



INSIDER

THE DESMOID TUMOR RESEARCH FOUNDATION — FUNDING RESEARCH ~ PROVIDING SUPPORT

DTRF CURRENT GRANT RECIPIENTS

NEWLY AWARDED GRANT*

The DTRF Supports Research to Find a Cure

Newly Awarded 2008 Grant Recipient

Richard D. Lackman, MD et al,
University of Pennsylvania

"The role of hydroxyurea as first line treatment for primary and recurrent/refractory desmoid tumors"

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."

** subject to contractual agreements*

COMPLETED PROJECT

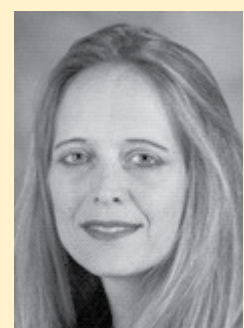
David Joyner et al, The Huntsman Cancer Center

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

DTRF Funded Research: Strides Towards a Cure

Groundbreaking Research to Change Patient Care

Sporadic desmoid tumors have a high tendency for local recurrence, even after thorough surgical resection. An exciting breakthrough by Dina Lev, MD at MD Anderson promises to identify which patients should be observed and which should be treated aggressively. Recent work has shown that deregulation of the beta-catenin pathway is common in sporadic desmoids. Dr. Lev's group has found that 85% of sporadic desmoid specimens studied in her lab harbor mutations in the beta-catenin pathway and that recurrence free survival differed among the three mutations identified. A high rate of recurrence can be predicted in patients whose tumors harbor one of these three mutations (45F). It can be determined whether a tumor harbors this gene mutation from tissue samples obtained from a biopsy of their tumor. While this work needs to be validated, Dr. Lev is hopeful that soon treating physicians can use these results from biopsy material to decide which patients should receive adjuvant therapy.



Dina Lev, MD

DTRF Funds Its First Clinical Trial



Richard Lackman, MD

Despite their classification as benign neoplasms, musculoskeletal desmoid tumors can exhibit aggressive growth and recurrence. Treatment strategies vary widely because none have demonstrated consistent and lasting results without significant toxicity. This UPenn study spearheaded by Richard Lackman, MD investigates the use of hydroxyurea, a normally well tolerated anti-neoplastic drug commonly used in the treatment of other cancers. The use of hydroxyurea in treating desmoid tumors was previously retrospectively investigated in pediatric patients at the Children's Hospital of Philadelphia where preliminary results showed partial response or stable disease in 79% of patients. There were even some cases of complete remission which is not generally seen with standard chemotherapy. The DTRF is lending support to build on this early promise of a treatment by funding a clinical study that prospectively examines the use of hydroxyurea as a treatment for both primary and recurrent or refractory desmoid tumors in adults and children.



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

Patient Support Symposium 2009

Plans are well under way for the 2009 Patient Support Symposium, which will be held on **Thursday, October 15th at the Ritz Carlton White Plains NY**, prior to the DTRF Gala. The meeting will be from 1:30pm to 5:30pm and refreshments will be served in the afternoon.

We have an exciting roster of speakers and topics lined up including the following:

Robert G. Maki, DTRF Honoree

MD, PhD, Medical Oncologist,
Co-Leader of the adult Sarcoma Disease Management Team, Memorial Sloan-Kettering Cancer Center. Doctor Maki will discuss current medical therapies for treatment of desmoid tumors.

Suzanne George, MD, the Dana-Farber Cancer Institute, Medical oncologist, Instructor, Dept. of Medicine Harvard Medical School. Doctor George will speak on traditional chemotherapeutic regimes used in treating desmoid tumors.

Raphael E. Pollock, MD, PhD, MD Anderson Cancer Center, Division Head, Surgery, Professor, Surgical Oncology and Molecular & Cellular Oncology. Doctor Pollock will present current surgical therapies.

Dina C. Lev, MD, MD Anderson Cancer Center, Cancer Biology: 2006, 2007 and 2008 DTRF Grant Recipient for "Molecular determinants of desmoid tumor development and progression." Doctor Lev will give an overview of the results of her research to date, as well as a discussion of all other areas of research being conducted on desmoid tumors.

Richard D. Lackman, MD, FACS, University of Pennsylvania Health System, Professor and Chair, Department of Orthopaedic Surgery; 2008 DTRF Grant Recipient for clinical trial being conducted on Hydroxyurea as a treatment for desmoid tumors. Dr. Lackman will discuss preliminary data of the clinical trial.

