



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

Issue 3, page 1; Summer 2009

# ADVOCURE NF2 INC. HAS 501(c)(3) STATUS!

**Advocure NF2, Inc. became an official tax-exempt public charity, retroactively effective to August 1, 2008.**

**All contributions to Advocure are now tax-deductible!**

[www.advocurenf2.org/determination\\_letter.pdf](http://www.advocurenf2.org/determination_letter.pdf)

Advocure is dedicated to strengthening efforts that expedite research contributing to systemic therapies to treat, and hopefully cure, NF2.

To help, please visit us at:



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

*Thank you for your support!*

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



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

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

**H**earing Improvement after Bevacizumab in Patients with NF2,  
The New England Journal of Medicine 2009; 361: 358-67., Scott Plotkin, M.D., Ph.D., et al.

<http://content.nejm.org/cgi/content/full/NEJMoa0902579>

**C**ould New Stem Cell Discovery Benefit NF2 Patients?  
<http://www.ctf.org/For-Scientists/could-new-stem-cell-discovery-benefit-nf2-patients.html>

**A**shley's Ride



2nd annual Benefit Motorcycle Event - July 25, 2009 in Manvel, TX, USA.

<http://ashleysride.com/>

**A**n easy way to contribute to NF2 is to purchase a **magazine subscription**. Forty percent (40%) of the proceeds will be donated to Advocure.



For a list of magazines, pls visit:

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

**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. Thanks!

[contact@advocurenf2.org](mailto:contact@advocurenf2.org)

**F**unding supports continued focus on rare disorders.



<http://ptct.client.shareholder.com//releasedetail.cfm?ReleaseID=389444>

**C**ongratulations Rebecca Dufek!

[www.firstgiving.com/myquest4nf](http://www.firstgiving.com/myquest4nf)



**N**ew NF2 Patient Packets for the newly diagnosed are now available, offering the essentials on NF2.

Additionally, there are the existing **NF2 Hospital Packets** which contain a variety of literature providing both general and specific information to assist NF2 patients, families, and caregivers. Hospital Packet materials include; a current newsletter, medical insurance guidelines, a list of helpful resources, *assistance in the hospital* for the hard-of-hearing or deaf patient, and information on the NF2 Crew, Advocure NF2, and other NF2 community support groups and services.

[www.nfinc.org/nf2news.shtml#hosp](http://www.nfinc.org/nf2news.shtml#hosp)

**R**ecent Publications on NF2:



[http://www.bioportfolio.com/indepth/Neurofibromatosis\\_2.html](http://www.bioportfolio.com/indepth/Neurofibromatosis_2.html)

**O**n May 31, 2009, a **"BEN"EFIT** for NF2 was held at the Oakhurst Country Club in Grove City, OH. They were able to raise a total of over \$47,000 USD.

**WOW!!!**

<http://www.madisonpress.com/local.asp?ID=1691&Story=3>

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[www.zazzle.com/Marie1052](http://www.zazzle.com/Marie1052)



# FLUTTERBY

A Quarterly Advocure Newsletter

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continued:

**H**elp Olivia Hernandez reach her goal!

<http://www.active.com/donate/nflonbeach2009/Olivia>

**P**atient Registry & Biobank - A Critical Resource

Bio-specimen research is inherently dependent upon an individual's willingness to donate biological materials such as DNA, blood, or tissue.

<http://www.biobankcentral.org>

Online Biobank survey.....

<http://www.ctf.org/For-Scientists/biobank-survey.html>

**O**rgan transplant drug [rapamycin] could treat meningioma

<http://www.virtualmedicalcentre.com/news.asp?artid=13772&title=Organ-transplant-drug-could-treat-meningioma&odr=&page>

**B**rain Science Foundation Pledges \$1.5 Million Towards Brain Tumor Research in 2009

[http://www.brainsciencefoundation.org/matrix/Arch/MultiPiecePage.asp\\_Q\\_PageID\\_E\\_274\\_A\\_PageName\\_E\\_BSFpledge08](http://www.brainsciencefoundation.org/matrix/Arch/MultiPiecePage.asp_Q_PageID_E_274_A_PageName_E_BSFpledge08)

Thank you for your recent donations:

- Steve and Deidra G Reiner
- Larry and Jeanette Baxter

And thank you to all those who continue to order magazine subscriptions through our site.

