

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

Issue 6, page 1; summer 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.*



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

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

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Advocure NF2 Inc. attended CTF's 2010 [NF Forum](#) April 9-11, in LV. A well organized and planned out "National Patient & Family Medical Symposium - Information, Support, Expert Advice". SOME topics of NF2 relevance included: *Lobbying; Advocacy; Tackling and Understanding U.S. Health Insurance; NF2 Clinical Trial Update; Managing Your Tumors and Why it is Important to the Patient; Facial Nerve Surgery Helping to Improve Facial Paralysis; What are the Options for Tinnitus Management and Treatment; Radiation Treatment and ABIs; and New Hearing Technologies.*



Advocure NF2 Inc. attended the [NF Society of Ontario \(NFSO\), bi-annual meeting](#), Sunday May 2nd, in Toronto. Topics included a proposed NF2 drug trial/ study, Nilotinib, (sister compound of Gleevec) – 'A Phase II study of Nilotinib on growing vestibular schwannomas'. Trial to begin this Fall 2010, in Toronto, Canada.

Principal Investigator: [Abhijit Guha, FACS, FRCSC, MD, MSc](#), phone: 416.603.5740 and/or 416.813.6688.

*"With Novartis we will evaluate Nilotinib in a single arm Phase2 study on growing vestibular schwannomas (VS) based on serial MRIs (>15% in 3mths). Rationale is based on our [published pre-clinical work](#). 30 patients will be enrolled (per statistical advice), with both sporadic and NF2 associated VS eligible. Patients will receive 400mg Nilotinib bid PO. Tumor response will be monitored with serial MRI using volumetric analysis at 1,3mths and q3mths for 2yrs. Treatment duration will be 1yr."*

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## NF2 in the News:



- CTF's ['NF2: State of the Trial' Workshop Yields Guideline Updates, New Collaborations](#). (Blog at CTF)  
"After two very exciting but very long days of 'NF2: State of the Art', CTF kept about 20 scientists and clinicians on for a small workshop: 'NF2: State of the Trial'. The group assembled has pledged to meet again one year from now and annually thereafter. It has been a terrific few days of NF2 meetings and everyone left today feeling truly inspired about the future of NF2 trials. Look for a full report on the meeting soon at CTF."





- ['NF2 Meeting: State of the Art'](#)  
In LV, top NF2 clinicians and researchers from around the world attended. The agenda topics ranged from NF2 clinical management, to use of PABI/ABI/CI's, to NF2 drugs in preclinical testing development, and of course the ongoing NF2 clinical trials. (see *Blogs below*)
  - [NF2: State of The Art – Afternoon of Day 2](#)
  - [NF2: State of The Art – Morning of Day 2](#)
  - [NF2: State of The Art – Afternoon of Day 1](#)
  - [NF2: State of The Art – Morning of Day 1](#)

- [Dr. Hanemann and Neurofibromatosis type 2 research](#) – A primary human in vitro model to test and translate new therapies for Neurofibromatosis type 2 (NF2) tumours into clinical trials.




MTV has produced an episode: ["True Life | I Have NF"](#). The story focused on three individuals with NF, one of whom is Bekah, a 19 years old with NF2 from Illinois.

-  The annual [NF Conference](#) brings together basic and clinical NF investigators from all over the world to present their latest research in NF1, NF2 and Schwannomatosis. (*Blogs at CTF*)
  - [2010 NF Conference: Day 4](#)
  - [2010 NF Conference: Day 3](#)
  - [2010 NF Conference: Day 2](#)
  - [2010 NF Conference: Day 1](#)

-  A msg from [NF Inc NE](#): "You can help by writing to your representatives in the House and Senate and tell them that you want continued, and increased funding for NF research at both the National Institutes of Health (NIH) and the Department of Defense's Congressionally Directed Medical Research Program (CDMRP-NFRP). To find your representatives in Congress go to this [link](#)."

**If you don't tell your Representative that NF research is important to you, they won't know!**

-  [Neurofibromatosis Factsheet at CDMRP-NFRP](#)  
The NFRP's vision is to find and fund the best research to eradicate the clinical impact of NF. Various award mechanisms have been supported over the years to meet these changing needs of the NF landscape including New Investigator, Investigator-Initiated Research, Therapeutic Development, and Clinical Trial, etc.
- [New Research Resources Initiative by the NFRP](#) - The NFRP now offers a service on our website featuring a listing of available NF research resources!! Our goal is to facilitate and speed NF research by publicizing new resources and aiding collaborations. The list displays available resources and repository or PI contact information. Please contact the repository or PI directly for information and requests.
- [Neurofibromatosis Research Highlights](#) (from FY01 to FY10).

