

The Children's Tumor Foundation Invites You to Join the NF Registry

The Children's Tumor Foundation is pleased to announce the creation of an online NF Registry. Launched at the 2012 NF Forum in New Orleans, LA, the purpose of the registry is to find people who may be eligible for clinical trials or other research studies being conducted in the field of neurofibromatosis (NF), and to determine the commonality of specific NF characteristics. The NF Registry can be found at www.nfregistry.org.

For those who participate in the NF Registry, after entering their information (or their child's information), the Children's Tumor Foundation will look for clinical trials or research studies



that are seeking people with the participant's NF characteristics and age. If they find a match, the Children's Tumor Foundation will provide the participant with contact information at the institution conducting the research, so that direct contact can be made.

The information contributors provide about their NF will be summarized along with data from other registry participants so that those researching NF can understand how common specific characteristics of NF are, and what treatments are being used. The Children's Tumor Foundation may share data in the registry with individuals or institutions conducting

clinical trials or research studies, companies developing potential drugs or other treatments for NF, or other parties involved in research of patients with NF, but **any information that identifies the participant will be removed.**

To join the NF Registry please go to www.nfregistry.com.

For more information about this important development in the fight against NF, please contact Annette Bakker, Chief Scientific Officer of the Children's Tumor Foundation, at 212-344-6633, ext. 7029 or abakker@ctf.org.



Jim Bob and Laurée Moffett receive an award of recognition at the NF Forum Awards Dinner for their dedication to fighting neurofibromatosis.

L-R: Laurée Moffett, Jim Bob Moffett, John Risner, Foundation President, Stuart Match Suna, Chairperson of the Board.

NF Forum 2012: Hope, Help, Heal

The Children's Tumor Foundation's fourth annual NF Forum was convened in New Orleans, LA, June 8-10, 2012, with the theme "Hope, Help, Heal." The largest number of Forum participants thus far, approximately 200, enjoyed a weekend of seminars, question-and-answer sessions, and social events that brought them into contact with the world's foremost NF researchers and gave them the opportunity to build supportive relationships with one another.

The Forum, co-chaired by Amanda Bergner, MS CGC of Johns Hopkins University, Dr. Tena Rosser of the Children's Hospital of Los Angeles, and Murray McCartan, NF Endurance Team Captain of the Twin Cities Marathon,

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Children's Tumor Foundation Invests \$884,000 in Neurofibromatosis Research and Development

The Children's Tumor Foundation is delighted to announce the funding of 11 Young Investigator Awardees (YIA) for the 2012 round. YIA research focuses on basic and translational biology of NF1, NF2, and schwannomatosis.

The 2012 YIA recipients include six postdoctoral and five predoctoral awardees.

YIA Postdoctoral Awardees



Jean De La Croix Ndong
Vanderbilt University
The Nf1osx -/- mice and CNP: a new inducible pre-clinical model and a novel strategy to understand and treat NF1 tibial pseudoarthrosis.



Tao Sun
Washington University in St. Louis, School of Medicine, Department of Pediatrics
Sex differences in cyclic AMP signaling impact NF1-associated gliomagenesis



Yuan Wang
University of Michigan
Therapeutic intervention of NF1-associated cognitive deficits and optic nerve gliomas during early postnatal stages



Pamela Vanderzalm
The University of Chicago
Dissecting merlin function at the membrane



Rebecca Dodd
Duke University Medical Center
Investigating tumor biology in a novel mouse model of inducible NF1-driven soft-tissue sarcoma



Rebecca Lock
Brigham and Women's Hospital, Inc.
Developing novel therapies for malignant peripheral nerve sheath tumors

YIA Predoctoral Awardees



Richard Hugh Frost Bender
Washington University in St. Louis
Neurofibromin ras-molecule specific regulation of neural stem cells.



Amish Patel
UT Southwestern Medical Center
Epigenetic mechanisms underlie malignant peripheral nerve sheath tumor development



Jeff Gehlhausen
Indiana University
Generation of a novel, accurate murine model of neurofibromatosis type 2 and the genetic validation of a therapeutic target for schwannoma development



Gerald Sun
Johns Hopkins University
Neurofibromin 1 and regulation of neural stem cell fate choice



Alexander Schulz
Fritz Lipmann Institute, Jena, Germany
Axonal merlin regulates Schwann cell behavior via neuregulin signalling

LOOKING FORWARD

Here are a few events that may be of interest. For a complete listing or more information, please see www.ctf.org/calendar

- 09/13 - Little Rock, AR**
Dancing with Our Stars
Red Carpet for Research Event
- 09/16 - Beaverton, OR**
End of Summer Picnic
- 09/16 - St. Louis, MO**
Porsche Club of America
Auto Show
- 09/30 - Boston, MA**
NF Symposium at
Massachusetts General
Hospital
- 10/06 - Westport, CT**
Fourth Annual Saugatuck Cup
- 10/08 - Washington, D.C.**
CureNFwithJack Golf Classic
- 10/19 - Rocklin, CA**
Third Annual Fiesta Night

A Night to Remember

Children's Tumor Foundation
Annual New England Fall Gala

Saturday, October 13, 2012

7:00 PM – Cocktails
8:00 PM – Dinner

Hyatt Regency Cambridge
575 Memorial Drive
Cambridge, MA

Silent and Live Auctions
Music • Dancing

For more information:
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