

FLUTTERBY

A Quarterly Advocure Newsletter

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

Issue 2, Page 1, Spring 2009

NF2 early intervention questionnaire

"Early intervention" is defined as being vestibular schwannoma (VS) surgery or radiation treatment performed on a pubescent or preteen NF2 individual, who are asymptomatic (opened from February 2, 2009 to March 2, 2009) Summary of results

www.advocurenf2.org/03_questionnaires.html

The full report of the 2008 NF Conference

It includes highlights on Avastin, Lapatinib, OSU03012, NXD3000, and radiotherapy

www.ctf.org/pdf/nfconference/2008_NF_Conference_Summary.doc



NF Midwest Newsletter 2009

www.nfmidwest.org/files/NF_Newsletter_spring_2008.pdf

Bio30 chart

Anyone who has had a recent MRI, please remember to notify Marie Drew so she can update the Bio30 chart.

Marie.Drew@comcast.net

NF Symposium

The second Harvard Medical School Center for Neurofibromatosis and Allied Disorders. Neurofibromatosis symposium will take place Sat, 9/26/2009 at Children's Hospital Boston.

www.childrenshospital.org/

www.nfincne.org/events/detail.asp?id=78

Inflammation and Cancer

While chronic inflammation is generally considered a consequence of obesity..

<http://www.cancer.gov/think-tanks-cancer-biology/page8>



Genetic Syndromes of the Ras/MAPK Pathway

August 1-2, 2009

Portland, Oregon, USA

Hosted by the UCSF Children's Hospital.

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

'BEN'EFIT for NF2

On May 31, 2009 at 2-6pm, A 'Ben'efit for NF2 will be held at the Oakhurst Country Club in Grove City, OH, featuring a raffle and auction. All proceeds benefit the Children's Tumor Foundation's NF Preclinical Consortium

www.active.com/donate/BenefitforNF2

www.ctf.org/for-scientists/ddi-nf-preclinical-consortium.html

Symposium

April 3-5, 2009 • Washington DC, USA
2009 NF Forum, *National Patient & Family Medical Symposium*.

Captioning will be provided.
Hosted by the CTF

<http://www.ctf.org/About-the-Foundation/nf-forum.html>

April 18, 2009 • Washington DC, USA
Neurofibromatosis: Today and in the Future

Location: Howard University Hospital.
Captioning will be provided.
Hosted by NF Inc. Mid-Atlantic

www.neurofibromatosisinmidatlantic.net/index.htm

June 13-16, 2009
2009 NF Conference, New Frontiers
Portland, Oregon, USA
Hosted by the CTF

www.ctf.org/



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

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SOM230

Phase II Study of SOM230 in patients with recurrent or progressive meningioma

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

http://www.hci.utah.edu/patientInformation/clinicalTrials~/trials/clinicalTrialsList.jsp?listName=Brain&trial=hci_irb26519

Sunitinib

Phase II Trial of Sunitinib (SU011248) in patients with recurrent or inoperable meningioma

<http://www.clinicaltrials.gov/ct2/show/NCT00589784?term=NCT00589784&rank=1>

Lapatinib

For recurrent ependymoma

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

Vestibular Schwannomas

<http://www.clinicaltrials.gov/ct2/show/NCT00863122?term=neurofibromatosis+2+%2CLapatinib&rank=1>

NIH NF2 Natural History study

<http://clinicaltrials.gov/ct2/show/NCT00598351?term=neurofibromatosis+2&rank=1>

Clinical Trials & Study Updates

Tarceva™ (erlotinib)

Anticancer drug works by blocking the EGFR receptor..

www.gene.com/gene/products/information/oncology/tarceva/egfr_factsheet.html

www.nature.com/nrclinonc/journal/v5/n8/full/nrclinonc1157.html

Sorafenib

Non invasive treatment for NF2 with the potential to transform management of this debilitating and long term condition.

http://www.firstscience.com/home/news/breaking-news-all-topics/research-to-lead-to-brain-tumor-therapies_45157.html

Avastin™

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.

www.theibta.org/AvastinReview.pdf

PTC299

Is a novel, orally administered, small molecule designed to inhibit the production of VEGF by targeting the post-transcriptional processes that regulate VEGF synthesis

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

Vatalanib

This phase II trial is studying how well vatalanib works in treating patients with recurrent or progressive meningioma.

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

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

more.....

clinicaltrials.gov/ct2/results?term=nf2



There are about 28,000 known butterfly species throughout the world



species

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Dr. D E Brackmann

An open dialogue with Dr. D E Brackmann (House Ear Institute of LA) about the potential role of cochlear implants with NF2 vestibular schwannomas

www.advocurenf2.org/03_cochlear_implant.html

Honorary Board

Currently, Advocure is in the process of investigating and making the necessary article changes to include the addition of an Honorary Board of International Representatives. The purpose of this board is to ensure easy dialogue and rapid dissemination globally throughout our community of any important or relevant NF2 information pertaining to drugs or clinical trials, and thereby honoring our goal of serving all peoples within the NF2 community. We feel it is particularly important to do this at this stage, as more drugs and trials are becoming available.

The Honorary Board will not be expected to participate in the day to day duties of Advocure, but simply to become part of an effective conduit of information for our worldwide community.

While discussions have commenced, the Board will not be instituted until our 501 status is in place, and other legal and insurance issues have also been fulfilled.

Please contact us if you are active within your community and believe that you can take on this role for the NF2 community in your country.

www.advocurenf2.org/05_contactus.html

NYU NF Clinic Needs NF2ers

www.ctf.org/pdf/nf-clinic-network/NYU%20Clinic%20Information.pdf

www.med.nyu.edu/patientcare/library/article.html?ChunkID=11650

Ashley's Memorial Ride

July 25th 2009

All proceeds go to Neurofibromatosis

www.northernchapter.com/

Thank You Donations

- Larry & Jeanette Baxter
- Mr. & Mrs. Craig Baumans

Rummage Sale

Rummage Sale

\$100 Thank You
Cindy H.



40% of all **magazine** sales help fund Advocure NF2, Inc. We appreciate your support in our mission to fast track a cure for NF2.

www.magfundraising.com/advocurenf2



Currently, **donations** are not yet U.S tax-deductible. We'll let you know when our 501(3) c application is approved.

www.advocurenf2.org/



Cups and Stuff

We take requests: Let us customize a product for you. T-shirts, cups, hats with logo's, family photo's, pet photo's.

www.Zazzle.com/Marie1052

Zazzle panel

<http://tinyurl.com/rc6v6b8>



Butterflies taste with their feet

