathy and Max Veeck

LAWSON’S FINEST LIQUIDS 6TH ANNIVERSARY
April 19, 2014 in Waitsfield, VT
Organizer: Sean Lawson

CORNHOLE TOURNAMENT
September 26, 2014 in Charlotte, NC
Organizer: Char Dumas
DTRF hosted three signature events providing fundraising and patient education.

**2014 DTRF SPRING FUNDRAISER**

DTRF’s spring fundraising dinner, featuring Broadway’s Up & Coming, took place at the Crowne Plaza in Suffern, New York on May 13. We were fortunate to welcome Rosie’s Theatre Kids for a special performance also!

**2014 DTRF ANNUAL PATIENT MEETING AND RUNNING FOR ANSWERS**

This event is an autumn weekend with events for both patients and caregivers. On Saturday, DTRF hosts a Patient Meeting and on Sunday, we host Running for Answers 5K & Kids’ Fun Run, followed by a Patient/ Caregiver Brunch.

• DTRF’s 2014 8th Annual Patient Meeting took place on September 27th at the Sheraton Downtown in Philadelphia. Over 275 patients and family members and friends came from 26 states and 7 countries as far away as Singapore. This day provided patients with desperately-sought answers and connections. They heard from expert clinicians during a full day of presentations and connected with other patients and families over shared experiences. For many, this was their first time meeting other desmoid tumor patients.
Our distinguished speakers included Joseph Erinjeri, MD, Memorial Sloan Kettering Cancer Center; Chandrajit P. Raut, MD, Harvard Medical School; Raphael E. Pollock, MD, PhD, Ohio State University Comprehensive Cancer Center; Mrinal Gounder, MD, Memorial Sloan Kettering Cancer; Benjamin Alman, MD, Duke University; Aaron Weiss, DO, Maine Medical Center; and, Shivaani Kummar, MD, National Cancer Institute.

Subjects discussed included: targeted therapy for young adult and pediatric patients; desmoid tumors and pregnancy; updates on clinical trials and DTRF’s Collaboration for a Cure; an overview of desmoid tumors; and, NIH studies in desmoid tumors.

• 2014 Running for Answers 5K & Kids’ Fun Run on September 28th in Fairmount Park welcomed over 800 participants from all over the country and raised over $200,000 for research! In preparation for this special event, patients are encouraged to recruit family and friends to join their run/walk teams, help raise funds for research and bring awareness to desmoid tumors.

Race day brought smiles, sunny weather and teams donning their favorite crazy socks and team shirts. CBS Anchor Pat Ciarrocchi and Sixers’ CEO Scott O’Neil reminded participants that we are on our way to a cure, and gave a heartfelt thanks for their support. Race founder Sera Snyder announced that 2014 would be the first RFA event she felt physically able to run, and offered comfort to those experiencing hardships with their tumors. Amanda Hoffman, desmoid survivor and event sponsor, expressed her commitment to DTRF through volunteerism, reminding participants that they are the drive behind the Foundation’s mission.

Because we see how patients and caregivers are affected by this special weekend, we hope for increased attendance every year. It renews our commitment to finding a cure and making a difference in the lives of patients.
OUR TEAM

LEADERSHIP AND STAFF VOLUNTEERS

MARLENE PORTNOY
Executive Director and Co-founder

JEANNE WHITING
President and Co-founder

LYNNE HERNANDEZ
Director of Events, Operations and Outreach

MRINAL GOUNDER, MD
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ROSIE O’DONNELL
Television Personality, Actress, Author and Comedian

MICHELLE O’DONNELL
Fundraising Chair

MARLENE PORTNOY
Executive Director and Co-founder, DTRF

KEVIN REILLY
Motivational Speaker

BARBARA ANN SELLINGER
Board of Directors, The Desmoid Tumor Research Foundation

SERA SNYDER
Manager of Physician Relationship Management Program,
Cancer Treatment Centers of America

JEANNE WHITING
President and Co-Founder, DTRF
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