



NF2 Compass

A QUARTERLY ADVOCURE ONLINE NEWSLETTER

Formerly known as "Flutterby"



Advocure NF2 Inc. is a Working Advocacy Group, Liason, and 501 (c)(3) Public Charity for the NF2 International Community and NF2 Crew.

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2011 Halloween Bash raises \$100,000 for children's tumor research!!



November 1, 2011 - The 2011 Halloween Bash has come and gone and it was a huge success. On Saturday, October 22nd, 300+ people packed the Redux Lounge in downtown Walnut Creek to attend the 7th annual Bash, a benefit through Advocure NF2 to fund children's tumor research. Over \$40,000 was raised that night and with contributions from Varsity Painting and the Thoms family, the total amount raised for research is \$100,000.....

Our Mission:

Advocure NF2 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: www.advocurenf2.org

[Advocure Brochure](#) [RSS Feeds](#)



How To Help

Advocure NF2 Inc. is a 501(c)(3) public charity. All contributions to Advocure NF2 Inc. are tax-deductible.

Thank You For Your Support!

Advocure NF2 Funds Research - This year (FY11), Advocure NF2 will be funding two NF2 researchers: **Dr. Marco Giovannini** at House Research Institute (HRI), who will be starting a Phase 2 clinical trial of RAD001 for NF2. In addition: **Dr. Brad Welling** at Ohio State University (OSU) is to develop a medical therapy for NF2 VS and meningiomas utilizing two novel small-molecule compounds, AR-12 and AR-42. As well as to screen a library of pure, structurally-defined natural compounds for potent growth inhibitory activity in schwannomas and meningiomas.

Psychosocial Aspects- Recurrent brain tumour: the impact of illness on patient's life - Despite advances in therapies that offer improved survival rates, clinical course of brain tumours leads to a progressive functional deterioration in patients with modifications in their psychological reaction to the disease. Patients with brain tumours are rarely assessed for quality of life and psychological variables, and even fewer studies have assessed patients who have experienced a recurrence of brain tumours...

Crucial Funding For NF Research - "Increasing pressures on the defense budget are resulting in cuts to various programs, and we need your help in sending the message to Congress that federal funding for NF research should continue at a robust level. This is more





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important now than ever before. The FY2012 Defense Appropriations Bill passed by the House of Representatives earlier this year included \$12.8 million for NF research. The Senate did not provide this level of funding in its version of the bill. We need your help in requesting that Congress retain the House-passed funding level for the NF CDMRP when House and Senate leaders meet to negotiate the differences in their two bills. Time is of the essence - please write your Member of Congress today! A template letter of support is included on this page to help make this easy."

[Click here to view and download template letter](#)

[Click here to search for your Representative](#)

[Click here to search for your Senator](#)

Children's Tumor Foundation Raises \$1.5 Million at recent

Benefit Dinner - The Children's Tumor Foundation's 2011 Annual Benefit Dinner was our largest and most successful event ever -- raising \$1.5 million and still counting for neurofibromatosis research (NF)...



NIH Offers Director's Transformative Research Awards of up to \$25M/Year for up to Five Years

opportunity at NIH: The Common Fund's NIH Director's Transformative Research Award initiative, formerly known as the Transformative Research Project (TR01), is created specifically to support exceptionally innovative and/or unconventional research projects that have the potential to create or overturn fundamental paradigms. These projects tend to be inherently risky and may not fare well in conventional NIH review. As compared to the other NIH Director's Awards - the Pioneer, New Innovator Award, and Early Independence Awards - the primary emphasis of the Transformative Research Awards initiative is to support research on bold, paradigm-shifting, but untested ideas, rather than to support exceptionally creative individuals who wish to pursue new, potentially high impact research directions. The receipt date is January 12, 2012.



3rd State of the Art International NF2 Conference - The Manchester NF2 Multidisciplinary Team would like to invite you to attend the third State of the Art International NF2 Conference, on May 21-22, 2012, in Manchester, UK. The meeting will focus

on Epidemiology, Genetics and Natural History of NF2, NF2 surgery and radiosurgery, Auditory Rehabilitation and Animal models and preclinical and clinical trials...

NF2 Webinar with Scott Plotkin, MD - NF Network is pleased

NF to present an all new NF2 webinar. You don't want to miss this webinar with guest presenter, and NF2 expert Dr. Scott Plotkin, MD, PhD. Just a couple of the topics Dr. Plotkin will discuss are advancements in NF2 research and the genetic inheritance of NF2. Wed, Nov 30, 2011 8:00 PM - 9:00 PM EST.

SOME NF2 Research Labs to be Supported - There are several excellent research labs currently studying NF2.

SOME NF Clinics with excellent and progressive NF2 components - SOME NF Clinical Centers with an excellent and progressive NF2 component that are currently participating in progressive NF2 care, NF2 drug trials, and/or NF2 studies.

In Reversing Motor Nerve Damage, Time Is of the Essence: 'Wait and See' in Injuries Like Carpal Tunnel Syndrome May Miss a Window for Recovery - When a motor nerve is severely damaged, people rarely recover full muscle strength and function. Neuroscientists from Children's Hospital Boston, combining patient data with observations in a mouse model, now show why... (would this have relevance to correcting NF2 facial nerve damage?) NF2, Dr. Gareth Evans - Background - NF2 & Schwannomatosis, Dr. Gareth Evans - Visual Traits to NF2?, Matthias Karajannis - What's happening with NF Clinical Trials, etc.