Website: [www.advocurenf2.org](http://www.advocurenf2.org)



## Clinical Trials & Study Updates:

### • **Natural History Study of Patients with Neurofibromatosis Type 2 (NF2).**

ClinicalTrials.gov Identifier: NCT00598351

<http://clinicaltrials.gov/ct2/show/NCT00598351?term=NF2&rank=2>

### Currently recruiting participants.

The National Institute of Neurological Disorders and Stroke (NINDS) is currently conducting a **Natural History study of NF2** designed to examine (over the long-term) the progress of patients with neurofibromatosis Type 2 (NF2).

It will study patients' tumors to learn how fast they can grow and if certain factors might affect their growth. It will also examine the effects of the tumors on patients' abilities to carry out activities of daily living.

Most expenses are reimbursed

For further information, please contact the Patient Recruitment Office at 800-411-1222, or at the NIH clinical studies information request page.

### • **PTC299 for Treatment of Neurofibromatosis Type 2.**

ClinicalTrials.gov Identifier: NCT00911248

### Not yet open for participant recruitment.

<http://clinicaltrials.gov/ct2/show/NCT00911248?term=nf2&rank=1>

[http://www.ptcbio.com/3.1.2\\_oncology.aspx](http://www.ptcbio.com/3.1.2_oncology.aspx)

### • **Concentration and Activity of Lapatinib in Vestibular Schwannomas,**

ClinicalTrials.gov Identifier: NCT00863122

### Not yet open for participant recruitment.

<http://clinicaltrials.gov/ct2/show/NCT00863122?term=nf2&rank=3>

**NE2**  
Advocure<sup>™</sup>  
advocates for a cure

email: [contact@advocurenf2.org](mailto:contact@advocurenf2.org)



### • **Sunitinib in Treating Patients with Recurrent or Unresectable Meningioma, Intracranial Hemangiopericytoma, or Intracranial Hemangioblastoma**

ClinicalTrials.gov Identifier: NCT00561665

### Currently recruiting participants.

<http://clinicaltrials.gov/ct2/show/NCT00561665?term=NF2&rank=7>

### • **Phase II Trial of Sunitinib (SU011248) in Patients with Recurrent or Inoperable Meningioma**

ClinicalTrials.gov Identifier: NCT00589784.

### Currently recruiting participants.

<http://clinicaltrials.gov/ct2/show/NCT00589784?term=nf2&rank=9>

### • **Monthly SOM230C for Recurrent or Progressive Meningioma**

ClinicalTrials.gov Identifier: NCT00859040

### Currently recruiting participants.

<http://clinicaltrials.gov/ct2/show/NCT00859040?intr=Pasireotide&rank=9>

### • **Lapatinib in Treating Young Patients with Recurrent or Refractory CNS Tumors**

ClinicalTrials.gov Identifier: NCT00095940

### Open, but no longer recruiting.

<http://clinicaltrials.gov/ct2/show/NCT00095940?term=Lapatinib+for+Recurrent+Ependymoma&rank=2>

### • **Vatalanib in Treating Patients with Recurrent or Progressive Meningioma**

ClinicalTrials.gov Identifier: NCT00348790

### Currently recruiting participants.

<http://clinicaltrials.gov/ct2/show/NCT00348790?term=meningiomas&cond=%22Neoplasms%2C+Vascular+Tissue%22&rank=5>

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Clinical Trials & Study continued:

• **Phase II Study of SOM230 in Patients with Recurrent or Progressive Meningioma**

ClinicalTrials.gov Identifier: NCT00813592

**Open, but no longer recruiting.**

<http://clinicaltrials.gov/ct2/show/NCT00813592?term=NCT00813592&rank=1>

• **Corticosteroids in Prevention of Facial Palsy after Cranial Base Surgery**

ClinicalTrials.gov Identifier: NCT00438087

**Currently recruiting participants**

<http://clinicaltrials.gov/ct2/show/NCT00438087?term=vestibular+schwannoma&rank=3>

• **Etoposide in Treating Young Patients with Relapsed Ependymoma**

ClinicalTrials.gov Identifier: NCT00278252

**Currently recruiting participants**

<http://www.clinicaltrials.gov/ct2/show/NCT00278252?term=NCT00278252&rank=1>

• **Avastin** is a biologic antibody designed to specifically inhibit the VEGF protein that plays an important role in development and maintenance of blood vessels, a process known as angiogenesis.