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*NF2 in the News cont.....*



“NF2 research activity, especially in the area of testing candidate drug treatments has increased significantly in the past several years....” (Blogs at CTF).

- [NF Bites: Progress in NF2 – Part One](#)
- [NF Bites: Progress in NF2 – Part Two – Developing Drug Therapies](#)

[Further genotype--phenotype correlations in neurofibromatosis 2](#)

DG Evans et al. "We present a comparison between the clinical presentations of patients with mutations that are predicted to produce truncated protein (nonsense/frameshift mutations) to those that results in loss of protein expression (large deletions) to elucidate further genotype-phenotype correlations in NF2...."



[For NF2, More Insight on Merlin Protein](#)

[Wizardry](#) (CTF blog) - A new study (see below) done on fruit flies shows that inside the cell merlin moves up and down on structures call microtubules, which form a scaffolding framework that controls changes in cell shape as well as function. In a stunning finding the study shows that a single amino acid change – the tiniest substitution in how merlin is encoded – markedly inhibits this movement, apparently by interfering with phosphorylation of merlin. In addition when present, this dysfunctional protein also prevented healthy merlin protein from moving around. [Microtubule-mediated transport of the tumor-suppressor protein Merlin and its mutants](#)

CTF's NF2 Young Investigator Finds Dual Role for Human 'Hippo' - CTF's Young Investigator Awardee Geoffrey Killili and his mentor Dr. John Kyriakis at Tufts University have uncovered novel ideas about the signaling pathways of merlin, the tumor suppressor protein made by the NF2 gene.



- [Neurofibromatosis type 2 \(NF2\): A clinical and molecular review](#) – by DG Evans.



**REQUEST FOR PROPOSALS:**

[Dr. Roswell Eldridge NF Research Fund](#)

Neurofibromatosis, Inc.-Mid-Atlantic is requesting proposals for research projects in neurofibromatosis (NF1 or NF2) or schwannomatosis..



New program to Advance Development of Drug Candidates for Rare and Neglected Diseases ~ NIH's new program: [Therapeutics for Rare and](#)

[Neglected Diseases](#) (TRND). NIH is considering initiating projects with promising drug candidates that are stalled in development for which there are clinical data, or for which a data package could be generated and compiled into an Investigational New Drug (IND) submission within one year of transfer of the project to TRND.



- [Funding Information from National Institute of Neurological Disorders and Stroke \(NINDS-NIH\)](#) - Funding Overview - NINDS (NIH) supports and conducts research, both basic and clinical, on the normal and diseased nervous system. Informative links:

- [NINDS Neurofibromatosis Information Page](#), and
- [Neurofibromatosis Fact Sheet \(at NINDS\)](#)



- [National Organization for Rare Diseases \(NORD\), Research Grant Program](#) ~NORD's Research Grant Program provides seed money in small grants to academic scientists studying new treatments or diagnostics for rare diseases.

# NF2 Compass

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NF2 in the News cont.....



## [Central Brain Tumor Registry](#)

[of the United States \(CBTRUS\)](#) - The Central Brain Tumor Registry of the United States, CBTRUS, is a not-for-profit corporation committed to providing a resource for gathering and disseminating current epidemiologic data on all primary brain tumors, benign and malignant.



## [CTF's Neurofibromatosis Clinical Trial](#)

[Awards](#) - The Children's Tumor Foundation (CTF) has developed the Neurofibromatosis Clinical Trial Awards of up to \$125,000 total, to support pilot-scale clinical testing of potential candidate therapeutics.



## [National Brain Tumor Society](#)

Leading through research and support

## [The National Brain Tumor](#)

[Society. Funding Opportunities](#) Apply for a grant - In order to fund the most promising research, the National Brain Tumor Society offers grants to qualified researchers each year



## [The Childhood Brain Tumor Foundation, 2010](#)

[Funding Opportunities](#) - The Childhood Brain Tumor Foundation (CBTF) is soliciting grant applications for the calendar year 2010



## [Neurofibromatosis type 2~NF2 Awareness movie](#)

"Please help us raise awareness and for finding a cure for NF2."



## [American Brain Tumor Association, 2010 Funding](#)

[Opportunities](#) - Listing of ABTA 2010 Funding Opportunities, and other sources.

