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Dear Friends,

Thank you for your interest in our Annual Report as we press forward to find new treatments for desmoid tumors! 2016 has been a year of exciting developments:

PRO Tool. We continue our work in developing the first validated Patient Reported Outcome (PRO) tool in desmoid tumors with Dr. Mrinal Gounder of Memorial Sloan Kettering Cancer Center and Quintiles. We have had great success in recruiting patients to aid in this process. This tool, which will provide the framework for collecting data on the patient’s experience with a particular treatment, is intended to facilitate a new regulatory endpoint that can be used in all future clinical trials. It will be a great advancement in the field for researchers worldwide and is intended to facilitate future FDA approval of treatments for desmoid tumors. We anticipate that the PRO will be trial-ready in early 2017.

DTRF Desmoid Tumor Patient Registry. We’re also nearing the finish line of accomplishing our goal of establishing a desmoid tumor patient registry. DTRF was fortunate to be one of twenty rare disease organizations selected for a natural history study project initiated by the National Organization of Rare Disorders (NORD), in partnership with the FDA. Our online registry has been created and is currently in the process of being customized for desmoid tumors. We look forward to going live in 2017.

Research Grant Funding. The funding of cutting-edge collaborative research continues to be our priority. This year we funded nine new or continuing multi-year grants as described below.

Facilitating tissue donation. DTRF is engaging its patient community to directly donate tissue samples through Pattern.org. DTRF is excited to be working with Pattern.org to empower patients to direct their excess desmoid tumor tissue samples to research projects. Initially, samples donated via Pattern.org will be sent to the Broad Institute of MIT and Harvard, where they will be used to attempt to develop research models.

If you or a patient you know has an upcoming surgery, you can visit Pattern.org to learn more about the project. In choosing to donate tissue, patients and their communities become partners in research, helping investigators like those at the Broad Institute.

Pattern.org links to an electronic consent form. Should a patient decide to provide consent, Pattern.org arranges for excess tissue to be shipped to a research lab.

DTRF’s partnership with Pattern.org and the Broad Institute is part of a larger effort to establish and genetically characterize cell lines, which are cells that keep dividing and growing over time, under certain conditions in a laboratory. In developing these cell lines, the Broad Institute is trying to enable the scientific community to improve our understanding of cancer, as well as desmoid tumors.
Expanding fundraising in Canada. The Desmoid Tumour Foundation of Canada (DFC) was founded in 2016 to allow Canadians to make tax-deductible donations to support desmoid tumor research grants made by DTRF. Funds raised through DFC in Canada will be tax deductible for Canadians and will go toward supporting DTRF research projects. This is an exciting opportunity to educate and unite the patient community in Canada and to expand our fundraising efforts. The DFC is seeking the patient community support for the first ever Canadian patient networking and fundraising initiative being organized for May 3, 2017 by the DFC Fundraising Committee.

Researchers Collaborate. In September, we held our Third International DTRF Desmoid Tumor Research Workshop in Philadelphia with another increase in attendance. Over 50 researchers from the United States, Europe and Asia participated. We are continuing to build worldwide collaborative networks for the advancement of the field.

New Scientific and Medical Advisory Boards. During our September, 2016 weekend in Philadelphia, we hosted our first meeting for our new Medical Advisory and Scientific Advisory Boards, under the guidance of our Scientific Director, Mrinal Gounder, MD (Memorial Sloan Kettering Cancer Center). Aimee Crago, MD (Memorial Sloan Kettering) and Aaron Weiss, MD (Maine Medical Center) will head up these boards and we are grateful for their commitment and leadership. Board meeting discussions this year revolved around the need for a cohort study as well as the development of a better desmoid tumor mouse model to enhance and facilitate research.

With continued momentum, strategic partnerships and the continued support of the community, we look forward to another successful year ahead. Thank you for being a driving force in this journey!

With warm regards,

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

Paint for a Purpose, DTRF Community Fundraiser
WHAT WE DO AND WHY IT MATTERS

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 solely 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 2016 tenth annual DTRF Patient Meeting held in Philadelphia, brought new information, new connections and hope.

Our 2016 Philadelphia weekend included the third 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-FUNDED 2016 GRANTS

DTRF is pleased to note the following new or continuing projects supported by DTRF funding in 2016.

