



Advocure NF2 Inc. is a working advocacy group, liaison, and 501(c)(3) public charity for the NF2 international community & NF2 Crew.

Issue 5, page 1; Spring 2010

Our Mission:

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



Email: contact@advocurenf2.org

Web: <http://www.advocurenf2.org/>

New!  [RSS Feeds](#)



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

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

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

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NF2 donations, (and in memory of those we lost):

Gladys (Lanita's mom)

The Thoms

Robert and Julia Noftzger

Matthew and Mandi Newton

Sarah R. Van Daele

Kimberly Payne

Linda S. Schoeffner

Catherine Coakley

Thank you for your support!

NF2 in the News

- U.S. House votes to approve \$13.75 million in FY10 for NF Research (CDMRP NFRP)
<http://www.ctf.org/How-You-Can-Help/advocacy.html>
- New Research Resources Initiative by the Neurofibromatosis Research Program (CDMRP NFRP)
<http://cdmrp.army.mil/nfrp/nfrpresources.htm>
- FY10 Neurofibromatosis Research Program (CDMRP NFRP) funding opportunities now available
<http://cdmrp.army.mil/funding/nfrp.htm>
- *Merlin/NF2 Suppresses Tumorigenesis by Inhibiting the E3 Ubiquitin Ligase CRL4^{DCAF1} in the Nucleus.*
[http://www.cell.com/abstract/S0092-8674\(10\)00064-4](http://www.cell.com/abstract/S0092-8674(10)00064-4)
- *Ivermectin inactivates the kinase PAK1 and blocks the PAK1-dependent growth of human ovarian cancer and NF2 tumor cell lines*
<http://www.ddtjournal.com/getabstract.php?id=264>

'NF2 Compass' was formerly known as 'Flutterby'

NF2 Compass

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NF2 in the News, cont.

- **The Center for Neural Tumor Research**

http://www.hei.org/research/neural_tumor/index.html

The Center for Neural Tumor Research at House Ear Institute (HEI) has a mission of understanding the cellular and molecular basis of neurofibromatosis type 2-related tumorigenesis as well as developing translational tools relevant for the treatment of the disease.

For further information, please contact: Dr. Marco Giovannini, mgiovannini@hei.org or (213) 353-7075, Fax:(213) 273-8088

- **Findings from Massachusetts General Hospital advance knowledge in *meningioma* therapy.**

<http://www.newsrx.com/newsletters/Biotech-Week/2010-02-17/6021720104849UW.html>

- **Full transcript of British Columbia Neurofibromatosis (BCNF), NF2/Schwannomatosis Information Day, held in June 2009.**

http://bcnf.bc.ca/linked/NF2_Information_Day_June_09.pdf

- **Artificial Muscles Save Eyesight by Restoring Ability to Blink**

<http://www.disabled-world.com/assistivedevices/prostheses/artificial-eye-muscles.php>

- **CNFAD's 2008 Conference Transcript**

"Why We Do Research And Where We Are." Presented by: James Gusella, PhD

http://www.cnfad.org/2008%20Symposium/Agenda%20and%20Faculty_files/Gusella%20Talk.html

- **NF2 NEWS - Autumn 2009, UK's NFA**

INSIDE THIS EDITION: *The NF2 Weekend, Facial Rehabilitation, Hearing Support, Fundraising News!*

<http://www.nfauk.org/uploads/September%202009.pdf>

- **New NF Patient Registry**

"The Children's Tumor Foundation (CTF) is currently planning the implementation of both an NF patient registry and NF tissue biobank, which is aimed to launch in 2010. In January, CTF will join with a number of other Foundations in an NIH-led meeting to plan for a collaborative patient registry that includes multiple diseases."

<http://www.ctf.org/798-patient-registry-a-a-vital-tool-for-research-progress.html>

- **DDI Grants Test New Approaches to NF2 Therapies**

1/ *Dr. Andrea McClatchey* (Harvard/MGH) to screen pan-ErbB inhibitors in NF2 tumor cells and mouse models.....

2/ *Dr. Marco Giovannini* (HEI) will screen drugs that target the cellular element hsp90 in mouse models of NF2 tumors.....

3/ *Dr. Joseph Kissil* (The Wistar Institute) will screen newly created chemical entities to block p21-activated kinases (PAKs), a promising drug target for NF2 tumor treatment.

<http://www.ctf.org/For-Scientists/drug-discovery-initiative-grants-test-new-approaches-to-nf2-therapies.html>

- **"Information Regarding NF2" at the NFA**

<http://www.nfauk.org/nf/18>

- **The mission of the CERN Foundation is to develop new treatments for *ependymoma***

<http://www.cern-foundation.org/Default.aspx>

- **The Second Annual "Ben"efit for NF2**

Sunday, May 2, in Grove City, OH. Proceeds to benefit the Children's Tumor Foundation's (CTF) DDI NF Preclinical Consortium.