- [New Tool for Operations on People With Severe or Profound Auditory Loss](#) - A team of engineers from the CEIT-IK4 technological centre and doctors from the University Hospital of Navarra have designed a new tool for operating on the inner ear with maximum precision, reducing the possibility of damage to the auditory function during the surgery .

- [Center for Paralysis Research](#) - The Center for Paralysis Research was founded to both develop and test new methods of treatment for spinal cord, brain injuries, and certain diseases of the nervous system.



[Save the Date - the 2010 Ohio Gathering!](#) - The 7th annual Ohio Gathering, for NF2ers, will be held Oct. 8-10 in Columbus, Ohio.



## [World Health Organization](#)

The World Health Organization (WHO) announced that long-

term use of cell phones [may be linked to elevated risk of some types of brain issues](#). The conclusion, which is reportedly still inconclusive, is derived from a landmark international study overseen by the WHO that has lasted for decades. - [Brain tumour risk in relation to mobile telephone use: results of the INTERPHONE international case-control study](#).

## ["BEN"EFIT FOR NF2](#)

Hosted by the Monerotti Family

## ["Ben"efit for NF2 in](#)

[Columbus, OH raises more than \\$37,000!!](#) Since its inception in 2009, the "Ben"efit for NF2 has raised more than \$85,000 for the Foundation's *NF Preclinical Consortium*.

- [Some Doctors tout NanoKnife for Tumor Removal](#) - Some doctors are using the NanoKnife, a series of needlelike steel probes with an electrical generator, to poke infinitesimal holes in a tumor's cellular walls, causing them to die naturally and be routinely discarded by the body.

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## SOME NF Clinics with an excellent NF2 component, to be Supported:

*The NF Clinical Centers listed below are currently participating in NF2 clinical trials and/or NF2 studies:*

**DISCLAIMER - please read:**

*This list of NF Clinics (with an excellent NF2 component) 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.

- MGH [Neurofibromatosis Clinic](#), (and/or [old website](#)).  
Boston, MA  
Clinic Director: [Scott Plotkin, M.D., Ph.D.](#)  
Clinic Coordinator: Marybeth Singh, NP  
Call for Appointment: 617-724-7856
  - *Bevacizumab (Avastin), and PTC299 phase 2*
- NYU Langone Medical Center, [Neurofibromatosis Center](#)  
New York, NY  
NF Clinic Directors: Jeffrey C. Allen, M.D., J. Thomas Roland, M.D., and John G. Golfinos, M.D.  
NF Clinic Coordinator: [Sandra Pile](#)  
Call for Appointment: 212-263-9695  
*Specialized NF2 Clinic/Center (within NYU's NF Clinic), led by: J. Thomas Roland, M.D. & John G. Golfinos, M.D.*
  - *Lapatinib, phase 0 & 2.*
- House Ear Institute (HEI), Los Angeles, CA  
[Center for Clinical Studies](#)  
Principal Investigator: William H. Slattery III, M.D.  
Clinical Coordinator: Roberta Leyvas  
[House Ear Clinic](#)  
Call for Appointment: (213) 483-9930
  - *Lapatinib, phase 0*

- Neurofibromatosis Clinic  
Central Manchester Foundation NHS  
Trust Regional Genetic Service, St. Mary's Hospital  
Manchester, UK  
Director: [D Gareth Evans, MD, FRCP](#)
- The Ohio State University (OSU), Eye and Ear Institute  
Department of Otolaryngology-Head and Neck Surgery  
Columbus, OH  
NF2 Clinic Director: [D. Bradley Welling, MD, PhD](#)  
Research Associate: [Beth A. Miles-Markley, MS](#)  
Phone: (614) 366-9244  
Fax: (614) 293-7292
  - *Lapatinib, phase 0*
- The Johns Hopkins [Comprehensive Neurofibromatosis Center](#)  
Baltimore, MD  
Clinic Director: [Jaishri Blakeley, MD](#)  
Clinic Coordinator: Amanda Bergner, MS, CGC  
Call for Appointment: 443-287-3724
  - *Lapatinib, phase 0*
- NIH [Clinical Center](#) (CC)  
Bethesda, MD  
E-mail: [prpl@mail.cc.nih.gov](mailto:prpl@mail.cc.nih.gov), Phone: 1-800-411-1222, or [Hetty DeVroom, R.N.](#), Surgical Neurology, NINDS  
Tel: 301-594-8111
  - *NF2 Natural History Study*
- Toronto Western Hospital, [University Hospital Network](#) (UHN)  
[Arthur & Sonia Lobbatt Brain Tumour Research Centre](#)  
Toronto, ON  
Co-director: [Abhijit Guha, FACS, FRCSC, MD, MSc](#)  
Clinical Assistant: [Joan, Balatbat](#)  
Phone: 416-603-5740
  - *Nilotinib, phase 2*

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## Fundraising:



### Zazzle™ - [Cups & Stuff](#)

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

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 [click here](#).



