



# FLUTTERBY

A Quarterly Advocure Newsletter

Advocure NF2, Inc. is a working advocacy group for the international NF2 community.

Issue 1, page 1; Winter 2008



Michel Kalamarides PhD, Rosemary Lee, and Louis Lee Prowse at the 6<sup>th</sup> International Congress on Meningioma and CVS, September 6, 2008. Boston MA, USA. Photo by the BSF.

**M**ore than 271 attended Meningioma Awareness Day in 2008, helping to bring an impassioned patient perspective to the 6<sup>th</sup> International Congress on Meningioma and Cerebral Venous Systems (CVS), held at the John B. Hynes Memorial Convention Center in Boston MA, on September 3-6, 2008. This event was co-sponsored by the Brigham and Women's Hospital, and the Brain Science Foundation.

**T**rial Talk (TT), an Advocure initiative, was successfully established in early 2007. TT is a streamlined and private yahoogroup™ email group list created exclusively for individuals with NF2 and/or their immediate family members to discuss clinical trials.

# TT

To subscribe to TT, please send an email (along with a very brief self-bio) to:

[NF2Trialtalk-subscribe@yahoogroups.com](mailto:NF2Trialtalk-subscribe@yahoogroups.com)

**A**dvocure NF2, Inc. is in the process of procuring 501(c)(3), non-profit/tax-exempt status because we are increasing our efforts to expedite research leading to systemic therapies to treat, and hopefully cure, NF2. Updates shall be posted as progress continues.

[www.advocurenf2.org/04\\_donate.html](http://www.advocurenf2.org/04_donate.html)

**Donate**



*Thank you for your support!*

**A**n easy way to contribute to NF2 (especially during the busy holiday season, when you need gift ideas) is to purchase a magazine subscription. Forty percent (40%) of the proceeds will be donated to Advocure. For a list of magazines, click:

[www.magfundraising.com/advocurenf2](http://www.magfundraising.com/advocurenf2)

**A**dvocure has decided to develop a brief ANONYMOUS questionnaire devoted to the vexed issue of making a decision to undergo pre-symptomatic early intervention surgery with Vestibular Schwannoma (VS).

Advocure is acutely aware of the agonizing and time-sensitive treatment decisions that individuals with NF2 and their families often must confront. Your participation (within a few weeks) is greatly appreciated.



Email: [contact@advocurenf2.org](mailto:contact@advocurenf2.org)  
Website: [www.advocurenf2.org](http://www.advocurenf2.org)

**A**dvocure would like to take this opportunity to thank all those who have contributed to keeping us afloat over the last three years, and more recently those that contributed to raising the funds for our 501(c)(3):

- Beverly Wendell
- Gail Petitto
- Henry Hipp
- Jane and Rusty
- Bill Reese
- Sharon Morrell
- Jaime Cirillo
- Elaine Powers
- Jennifer Hayes
- David Baxter
- Cindy Henrion
- Roberto da Silva
- Jamie Przybysz
- Marie Drew
- Rosemary Lee
- Joyce Herndon
- the Ohio Gathering group '08



Ohio NF2 Gathering, October 2008

**A**s outlined in our mission statement, Advocure NF2, Inc. is an all volunteer parent/patient advocacy group with a core of office bearing directors, and other rotating members from our international community. If you are a patient or have a family member with NF2 and are interested in volunteering, please contact us via email: [contact@advocurenf2.org](mailto:contact@advocurenf2.org)



Butterflies can't hear, but they can feel. The original name for the butterfly was 'flutterby'.

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## Clinical Trials & Study Updates:

**A** Prospective Natural History Study of Patients with Neurofibromatosis Type 2 (NF2). Protocol Number: 08-N-0044. [[www.tinyurl.com/NIH-08-N-0044](http://www.tinyurl.com/NIH-08-N-0044)]

The National Institutes of Health (NIH) is currently conducting a Natural History study of NF2 tumor development and progression. For more information, please contact the Patient Recruitment Office at 800-411-1222, or at the NIH clinical studies information request page.

