



INSIDER

THE DESMOID TUMOR RESEARCH FOUNDATION — FUNDING RESEARCH ~ PROVIDING SUPPORT

DTRF 2008 GRANT RECIPIENTS

ONGOING RESEARCH PROJECTS

The DTRF Supports Research to Find a Cure

Dina Lev et al,
MD Anderson Cancer Center

"Molecular determinants of desmoid tumor development and progression."

Ben Alman et al,
Hospital for Sick Children

"Identifying the desmoid initiating cell"

Matt van de Rijn et al,
Stanford University

"ROR2, a potential novel therapeutic target in desmoids tumors."

Newly Awarded 2008 Grant Recipient

Check www.dtrf.org before year end for announcement

COMPLETED PROJECT

David Joyner et al,
The Huntsman Cancer Center

"Do growth factors mediate desmoid tumor invasiveness and drug sensitivity"

2008 DTRF Gala & Patient Support Symposium a Resounding Success

Approximately 65 patients and family members attended our second patient support meeting on May 29, 2008. Attendees had the opportunity to listen to presentations on the research currently being funded by the DTRF and on the current treatment options available to them. Our distinguished panel answered many questions from the audience. This was followed by an emotional discussion amongst the group when fellow desmoid patients shared their stories and lent support to each other.



Our distinguished panel included **Benjamin Alman, MD**, grant recipient from the Hospital for Sick Children in Toronto; **John Chabot, MD**, New York-Presbyterian Hospital; **James Church, MD**, from the Cleveland Clinic; **David E. Joyner, PhD**, grant recipient from the Huntsman Cancer Institute, University of Utah; **Dina Lev, MD**, grant recipient from MD Anderson Cancer Center; **Raphael Pollock, MD, PhD**, MD Anderson Cancer Center; **Bruce Shriver, PhD**, founder of the Sarcoma Initiative; **Matthew van de Rijn**, grant recipient from Stanford University.

Following the patient symposium close to 300 people were regaled by delicious food, great music and a wonderful silent and live auction at the third annual gala. Over \$175,000 was raised. Some excited auction winners are heading off to the Red Carpet at the Oscars, spending a "Dream Day" with the NY Giants, or off to vacation at Cabo San Lucas!



A poignant video from family members who lost loved ones due to their desmoid tumors was shown at the Gala and a speech was given by Lyon Herron, a brave young man with Gardners Syndrome highlighting the reason we were all there-to find a cure for this rare disease.

The DTRF Teams with The Sarcoma Foundation to Learn from Patient Registry

Progress in perfecting the treatment for desmoid tumors can only be made with a better understanding of all sarcomas, of which desmoid tumors are a subset. There is currently no universal database for these rare tumors for researchers and clinicians to refer to for their studies. Such information will allow for the study of genetic pathways and identify potential therapeutic agents. The Sarcoma Foundation of America has created a comprehensive Sarcoma Patient Registry which will track the progress of patients with all forms of sarcomas. This information will be available to all DTRF researchers.

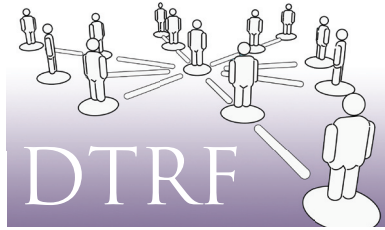
A link to this registry can be found on the DTRF website (www.dtrf.org)



For up-to-date information visit our site, www.dtrf.org

DTRF LINKS PATIENTS TO EACH OTHER & RESEARCHERS

DTRF continues its important work of facilitating patient donation of tissue samples to research hospitals and being a clearinghouse of information on desmoid tumors to patients and physicians. One of the more gratifying things DTRF does is to link patients to others with the same experiences. Just knowing that they are not alone provides relief and hope to patients all over the world.



DTRF Participates in International Meeting

Members of the the DTRF Scientific Advisory Board attended the CTOS (*Connective Tissue Oncology Society*) meeting in London on Nov 13-15. This year an entire afternoon of the meeting was dedicated to desmoid tumors, with presentations by some of our grant recipients. The video, created by DTRF for our fundraiser was shown, spreading the awareness of our organization as well as inspiring the researchers to continue their important work.



Desmoid Tumors are Recognized by NORD

The National Organization of Rare Disorders, Inc.

(NORD) is a unique federation of individuals and organizations working together to build a better world for people affected by rare diseases. Inclusion in the list of rare diseases recognized by NORD affords national and international attention, enhancing the potential for research, education and patient advocacy. Desmoid tumors have now been accepted by NORD as one of their recognized rare disorders.



Fundraising Across the Country to Support DTRF

Efforts to raise money to fund DTRF's sponsored research have been launched from the east coast to the west coast, from small events to large galas. Every dollar is important to us and every endeavor undertaken as meaningful. Because desmoid tumors are so rare, we must rely on grass root efforts.

Lyon Herron presented a \$15,000 check to DTRF at the 2008 dinner gala. This money was raised from a surfing contest, The Malibu Invitational, in his hometown of Malibu, California.

Lora Halvorson raised approximately \$5000 from a letter writing campaign. She sent letters to neighbors and friends, many she has not seen for many years!

Katy Yam and **Rick Rubano** donated \$1000 in honor of the guests who attended their wedding.

Tina Perry registered DTRF onto an online shopping portal at www.shoptoearn.net/dtrf. Make all your holiday purchases online and support DTRF.

The Dynamics

A Cappella Group donated their \$1000 winning prize from a recent charity talent show in Massachusetts.

Jessica Gordon, a member of the group, was responsible for choosing DTRF as the recipient of the award.



Daniel Mendel, aged 17, raised over \$5000 for DTRF at a fundraiser at Pope High School in Marietta, Georgia.



Go to www.shoptoearn.net/dtrf and shop for a cure!

DT DESMOID TUMOR
RF RESEARCH FOUNDATION
funding research ~ providing support

UPCOMING '09 FUNDRAISER

The fourth annual DTRF event is being planned for the fall of 2009. Details to follow but we can promise a new exciting twist.

You can help DTRF continue its mission of funding research and providing support.

- > Please send a check to DTRF,
P.O. Box 273, Suffern, NY 10901
- > or make a donation online at www.dtrf.org