Multi-year Grants continuing in 2016

» Mushriq Al-Jazrawe, PhD, candidate, and Benjamin Alman, MD, Duke University & The Hospital for Sick Children, Toronto, Canada, “Single cell-derived clonal analysis of desmoid tumors to investigate tumor-stroma interactions.”

» Raphael E. Pollock, MD, PhD, Ohio State University Comprehensive Cancer Center, “Reactivation of apoptosis: a potential therapeutic target for desmoid tumors with CTNNB1 S45F mutation.”

» Matt van de Rijn, MD, PhD, Stanford University, “Next generation sequencing approach to desmoid tumors.”

» Mrinal Gounder, MD, Memorial Sloan Kettering Cancer Center, “Development of a patient reported outcome (PRO) tool in desmoid tumors.”

» Benjamin Alman, MD, Duke University, with collaborators Robert Maki, MD, PhD, Northshore Health Systems; Alexander Lazar, MD, PhD, MD Anderson Cancer Center; Alessandro Datti, PhD, Samuel Lunenfeld Research Institute, “Collaboration for a Cure: Identifying new therapeutic targets for desmoid tumors.”

New 2016 Grants

» Shivaani Kummar, MD, FACP, Stanford University, in collaboration with Jaw-Town Lin, MD, PhD, Fu Jen University, Taiwan, “Desmoid Tumors for Big Data Linkage.”

» Kelly Mercier, PhD, RTI International, “A metabolomics pilot study on desmoid tumors and novel drug candidates.”

» Kris Vleminkx, PhD, Ghent University, Belgium, “Identifying targets for therapy in a novel genetic Xenopus model for desmoid tumor formation.”

» Bree Lyn Wilky, MD, Sylvester Comprehensive Cancer Center, University of Miami, “Correlation of CTNNB1 mutation status with chemotherapy response by MRI in patients with desmoid tumors.”
“I am confident that the work of the DTRF, and the researchers it supports, will find a cure.”

Benjamin Alman, MD, Duke University

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  
2016 IRS Form 990  
2016 Audited Financial Statement

NOTE: Programming Expenses as a percentage to total were lower compared to 2015 as a result of the timing of Grant payments that are usually paid in December 2016, were reallocated to the first Quarter of 2017.
“I AM living the dream. And DTRF is HUGE part of that success story, and will continue to be. We are in this together”

Dana Pounds, Desmoid tumor survivor and above-the-knee amputee
THIRD INTERNATIONAL DESMOID TUMOR RESEARCH WORKSHOP

DTRF holds an annual research workshop to facilitate international scientific education and collaboration. This year the number of attendees doubled, with more than 50 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:

- Beta Cat Pharmaceuticals
- Centre Oscar Lambret
- Children’s Mercy Hospital
- Dana- Farber Cancer Institute
- Duke University
- Erasmus MC
- Fondazione IRCCS Istituto Tumori di Milano
- Ghent University
- Harvard Medical School
- Huntsman Cancer Center
- Johns Hopkins Medicine
- Maine Medical Center
- Mannheim University Medical Center
- Mauro Baschirotto Institute for Rare Diseases- B.I.R.D. Foundation
- MD Anderson Cancer Center
- Memorial Sloan Kettering Cancer Center
- Nagoya University
- National Cancer Institute, NIH
- Netherlands Cancer Institute
- Pfizer, Inc.
- Quintiles Advisory Services
- RTI International
- Sante Ventures
- Stanford University Medical Center
- The Mayo Clinic
- The Ohio State University Comprehensive Cancer Center
- University of Miami
- University of Toronto

The following presentations were given at the 2016 Research Workshop:

- **“Introduction and Report on Collaboration for a Cure project.”** Benjamin Alman, MD, Department Chair, Orthopedic Surgery, Duke University.
- **“Identifying targets for therapy in a novel genetic Xenopus model for desmoid tumor formation.”** Kris Vleminckx, PhD, Professor of Developmental Biology, Ghent University.
- **“Tegatrabetan (BC-2059) – A new approach to targeting beta catenin and Wnt activation.”** Stephen Horrigan, PhD, Chief Scientific Officer, BetaCat Pharmaceuticals.
- **“Initial studies of Tegatrabetan (BC-2059) in desmoid tumor cell strains.”** Danielle Braggio, PhD, Post-Doctoral Researcher, The Ohio State University.
- **“Development of PRO tool in desmoid tumors.”** Mrinal Gounder, MD, Assistant Professor and Medical Oncologist, Memorial Sloan Kettering Cancer Center.
- **“A model for international, multi-institutional, multi-disciplinary sarcoma videoconferencing.”** Steven Attia, DO, Assistant Professor of Oncology, The Mayo Clinic.
- **“The French Patient Registry Project.”** Nicholas Penel, MD, PhD, Medical Oncology, Centre Oscar Lambret.
- **“Outcome of non-surgical management of extra-abdominal and abdominal desmoid-type fibromatosis: a population based study.”** Danique van Broekhoven, MD, Surgical Oncology, Erasmus MC.
- **“Gene expression profiling of desmoid tumors.”** Matt van de Rijn, MD, PhD, Professor, Department of Pathology, Stanford University Medical Center.
- **“Investigation of antitumor effects of sorafenib on desmoid tumors.”** Danielle Braggio, PhD, Post-Doctoral Researcher, The Ohio State University.
- **“Update on clinical trials on Pfizer compound, a potential new treatment.”** Lara Sullivan, MD, MBA, Vice President, Pfizer CURES, Pfizer, Inc.
- **“An analysis of incidence and significance of trauma prior to desmoid tumor formation.”** Peter Hohenberger, MD, PhD, Mannheim University Medical Center.
- **“Targeting hyaluronic acid in desmoid tumors.”** Nancy Cho, MD, Assistant Professor of Surgery, Harvard Medical School.
- **“Whole Exome Sequencing in patients under Wait & See (W&S): a preliminary analysis.”** Chiara Colombo, MD, Surgical Oncology, Instituto Tumori di Milano.
- **“In vitro studies of the microenvironmental factors responsible of the proliferation and aggressiveness of desmoid tumor cells.”** Daniela Segat, PhD, Senior Researcher, “Mauro Baschirotto” Institute for Rare Diseases – B.I.R.D. Foundation.
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/fundraisers who helped fund research this year:

NIGHT FOR THE FIGHT
March 5, 2016 in Merion Station, PA
Organizers: Donald & Jeanne Conner of Conner Catering

VENDOR BINGO
March 20, 2016 in Kutztown, PA
Organizers: Corinne Conrad & Rochelle Miller

ST. PATRICK’S DAY PARTY
March, 2016 in Chicago, IL
Organizers: The O’Boyle Family

PONG- A- PALOOZA: A CHARITY BEER TOURNAMENT
May 14, 2016 in Philadelphia, PA
Organizer: Claudia Gomez

A CELEBRATION OF HOPE
May 21, 2016 in Pleasant Unity, PA
Organizers: Denise Wilmarth & Shelly Cohen Gallagher

CLOTHING DRIVE AND CHICKEN DINNER
June 11 & 12, 2016 in Lyons, PA
Organizers: Corinne Conrad and Rochelle Miller

8TH ANNUAL LAP4LIFE
June 20, 2015 in Newburgh, NY
Organizer: Maddalena Casabianca Reade

“CARRIE ON” Walk-a-thon and Picnic
August 20, 2016 in Hemlock, MI
Organizers: Nancy Deibel and family

PERFECTLY POSH FUNDRAISER
August, 2015 in Eagleville, PA
Organizer: Kathy Veeck

FOURTH ANNUAL DESMOID DASH
October 1, 2016 in Mendota Heights, MN
Organizers: The Zechmann Family

HALLOWEEN CO-ED VOLLEYBALL TOURNAMENT
October 29, 2016 in Peoria, AZ
Organizer: Joe Erickson

CHRISTMAS MARKET IN THE SWISS ALPS
November, 2016 in Switzerland
Organizer: Ciara Barrell

BEER PONG TOURNAMENT
November 13, 2016 in New York, NY
Organizers: Brittany Longenbach & Danielle Portnoy

TUCKING FOR TUMORS
November 29, 2016 in Cary, NC
Organizer: Dr. Kelly Mercier
SIGNATURE DTRF EVENTS

DTRF hosted two signature fundraising events this year.