### FIRST ANNUAL SOUTH JERSEY RIDE4NF 2010

#### [First Annual South Jersey Ride4NF Poker Run/Benefit.](#)

Join Mullica twp. residents Jaime and Jim Cirillo on Sunday July 11th, as they ride for a cure! All proceeds from this ride and benefit will go to research funding to help find a cure for NF (NF Inc. and Advocure NF2 Inc). For more information please call either Jaime or Jim at (609) 965-0848. Thank you!!! With your help, we will find a cure for Neurofibromatosis. [Facebook page](#).



Painting auctioned!!

**Thank you!**

Proceeds to NF2 research & advocacy, via Advocure NF2, Inc.

## Symposiums of NF2 Interest:

- [2010 NF Conference](#), *Back to the Future*  
June 5-10, 2010 • Baltimore MD, USA  
[Agenda](#)  
Hosted by the Children's Tumor Foundation (CTF)
- [14<sup>th</sup> European NF-Meeting](#), *2010 Oslo*  
September 9-12, 2010 • Oslo, Norway  
[Program](#)  
Hosted by the Norwegian NF Association  
in cooperation with Frambu.
- [NF Symposium](#)  
Sunday, October 24. 2010 • Boston, USA  
Sponsored by the [Center for Neurofibromatosis and Allied Disorders](#) (CNfAD).

## CDMRP's current NF Consortium:

*Fyi, the CDMRP's [NF Consortium](#) is dedicated to conducting clinical trials to improve the quality of life of persons with neurofibromatosis. The current 10 NF Consortium Centers are:*

- [Children's Hospital](#), Boston
- [Children's Hospital at Westmead, University](#) of Sydney
- [Children's National Medical Center](#) (Washington, D.C.)
- [Cincinnati Children's Hospital Medical Center](#)
- National Cancer Institute (Bethesda, MD)
- [University of Alabama at Birmingham](#)
- [University of Chicago](#)
- University of Pennsylvania
- University of Utah
- [Washington University](#) (St. Louis)



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## Update: CDMRP's NF Consortium

### Inquiry on expanding to include NF2, and their Reply:

**Some background:** In 2006, the CDMRP-NFRP established a consortium of exceptional centers (listed above) that were mandated to conceive, develop, and conduct collaborative pilot and Phase I and II clinical evaluations of promising new therapeutic agents or approaches, but for the management or treatment of neurofibromatosis type 1 (NF1) only.

From: [jamie@advocurenf2.org](mailto:jamie@advocurenf2.org)  
Sent: Friday, April 16, 2010 2:52 PM  
To: [NF\\_Consortium@genetics.uab.edu](mailto:NF_Consortium@genetics.uab.edu)  
Cc: [naba.bora@amedd.army.mil](mailto:naba.bora@amedd.army.mil)  
Subject: NF Consortium

Dear Doctor Korf:

I am writing as a member of the neurofibromatosis community to gather basic information on the NF Consortium. I hope you or your staffs are willing to help. Thank you, in advance, for your time and assistance.

On the Frequently Asked Questions page of the NF Consortium's website (<http://nfconsortium.org/FAQ.html#FAQ3>), the answer states, **"the NF Consortium has focused on clinical trials for NF1, but the Consortium is working to expand its activities into other forms of neurofibromatosis."**

Will you please elaborate on the actions taken since 2006 to advance this objective for NF2 and Schwannomatosis, as well as current and future plans?

Thank you for any and all information you are able to provide. Your service and dedication to the neurofibromatosis community are tremendously appreciated.