Matt Alsante, Executive Director of Sarcoma Foundation of America, will bring us up to date on the efforts and goals of the Sarcoma Foundation of America to develop a comprehensive patient registry which includes desmoid tumors. The registry's endeavor is to collect, store, analyze and interpret data on sarcoma patients.

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For frequent updates on the details of the Patient Support Symposium, please log on to our web site, www.dtrf.org. To register, or for other questions related to the meeting, please direct your emails to Betsy Cormany at dtrf.betsy@gmail.com.
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FUNDRAISER UPDATE



2009 FUNDRAISER

RITZ CARLTON

White Plains, NY

October 15, 2009

7-10 pm



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**Honoree/Guest Speaker
Ted Kennedy, Jr.**
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**Entertainment by
Beatles Band, Obladiblada**
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Exciting Silent/Live Auction

FOR INFORMATION

- on the new Ritz Carlton Hotel visit www.ritzcarlton.com
- and for information on the band please visit their website at www.obladiblada.com/Band.htm





Highlight: Benjamin Alman, MD

Benjamin Alman is the A.J. Latner chair of orthopaedic surgery at the University of Toronto and a pediatric orthopaedic surgeon at the Hospital for Sick Children. Doctor Alman runs a basic science lab focusing on developing improved treatments for orthopaedic tumors and injuries. The Desmond Tumor Research Foundation is currently funding his research on desmoid tumor initiating cells.



Benjamin Alman, MD

Q&A

How did you become interested in desmoid tumors?

While I was a resident in Boston at Tufts University I participated in the treatment of a six year old boy who underwent an arm amputation for a desmoid tumor. I just couldn't accept that a supposedly benign tumor would require such a devastating treatment and it was then that I decided to pursue research on this tumor.

What is the basis for your research?

In my study of the role of growth factors in desmoid tumors I learned that a mutation that activates a protein called beta-catenin turns on various genes. This concept became the basis for pathology tests to diagnose desmoid tumors, for developing mouse models that can be used to test treatments for desmoid tumors, and for identifying potential new therapeutic approaches. I am now studying these genes regulate the way the tumor cell behaves, in hopes of identifying a novel, improved drug treatment.

Tell us about your work with stem cells.

There are a small number of cells in normal tissue, called stem cells, that provide new mature cells when there is an injury. They are called stem cells, because they act like the stem of a plant and can re-grow the leaves or flowers. There is growing evidence that tumors also contain a population of such stem cells. While traditional drug treatments for tumors target the bulk of tumor cells, targeting these stem cells has the potential to completely eradicate the lesions. In this respect the tumor can be thought of like a branch of a tree. Traditional drug therapy will kill the leaves, but if the base of the stem survives, this will regrow. The stem cells are like the base of the stem, and if this is killed, it will not regrow. As such, identifying tumor stem cells and finding ways to damage the stem cells has a good chance of curing the tumor. My hope is that identifying the stem cells from desmoid tumors, and determining unique properties of these cells will lead to development of a treatment.

What has the DTRF support meant to you?

It is only by applying better understanding of the cause of desmoid tumors that better therapies can be developed. This is best accomplished by getting the top notch scientists working with forward thinking clinicians. Because desmoid tumors are relatively rare, national funding agencies whose focus is on improving public health are less likely to fund research into this tumor type. However, it is a very problematic tumor for patients and their doctors. The work of the Desmond Tumor Research Foundation is helping to fund research in desmoids tumors, and to foster the kinds of collaborations between researchers and clinicians that will go a long way to cure desmoid tumors. With help from the foundation, I hope that new treatments will prevent a child like the one I met as an orthopaedic resident from ever requiring an amputation.

We Need Your Help to Continue Our Important Work

The Desmond Tumor Research Foundation (DTRF) seeks to advance the science related to desmoid tumors by:

- Funding research related to the diagnosis and treatment of desmoid tumors;
- Facilitating and enhancing dialogue among members of the medical and scientific communities about research related to desmoid tumors;
- Providing informational support for desmoid tumor patients and their families and friends, and heightening awareness of desmoid tumor diagnosis and treatment.

We are certain that our efforts to fund the most cutting-edge desmoid tumor research will bring us closer to our ultimate goal- a cure.

Please support DTRF by making a donation or by sponsoring a fundraiser. We cannot do this without you!