<http://www.active.com/donate/2010benefitforNF2>

- **Climb Kilimanjaro for NF2**

Trek to the Roof of Africa and Help Raise Awareness for NF2!

<http://climbforNF2.org/wordpress/>

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Fundraising

NF2 Fundraiser

By Roland Thoms

On February 4th, Roland Thoms (father of Camille, 12y/o with NF2) held a fundraiser for Advocure NF2 Inc. Over 100 of Roland's customers with *Varsity Painting* (a Northern California Painting contractor) attended an evening of dining, drinking and dancing. Over 25 silent auction items were donated and then acquired to raise \$1200 for the local *Children's Hospital Oakland* and \$1200 for *Advocure NF2 Inc.*

Camille was diagnosed with NF2 when she was 7 and had brain surgery to remove a tennis-ball sized meningioma. Since then, MRIs have monitored the growth of her vestibular schwannomas (VS) and other tumors. Camille had surgery to remove her left VS by Dr. Brackmann in November. Sadly, while her cochlear nerve remained intact while the VS was removed, she lost her hearing. Otherwise, she is a happy life-loving 6th grader.



Camille Thoms and Roland Thoms



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



Why Fundraise?

By John and Linda Manth

When our daughter was diagnosed two years ago at age 7 with NF2 we decided as parents that we needed to do something to help her and others with NF. We did not want invasive surgeries to be the only treatment, we wanted medications to stop and or shrink growth of tumors before surgery would ever be needed. We decided the best thing we could do for her was to raise money for research in these areas. We raised \$55,000 our first year and \$42,000 last year. For us it gives us something positive to focus on during stressful times and the feeling doing something when there is nothing else to do. As our friends and co-workers found out about Leah's condition and prognosis they all wanted to do something to help. Fundraising gave them the vehicle to extend their love and willingness to help. Our



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Fundraising, cont.

family, friends and community have given and continue to give their time and money for Leah and everyone with NF2.

Direct YOUR Money

It is sometimes easy to say “we should do a fundraiser,” but the question that must accompany that is; “where will our hard earned money go?” As we learned more about NF2 we were disappointed in the lack of research being done and it became evident that there was a need for more. As research is slowly starting to increase maintaining interest in NF2 based research and sparking new interest and ideas is also important. Many NF2 families and patients have raised money with the hopes of finding a treatment or cure for NF2. The problem is that many people fundraised through organizations and may have had no idea where their hard earned money went. The first question we asked when choosing an organization to work with was “Where will the money go to?” and “Do we have a say in where it goes?” These are questions that you should be asking when you work with an organization. We have been able to direct our money in two areas. We have sponsored two private research studies at Harvard Medical School / MGH’s *Center for Neurofibromatosis and Allied Disorders (CNFAD)* <http://www.cnfad.org/>, as well as donated a portion of our money to an NF advocacy group.

Advocate

Advocacy is an area that many NF2 patients and families are unfamiliar with and as a result may or may not be interested in participating in. The United States government funds research for NF1, NF2, and Schwannomatosis through the *Neurofibromatosis Research Program (NFRP)* at *Congressionally Directed Medical Research Programs*

(CDMRP) <http://cdmrp.army.mil/nfrp/default.shtml>, and through the *National Institutes of Health (NIH)* <http://www.nih.gov/>.

These two agencies currently fund millions of dollars toward research. We need to advocate for not only the continuation of this funding, but the increasing of it, specifically in the area of NF2. Consider donating or directing your fundraising efforts to advocacy. Thousands of dollars can turn into millions of dollars. You may also consider writing or emailing your congressman to support NF2 research funding. Money could also be directed to assisting in the cost of sending someone to Washington, DC in person and advocate on NF’s behalf.

In conclusion, we have learned a lot in our short 2 year NF2 journey and know more is yet to come. We are more than willing to share some of what we have learned along the way. For those just beginning or already in it these are just some ideas to consider if fundraising is in your future. For any questions please feel free to contact us at jmanth7028@aol.com, or check out our blog and fundraising page at: <http://www.leahmanth.com>.



Leah Manth



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SOME NF2 Research Labs to be Supported

DISCLAIMER - please read:

This list of research labs with a major interest in NF2 is incomplete.

We are not medical experts nor affiliated with any healthcare organization or any other company. No assurance can be made to the accuracy or completeness of the information provided herein. Furthermore, no assurance can be made to the accuracy of other sites to which this site links,

• **Center for Neural Tumor Research ****

House Ear Institute (HEI)

http://www.hei.org/research/neural_tumor/index.html

Director: Marco Giovannini, MD, Ph.D.