Sincerely,  
Jamie Przybysz  
Advocure NF2, Inc.  
[www.advocurenf2.org](http://www.advocurenf2.org)

### Reply:

From: 'Karen Cole - Plourde'  
Date: Mon, 19 Apr 2010 09:03:52 -0500  
To: 'jamie@advocurenf2.org'  
Cc: 'Bora, Naba Dr CIV USA MEDCOM CDMRP'; 'Bruce RKorf'  
Subject: Re: Response to NF Consortium email inquiry Friday, April 16, 2010

Dear Ms. Przybysz:

On behalf of the Consortium, some actions taken to expand activities for NF 2 include:

1. Last year, we began collaborations with Dr. Scott Plotkin on an NF 2 grant titled, "A Phase II trial of bevacizumab in treatment of symptomatic vestibular schwannoma". Dr. Scott Plotkin has obtained funding from Genentech to support this study and will utilize the NF Consortium to include patient recruitment from participating sites. The NF Operations Center at UAB will serve as the Operations Center for trial management. Currently, specific duties and timelines are being discussed. Further reports will be available as we progress. Dr. Plotkin will also be a guest at the upcoming NF Steering meeting in June for planning purposes.
2. Last year the Consortium activated an NF 2 Committee to further efforts aimed in this direction: Dr. James Tonsgard from Chicago was named as Chair of this committee, Dr. Nichole Ullrich is co-chair and one more person will be nominated on this committee in June. The committee has been charged with identification of candidate clinical trials for patients with NF2 and developing protocols for future implementation by the NF Consortium.

Please feel free to contact us again if you should have any further questions.

Kindest regards,  
Karen A. Cole-Plourde, BS, Program Manager  
NF Consortium Operations Center  
205.934.5140

## NF2 Clinical Trials & Studies:

- [Natural History Study of Patients with Neurofibromatosis Type 2 \(NF2\)](#)

ClinicalTrials.gov Identifier: NCT00598351

**This study is currently recruiting participants.**

This study will examine over the long-term the progress of patients with neurofibromatosis Type 2 (NF2), a condition associated with tumors of the nerves, brain and spinal cord. 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.

People between 8 and 75 years of age with NF2 may be eligible for this study, *(most expenses are reimbursed)*.

- [Concentration and Activity of Lapatinib in Vestibular Schwannomas](#)

ClinicalTrials.gov Identifier: NCT00863122

**This study is currently recruiting participants.**

This study is exploring whether a drug that is approved by the FDA and is currently used to treat breast cancer might also work to treat VS. This study will measure the amount of drug that travels from the bloodstream and arrives at the tumor. This drug is safe and has few side effects. If this drug is shown to reach the tumor, it might be used in the future to treat VS without needing surgery or radiation.

This study is recruiting people who are having surgery for VS. If you are going to have surgery to treat a VS, you may be eligible to participate

- [Neurofibromatosis Type 2 Associated Color Vision Anomalies and Birth Defects: Incidence and Insights](#)

**This study is currently recruiting participants**

What is the purpose of the study? 1) Determine the frequency of birth defects and miscarriages in patients with NF2. 2) Determine the frequency of color blindness in NF2 patients

- [PTC299 for Treatment of Neurofibromatosis Type 2 \(NF2\)](#)

ClinicalTrials.gov Identifier: NCT00911248

**This study is currently recruiting participants.**

PTC299 is an oral drug that has been shown to decrease production of VEGF in animal models of human cancer. In these animal models, oral PTC299 administration decreases VEGF levels in the tumor and in the bloodstream, decreases blood vessel numbers in the tumor, and significantly slows or halts tumor growth. Safety studies in research animals indicate good tolerability at doses and drug levels that are higher than those planned for the clinical studies. Results from Phase 1a studies in healthy volunteers indicate that PTC299 achieves levels of PTC299 in the bloodstream that are known to be active in animal models of human tumor. This Phase 2 study is designed to test the hypothesis that PTC299 will be tolerable and will show evidence of VEGF reduction, antitumor activity, and hearing improvement when administered orally to patients with NF2.

- [Oncology – PTC299](#)

- [Neurofibromatosis Type 2 Clinical Trial Overview](#)

- [Neurofibromatosis Type 2 Trial FAQ](#)

- [Phase II Trial of Bevacizumab in Patients With Recurrent or Progressive Meningiomas](#)

ClinicalTrials.gov Identifier: NCT01125046

**This study is not yet open for participant recruitment.**

RATIONALE: Monoclonal antibodies, such as bevacizumab, can block tumor growth in different ways. Some block the ability of tumor cells to grow and spread. Others find tumor cells and help kill them or carry tumor-killing substances to them.

PURPOSE: This phase II trial is studying how well bevacizumab works in treating patients with recurrent or progression meningiomas.