<http://www.forbes.com/feeds/hscout/2009/07/08/hscout628844.html>

<http://www.sciencedaily.com/releases/2009/07/090708181156.htm>

<http://www.theibta.org/AvastinReview.pdf>

• **Ataluren** (formerly PTC124™), investigational new drug designed to enable the formation of a functioning protein in patients with genetic disorders due a nonsense mutation.

[http://www.ptcbio.com/3.1.1\\_genetic\\_disorders.aspx](http://www.ptcbio.com/3.1.1_genetic_disorders.aspx)



• **Sorafenib**, non invasive treatment for NF2 with the potential to transform management of this debilitating and long term condition.

[www.firstscience.com/home/news/breaking-news-all-topics/research-to-lead-to-braintumor-therapies\\_45157.html](http://www.firstscience.com/home/news/breaking-news-all-topics/research-to-lead-to-braintumor-therapies_45157.html)

• **Tarceva** (erlotinib), anti-cancer drug works by blocking the EGF receptor.

<http://www.nature.com/nrclinonc/journal/v5/n8/full/nrponc1157.html>

• Auditory brainstem implant (ABI) patients needed for research study at MEEI and MDH.

[http://harvardabi.org/harvardabi\\_researchforums.htm](http://harvardabi.org/harvardabi_researchforums.htm)

• NF2 patients may be eligible to participate in some of the ongoing Phase I studies at MD Anderson Cancer Center in Houston, Texas. USA.

<http://www.mdanderson.org/>

For further information, please visit the website above and click on Appointments and Referrals.

Alternatively, contact Christie Carver-Fryer, Patient Access Supervisor at (713) 563-9819.

*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)

*For more trials and/or studies, please see:*  
[www.clinicaltrials.gov/ct2/results?term=nf2](http://www.clinicaltrials.gov/ct2/results?term=nf2)

*When there, please try inputting "neurofibromatosis type 2", or a NF2 tissue type, such as; "Vestibular Schwannoma", "Schwannoma", "Meningioma", "Glioma", "Ependymoma", or "Astrocytoma", within the relevant search field.*

## Symposiums of NF2 interest:

**NF Forum 2009**, Inaugural National Patient & Family Medical Symposium was held on April 3-5 in Washington DC, USA.

[http://www.ctf.org/images/stories/spring\\_09\\_newsletter.pdf](http://www.ctf.org/images/stories/spring_09_newsletter.pdf)

**NF Conference 2009**, New Frontiers was held on June 13-16, 2009 in Portland OR, USA.

<http://www.ctf.org/View-by-tag/2009+NF+Conference/>

**NF2 & Schwannomatosis Info Day** on June 18, 2009 in Vancouver BC, Canada

<http://bcnf.bc.ca/events/first-ever-nf2-schwannomatosis-info-day/>

**Genetic Alliance** will hold its **Annual Conference** on July 17-19, 2009 in Washington DC, USA.

[http://geneticalliance.org/ws\\_display.asp?filter=conference09&char=N&s\\_Diseases](http://geneticalliance.org/ws_display.asp?filter=conference09&char=N&s_Diseases)

**Genetic Syndromes of the Ras/MAPK Pathway** on August 1-2, 2009 in Berkeley Marina, CA, USA.

<http://cancer.ucsf.edu/raspathway2009/index.php>

**NF Symposium** on Sept 26, 2009. at Children's Hospital Boston.

<http://cnfad.org/2009%20Symposium/2009%20Symposium%20General%20Information.html>



\*Layout and design by Joyce H. & Roberto D.