**S**UNITINIB in Treating Patients With Recurrent or Unresectable Meningioma, Intracranial Hemangiopericytoma, or Intracranial Hemangioblaston. Relevant to NF2. ClinicalTrials.gov Identifier: NCT00561665. [[www.tinyurl.com/NCT00561665](http://www.tinyurl.com/NCT00561665)]

**P**hase II Trial of SUNITINIB (SU011248) in Patients With Recurrent or Inoperable Meningioma. Relevant to NF2. ClinicalTrials.gov Identifier: NCT00589784. [[www.finyurl.com/NCT00589784](http://www.finyurl.com/NCT00589784)]

**V**ATALANIB in Treating Patients With Recurrent or Progressive Meningioma. Relevant to NF2, 18 years and above. ClinicalTrials.gov Identifier: NCT00348790. [[www.finyurl.com/NCT00348790](http://www.finyurl.com/NCT00348790)]

If there is any other information about NF2 drugs or drug trials that you wish to bring to our attention, please contact us at: [contact@advocurenf2.org](mailto:contact@advocurenf2.org)

**E**TOPOSIDE in Treating Young Patients With Relapsed Ependymoma. Up to 21 years. ClinicalTrials.gov Identifier: NCT00278252. [[www.tinyurl.com/NCT00278252](http://www.tinyurl.com/NCT00278252)]

**A** Phase II Study of SDM230 in Patients with Recurrent or Progressive Meningioma Who Have Previously Undergone or Are Not Candidates for Additional Surgery. Protocol No. HCI IRB # 26519. [[www.tinyurl.com/HCI-IRB-26519](http://www.tinyurl.com/HCI-IRB-26519)]

**H**igh-Dose METHOTREXATE in Treating Young Patients With Residual Ependymoma. 3 months to under 3 years. ClinicalTrials.gov Identifier: NCT00287924. [[www.tinyurl.com/NCT00287924](http://www.tinyurl.com/NCT00287924)]

**C**ombination Chemotherapy Followed by Radiation Therapy in Treating Children With Localized Ependymoma. 3 to 20 years. ClinicalTrials.gov Identifier: NCT00004224. [[www.tinyurl.com/NCT00004224](http://www.tinyurl.com/NCT00004224)]

**R**adiation Therapy and Combination Chemotherapy Followed by Autologous Stem Cell Transplant in Treating Patients With Newly Diagnosed Medulloblastoma, Supratentorial Primitive Neuroectodermal Tumor, or Atypical Teratoid Rhabdoid Tumor 3 to 21 years. ClinicalTrials.gov Identifier: NCT00085202. [[www.tinyurl.com/NCT00085202](http://www.tinyurl.com/NCT00085202)]

**R**adiation Therapy and Combination Chemotherapy in Treating Young Patients With Medulloblastoma, Supratentorial Primitive Neuroectodermal Tumor, or Ependymoma. Up to 21 years. ClinicalTrials.gov Identifier: NCT00303810. [[www.tinyurl.com/NCT00303810](http://www.tinyurl.com/NCT00303810)]

**N**F2 patients may be eligible to participate in some of the ongoing Phase I studies [[www.tinyurl.com/Clinical-Trial-Opportunities](http://www.tinyurl.com/Clinical-Trial-Opportunities)] at the Department of Investigational Cancer Therapeutics at MD Anderson Cancer Center. For further information, please contact Christie Carver-Fryer, Patient Access Supervisor at (713) 563-9819.

**M**assachusetts General Hospital (MGH): Brain Tumor Imaging in Clinical Trials. [[www.tinyurl.com/Brain-Tumor-Imaging](http://www.tinyurl.com/Brain-Tumor-Imaging)]

**R**esearchers at MEEI, MIT, and Harvard Medical School are now recruiting NF2 patients who are ABI users/nonusers for an important clinical research study [[www.harvardabi.org](http://www.harvardabi.org)]. Travel and lodging for qualified research patients will be covered by the study.

For more trials and/or studies, please see: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

Try inputting "neurofibromatosis type 2", or a NF2 tumor tissue type, such as "Vestibular Schwannoma", "Schwannoma", "Meningioma", "Glioma", "Ependymoma", or "Astrocytoma" for example, within the search field.

**NF2**  
Advocure Inc.  
advocates for a cure

Email: [contact@advocurenf2.org](mailto:contact@advocurenf2.org)  
Website: [www.advocurenf2.org](http://www.advocurenf2.org)

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