



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

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Mission:

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



contact@advocurenf2.org
<http://www.advocurenf2.org/>

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How to Help:



http://www.advocurenf2.org/04_donate.html

Advocure NF2, Inc. is a 501(c)(3) charity.

All contributions to Advocure NF2 Inc. are tax-deductible!

NF2 donations, and in memory of those we lost:

Cindy Henrion (Spaghetti dinner, pg 3)

In memory of *Louis Lee Prowse (1993-2009):*

- Michelle Zajic*
- Dorothy Barnier*
- Roberto da Silva*
- Marie Drew*
- Melissa Taylor*
- Emily Skopov*
- Gill McCaughey*
- Thomas Vitale*
- Syfy Network*

Thank you for your support!

NF2 in the News

- *Consensus Recommendations to Accelerate Clinical Trials for Neurofibromatosis Type 2*
http://www.ncbi.nlm.nih.gov/pubmed/19671848?ordinalpos=1&itool=Email.EmailReport.Pubmed_ReportSelector.Pubmed_RVDocSum
- **U.S. House votes to approve \$13.75 million for NF Research (CDMRP NFRP) for FY2010**
<http://www.ctf.org/How-You-Can-Help/advocacy.html>
<http://www.nfinc.org/advocacy.shtml>



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NF2 in the News cont.

- *Neurofibromatosis type 2 (NF2): A clinical and molecular review 2009*
<http://www.ojrd.com/content/4/1/16>
- *Bevacizumab [Avastin] induces regression of vestibular schwannomas in patients with neurofibromatosis type 2*
<http://neuro-oncology.oxfordjournals.org/cgi/content/abstract/nop010>
- The report of the 2009 NF Conference held in Portland, Oregon:
<http://www.ctf.org/images/pdf/2009nfconferencereport.pdf>
- *CAPE (caffeic acid phenethyl ester)-based propolis extract (Bio 30) suppresses the growth of human neurofibromatosis (NF) tumor xenografts in mice.*
http://www.ncbi.nlm.nih.gov/pubmed/18726924?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum
- *Advances in NF2 Clinical Trials*
<http://www.ctf.org/Living-with-NF/nf-research-overview-advances-in-nf2-clinical-trials.html>
- *NF2 Bevacizumab [Avastin] Trial Stirs Discussion in New England Journal of Medicine.*
<https://www.ctf.org/762-nf2-bevacizumab-trial-stirs-discussion-in-new-england-journal-of-medicine.htm>

- **NF2 and the CI. Yes you can!**
http://www.advocurenf2.org/03_cochlear_implant.html
- *Potential Clinical Trial of **Sorafinib** in the UK,* by Professor Dr. Oliver Hanemann.
If funded, this trial could start in late 2010,
http://www.advocurenf2.org/00_news_Sorafinib.html

For further details, please contact:

Nicola.Hillary@pms.ac.uk

Fundraising



Zazzle™ - Cups & Stuff

Let us customize a product for you; T-shirts, cups, hats with logos, family photos, pet photos, etc.

www.zazzle.com/Marie1052

An 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, please visit:

www.magfundraising.com/advocurenf2





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Fundraising cont.

Spaghetti Success!

ALDA Suncoast and **Advocure NF2, Inc.** wish to thank members, friends, and family who came and/or made individual donations to our fund-raiser dinner November 14th, 2009. You guys made it most enjoyable with your generosity, good cheer, and spirits.

The numbers will be in after the expenses are prorated, but it's safe to say we made close to \$500 and had fun doing it.

Thank you Bill for superb bar tending, Beverly (aka mom) and Barbara for getting the food out flawlessly, the silent auction donators, organizers, and buyers! Thank you Barb for the awesome Mojitos and baked shells. And thank you Debbie for getting us the use of the room.