DTRF Golf Classic, Suffern, NY

DTRF hosted over 135 golfers and over 170 dinner attendees at the beautiful Tuxedo Club in Tuxedo, NY, on Monday, June 13th. Attendees enjoyed gorgeous weather and a spectacular setting followed by a silent auction and dinner on Tuxedo Lake. DTRF thanks the volunteer committee who worked countless hours to help organize this special event.

Seventh Annual Running for Answers 5K & Kids’ Fun Run

Running for Answers returned to Philadelphia for 2016. The race was held at the Please Touch Museum and weaved through Fairmount Park on a gorgeous fall day. This event is an opportunity for patients to gather their friends and family to raise funds and rally around our shared goal: a cure for desmoid tumors.

Over 500 runners and walkers joined us for the 5K and Kids’ Fun Run. Over 35 teams were with us on race day, along with Team Margie, who joined us from Ecuador!

Opening ceremonies started with DeAnn Sorenson and Dana Pounds addressing the crowd and sharing their journeys of hope in the face of desmoid tumors. Both Maddalena Casabianca Reade and Kevin Reilly managed our award ceremonies, with the help of RFA Founder Sera Snyder. The morning ended with a handful of teams coming together for a special moment of impromptu zumba.

Free cheesesteaks and ice cream cones were provided to participants; race snacks and coffee were provided by a generous event sponsor, Conner Catering. Other sponsors included Carlos Clintron Photography and Motus Video Design.
Every year, in connection with the Running for Answers event, DTRF hosts an annual Patient Meeting. This year, we welcomed roughly 200 patients and caregivers for a day of learning and connecting. For some, this was their first time meeting another person facing the desmoid tumor journey. During registration and breaks, patients connected, shared stories and reached out to others with similar experiences.

Our patient meeting presentations included:

“Collaboration for a Cure: what we’ve learned so far.” Benjamin Alman, MD, Department Chair, Orthopedic Surgery, Duke University.

“Natural History Study and DTRF Patient Registry.” Kelly Mercier, PhD, Research Scientist in Metabolomics, RTI International.

“Data gleaned from development of a PRO tool in desmoid tumors.” Mrinal Gounder, MD, Assistant Professor and Medical Oncologist, Memorial Sloan Kettering Cancer Center; Jean Paty, PhD, Principal, and LeAnne Maddux, MA, Consultant, Quintiles Advisory Services.

“Learn about update on clinical trials on Pfizer compound/a potential new treatment.” Lara Sullivan, MD, MBA, Vice President, Pfizer CURES, Pfizer Medical, Pfizer Inc.

“Understanding the S45F and T41A mutations in desmoid tumors. What is their significance?” Raphael E. Pollock, MD, PhD, Professor of Surgery; Director, Division of Surgical Oncology, Ohio State University Comprehensive Cancer Center.

“Fishing for New Therapeutic Targets in the Frog Pond.” Kris Vleminckx, PhD, Professor, Department of Molecular Biomedical Research Unit of Developmental Biology VIB, Ghent University.

“NCI’s Phase II trial of PF-03084014 in adults with desmoid tumors/aggressive fibromatosi.” Geraldine O’Sullivan Coyne, MD, PhD, Staff Clinician (VP), Investigational Drug Branch, NCI- NIH.

“New Approach to Inhibiting Beta- Catenin.” Sunil Sharma, MD, Division Chief, Medical Oncology at University of Utah School of Medicine, Expert in Oncology Drug Development.

“Magnetic resonance guided high intensity focused ultrasound for the treatment of desmoid tumors.” Raffi Avedian, MD, Assistant Professor of Orthopedic Surgery at The Stanford University Medical Center.

Integrative Health Panel:

“Naturopathic Oncology: What is it, and how can it help?” Ian Bier, ND, PhD, LAc, FABNO, Human Nature Natural Health.

“Reiki: A Caring Touch.” Darrin Richman, RPh, CRMT, Fox Chase Cancer Center.

“Optimizing Movement to Improve the Human Experience.” Secili DeStefano, PT, DPT, OCS, Bodies in Motion Physical Therapy.
OUR TEAM

Leadership, Volunteering and Staff

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JEANNE WHITING
President and Co-founder

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Director of Events, Operations and Outreach

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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