Deputy Directors: Fabrice Chareyre, Ph.D.;

Oliver Hanemann, MD, FRCP; Michel Kalamarides, Ph.D.

Email: mgiovannini@hei.org

Phone: (213) 353-7075

• **McClatchey Laboratory ****

Harvard Med School / Mass. General Hospital (MGH)

<http://www.massgeneral.org/cancer/research/researchlab.aspx?id=1184>

Director: Andrea McClatchey, Ph.D.

Deputy Director: Ichiko Saotome, Ph.D.

Email: mcclatch@helix.mgh.harvard.edu

Phone: (617) 726-5648

*** A part of CTF's DDI NF preclinical consortium.*

Tumor focus: NF2 schwannoma, meningioma.

Others:

• **Di Tomaso Laboratory**

Harvard Med School / Mass. General Hospital (MGH)

<http://www.massgeneral.org/cancer/research/researchlab.aspx?id=1208#>

Director: Emmanuelle di Tomaso, Ph.D.

Email: ditomasso@steele.mgh.harvard.edu

Phone: (617) 726-2178

• **Center for NF and Allied Disorders (CNFAD)**

Harvard Med School / Mass. General Hospital (MGH)

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

http://www.massgeneral.org/neurology/researcher_profile/s/gusella_james.aspx

Director: James F. Gusella, Ph.D.

Email: gusella@helix.mgh.harvard.edu

Phone: (617) 643-3388

• **Dr. C. Oliver Hanemann, MD, FRCP**

<http://www.scienceroom.org/neurofibromatosis>

Peninsula Medical School and Dentistry (*in the UK*)

Email: oliver.hanemann@pms.ac.uk

Phone: +44 1752 437419

• **Jonathan Chernoff, MD, Ph.D,**

<http://www.fccc.edu/research/pid/chernoff/>

Fox Chase Cancer Center

Email: Jonathan.Chernoff@fccc.edu

Phone: (215) 728-5319

• **Shanta Messerli, Ph.D.**

Marine Biological Laboratory

http://www.biocurrents.org/Shanta_Bio_sketch09.pdf

Email: smesserli@mbl.edu

Phone: (508) 289-7389

• **Filippo Giancotti, MD, Ph.D,**

<http://www.mskcc.org/mskcc/html/10756.cfm>

Memorial Sloan Kettering Cancer Center

Email: f-giancotti@ski.mskcc.org

Phone: (212) 639-7003

• **Molecular Neurosurgery Laboratory - Gene Therapy**

Harvard Med School / Mass. General Hospital (MGH)

<http://btrc.mgh.harvard.edu/MNL/>

Director: Robert Martuza, MD

Phone: (617) 726-6817

Email: rmartuza@partners.org

• **The Ohio State University Eye & Ear Institute (OSU)**

"New drug development targeting vestibular schwannomas and meningiomas". Mark Inman, MBA (administrator)

Email: mark.inman@osumc.edu

Phone: (614) 293-3470

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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>

• **PTC299 for Treatment of Neurofibromatosis Type 2 (NF2)**

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

http://www.ptcbio.com/6.2.2_ptc299_nf2_trial.aspx

http://www.ptcbio.com/6.2.2_PTC299_NF2_FAQ.aspx

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

ClinicalTrials.gov Identifier: NCT00973739

This study is ongoing, but not 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>

• **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>

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

http://harvardabi.org/harvardabi_researchforms.htm



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NF2 Clinical Trials & Studies, cont.

• **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>

• **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>

• **Safety and Efficacy Study of BrainPort® Balance Device in Peripheral Vestibular Dysfunction.**

ClinicalTrials.gov Identifier: NCT00768378

This study is currently recruiting participants.

<http://www.clinicaltrials.gov/ct2/show/NCT00768378?term=BrainPort&rank=1>

- Wicab is sponsoring clinical studies to evaluate the effectiveness of the BrainPort® balance device for improving balance in people with balance difficulties.

<http://wicab.us/research/clinical-studies.php>

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://ctf.org/nforum/>
- **NFSO, bi-annual meeting.**
May 2, 2010 • Toronto ON, Canada.
Topics to include: NF2 research (potential drug trial in Canada), and a probable NF Clinic (in Toronto).
Hosted by the NF Society of Ontario (NFSO).
http://www.nfon.ca/events_calendar.php
- **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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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-](http://www.firstscience.com/home/news/breaking-news-all-topics/research-to-lead-to-braintumor-therapies_45157.html)

[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)

<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&itool=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/NF2_Compass_2010spring.pdf

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