Symposiums of NF2 Interest

- **2010 NF Forum,**
National Patient & Family Medical Symposium
April 9-11, 2010 • Las Vegas NV, USA
Hosted by the Children's Tumor Foundation (CTF)
<http://www.ctf.org/Patient-Info/nf-forum-for-2010.html>
- **NF2 Meeting: *The State of the Art***
May 2-4, 2010 • Las Vegas NV, USA
Sponsored by the House Ear Institute
<http://www.ctf.org/For-Scientists/NF2-Meeting/>
- **2010 NF Conference, *Back to the Future***
June 5-10, 2010 • Baltimore MD, USA
Hosted by the Children's Tumor Foundation (CTF)
<http://www.ctf.org/For-Scientists/2009-NF-Conference/>



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NF2 Clinical Trials & Studies

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

ClinicalTrials.gov Identifier: NCT00598351

This study is currently recruiting participants.

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

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

This study is currently recruiting participants.

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

http://www.ptcbio.com/3.1.2_oncology.aspx

• **Lapatinib Study for Children and Adults With Neurofibromatosis Type 2 (NF2) and NF2-Related Tumors**

ClinicalTrials.gov Identifier: NCT00973739

This study is currently recruiting participants.

<http://www.clinicaltrials.gov/ct2/show/NCT00973739?term=nf2&rank=1>

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

ClinicalTrials.gov Identifier: NCT00863122

This study is currently recruiting participants.

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



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NF2 Clinical Trials & Studies cont.

• **Neurofibromatosis Type 2 Associated Color Vision Anomalies and Birth Defects: Incidence and Insights**

This study is currently recruiting participants.

<http://www.ctf.org/images/for-scientists/nf2%20flyer-revised.pdf>

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

ClinicalTrials.gov Identifier: NCT00561665

This study is 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.

This study is currently recruiting participants.

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

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

ClinicalTrials.gov Identifier: NCT00859040

This study is currently recruiting participants.

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

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

ClinicalTrials.gov Identifier: NCT00813592

This study is ongoing, but not recruiting participants.

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

• **Everolimus (RAD001) for the Treatment of Malignant Pleural Mesothelioma With Merlin/NF2 Loss as a Biomarker to Predict Sensitivity**

ClinicalTrials.gov Identifier: NCT01024946

This study is currently recruiting participants.

<http://www.clinicaltrials.gov/ct2/show/NCT01024946?term=nf2&rank=8>



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NF2 Clinical Trials & Studies cont.

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

ClinicalTrials.gov Identifier: NCT00438087

This study is currently recruiting participants.

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

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

http://harvardabi.org/harvardabi_researchforms.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.

SOME Pharmaceuticals of NF2 Interest:

If you have any questions about these, please discuss with your primary caregiver and/or oncologist.

• **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://stage.ctf.org/pdf/professionals/ddi/2007-07-005.pdf>

• **Avastin** (bevacizumab) 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.ncbi.nlm.nih.gov/sites/entrez>

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

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

• **Nexavar (sorafenib)**

www.firstscience.com/home/news/breaking-news-all-topics/research-to-lead-to-braintumor-therapies_45157.html



FLUTTERBY

A Quarterly Advocure Newsletter

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NF2 Clinical Trials & Studies cont.

• **Tarceva** (erlotinib)

<http://www.nature.com/nrclinonc/journal/v5/n8/full/ncponc1157.html>

• **AR-42** (OSU-HDAC42)

http://www.arnothera.com/osu_hdac42.html

• **AR-12** (OSU-03012)

http://www.arnothera.com/osu_03012.html

• **Curcumin**

<http://www2.mdanderson.org/depts/oncolog/articles/07/9-sep/9-07-2.html>

• **Propolis** (Bio30)

http://www.ncbi.nlm.nih.gov/pubmed/18726924?ordinalpos=1&tool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

• **Valproic acid**

<http://www.nature.com/emboj/journal/v20/n24/abs/7594185a.html>

• **Rapamycin**

<http://cat.inist.fr/?aModele=afficheN&cpsidt=21781337>

• **Cetuximab**

<http://www.cancer.gov/drugdictionary/?CdrID=42384>

• **Trastuzumab**

<http://www.cancer.gov/drugdictionary/?CdrID=42265>

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

For more trials and/or studies, please see:

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.

Forward to a friend

Know someone who would like to read this newsletter?

Why not forward it to them?

http://www.advocurenf2.org/newsletter/FLUTTERBY_2010winter.pdf