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## NF2 Clinical Trials & Studies, cont.

- [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.**

Lapatinib is an oral drug that is approved by Food and Drug Administration (FDA) for other types of tumors, it is not approved by the FDA for treatment of NF2 related tumors. The investigators know a lot about how well it is tolerated, but the investigators do not know if it is effective in treating your condition, therefore it is considered to be an investigational medication. This study will test whether Lapatinib may shrink tumors commonly found in patients with NF2 or stop them from growing. This will help us to decide if Lapatinib should be used to treat NF2 patients in future. Lapatinib is a drug that has been used for over 10 years to treat various forms of cancer. It has not been studied for the treatment of tumors in NF2 patients.

- [Sunitinib in Treating Patients with Recurrent or Unresectable Meningioma, Intracranial Hemangiopericytoma, or Intracranial Hemangioblastoma](#)

ClinicalTrials.gov Identifier: NCT00561665

**This study is currently recruiting participants.**

This phase II trial is studying sunitinib to see how well it works in treating patients with recurrent or unresectable meningioma, intracranial hemangiopericytoma, or intracranial hemangioblastoma

- [Phase II Trial of Sunitinib \(SU011248\) in Patients with Recurrent or Inoperable Meningioma](#)

ClinicalTrials.gov Identifier: NCT00589784.

**This study is currently recruiting participants.**

Sunitinib is a drug approved for advanced kidney cancer. Sunitinib is also being studied for other tumors. It may be useful in the treatment of brain tumors because it can prevent formation of new blood vessels that allow tumor cells to survive and grow.

- [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.**

For patients with malignant pleural mesothelioma that has grown despite treatment with standard chemotherapy, no treatment has yet proven beneficial. The purpose of this study is to find out what effects, both good and bad, that everolimus has on the cancer. Everolimus works by blocking a protein that helps the cancer grow. The goal of this clinical research study is to learn if the study drug everolimus can shrink or slow the growth of mesothelioma. The safety of this drug will also be studied. The patients' physical state, changes in the size of the tumor, and laboratory findings taken during the study will help us decide if everolimus is safe and effective.

- [Monthly SOM230C for Recurrent or Progressive Meningioma](#)

ClinicalTrials.gov Identifier: NCT00859040

**This study is currently recruiting participants.**

The purpose of this research study is to evaluate the effectiveness and safety of SOM230C in treating recurrent meningiomas. SOM230C is a newly discovered drug that may stop meningioma cells from growing abnormally. This drug has been used in treatment of other tumors, and information from those other research studies suggests that SOM230C may help to stop the growth of meningiomas.

- [Phase II Study of SOM230 in Patients with Recurrent or Progressive Meningioma](#)

ClinicalTrials.gov Identifier: NCT00813592

**This study is ongoing, but not recruiting participants.**

This is a single-arm, phase II trial of SOM230 in patients with documented recurrent or progressive intracranial meningioma who have failed conventional therapy and are not candidates for complete surgical resection of their tumors and/or radiation at the time of study entry.



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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.**

Facial palsy after surgical removal of cranial base tumors adherent to the nerve can partly be explained by inflammation.

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

A clinical research study of patients who have an auditory brainstem implant (ABI) is being conducted jointly by researchers. We will use specialized hearing testing to better understand how your brain responds to stimulation from your ABI.

### • [Safety and Efficacy Study of BrainPort® Balance Device in Peripheral Vestibular Dysfunction.](#)

ClinicalTrials.gov Identifier: NCT00768378

**This study is currently recruiting participants.**

The purpose of this study is to assess the safety and efficacy of the BrainPort balance device in improving balance and gait as measured by clinically accepted standardized balance assessments in subjects with peripheral vestibular dysfunction.

Wicab is sponsoring [clinical studies](#) to evaluate the effectiveness of the BrainPort® balance device for improving balance in people with balance difficulties.

## 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://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.

- [Nexavar](#) ([sorafenib](#))
- [Valproic acid](#)

- [Tarceva](#) (erlotinib)
- [Rapamycin](#)

- [AR-42](#) (OSU-HDAC42)
- [Cetuximab](#)

- [AR-12](#) (OSU-03012)
- [Trastuzumab](#)

- [Curcumin](#)
- [Nilotinib](#)

- [Propolis](#) ([BIO30](#)™ propolis)

*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.*

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'NF2 Compass' was formerly known as 'Flutterby'