Taking the REINS on Neurofibromatosis Clinical Trial Design

As neurofibromatosis clinical trials increase in number, the clinicians leading them are keen to design the trials to be as effective and meaningful as possible. A key part of this effort is developing the right trial endpoints - measures and metrics that can be used to determine if a drug or intervention is effective or not. To tackle this area, a team of neurofibromatosis clinicians and researchers has formed a working group called Response Evaluation in Neurofibromatosis and Schwannomatosis (REINS). Spearheaded by Dr. Scott Plotkin (MGH) and Dr. Brigitte Widemann (NCI) and





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first convened in June at the Children's Tumor Foundation 2011 NF Conference, around 30 leading NF clinicians and researchers participating in the REINS met in Boston to continue their planning and discussions.

Call for Entries to the 2012 Neuro Film Festival - The American Academy of Neurology Foundation is calling on all neurology patients, caregivers and others to submit a short video to its 2012 Neuro Film Festival, telling their story about why more research is needed into finding cures for brain disorders. Winners could win up to \$1,000 and a trip to New Orleans. The deadline to enter is January 31, 2012. A good way to get NF2 awareness out there in a big way. Deadline is January 31, 2012.

University Hospitals Neurofibromatosis 2 Center - UH Neurofibromatosis 2 Center in Cleveland, OH is comprised of a multidisciplinary group of surgeons and specialists in neurosurgery, neurology, oncology, otolaryngology and genetics.... They offer standard and innovative treatment options including management through medication, radiation or surgery. Hearing rehabilitation using auditory brainstem implants (ABI) or cochlear implantations (when appropriate) are available as well.

2012 NF Forum Topics Survey - In preparation for the 2012 NF Forum: CTF is conducting a survey to gauge interest in what topics everyone wants at the next NF Forum. The proposed NF2 topic selections are limited. However, in the next step, it allows you to free form as many NF2 topics as you want. So, tell them what you want! Save the Date: NF Forum 2012, Hilton New Orleans, on June 8-10, 2012.

Facial Reanimation of Five Patients with Neurofibromatosis Type 2 - Patients were treated between 2006 and 2009. Three patients were men and two were women. The age of presentation of debilitating facial paralysis ranged from 13 to 50 years old. All patients were treated with a single stage free gracilis muscle transfer for smile reanimation. Each obturator nerve of the gracilis was coapted to the masseteric branch of the trigeminal nerve. Measurement of oral commissure excursions at rest and with smile, preoperatively and postoperatively, revealed

improved and near symmetric smile in all cases...

NF2 Workshop held in LV last year, to be published - The Children's Tumor Foundation is delighted to announce that a Foundation-spearheaded paper outlining progress in NF2 clinical trials and strategies for further accelerating these trials has been accepted for publication in the American Journal of Medical Genetics (AJMG). This paper, "Consensus Recommendations for Current Treatments and Accelerating Clinical Trials for Patients with Neurofibromatosis Type 2" was authored by 17 international NF2 clinical and research experts. The new AJMG publication should appear in the near future.

Sorafenib in an NF2 study, in the UK - Adults who have Neurofibromatosis 2 (NF2) and skin tumours (schwannomas) are invited to participate in a research study being undertaken in Plymouth and Manchester; **Professor C. Oliver Hanemann**, a consultant neurologist at the Peninsula College of Medicine and Dentistry in Plymouth is the Chief Investigator...

Medical Drug Shortages - Doctors and officials from Health and Human Services and the Food and Drug Administration testified on the effects of drug shortages on cancer patients.

Key Molecule That Blocks Abnormal Blood Vessel Growth in Tumors Identified - A new and better understanding of blood vessel growth and vascular development (angiogenesis) in cancer has been made possible by research carried out by a team of scientists from Moffitt Cancer Center, the University of Florida, Harvard University, Yale University and the Children's Hospital of Los Angeles.

Results of world-first viral therapy trial in Ottawa cancer patients published in Nature - News Release - Researchers from the Ottawa Hospital Research Institute (OHRI), the University of Ottawa (uOttawa), Jennerex Inc. and several other institutions today reported promising results of a world-first cancer therapy trial in renowned journal Nature. The trial is the first to show that an intravenously delivered viral therapy can consistently infect and spread within tumours without harming normal tissues in humans. It is also the first to show tumour-selective expression of a foreign gene after intravenous delivery...





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[New strategy likely to speed drug development for rare cancers \(ependymomas\)](#) - Researchers have identified promising new therapies for ependymoma, a rare tumor with few treatment options. St. Jude Children's Research Hospital investigators led the effort, which used a new, faster drug development system that combines the latest drug screening technology with the first accurate animal model of the tumor. Investigators identified several dozen new and existing drugs as possible ependymoma treatment candidates. The drugs were found by screening 5,303 existing medicines, natural products and other compounds for activity against the tumor, which develops in the brain and spine of children and adults. The work is published in the Sept. 13 edition of the scientific journal [Cancer Cell...](#)

[Cancer Growth In Head And Neck Suppressed By Turmeric](#) - According to investigators at UCLA's Jonsson Comprehensive Cancer Center a pilot study using human saliva revealed that curcumin, the primary component in the spice turmeric, suppresses a cell-signaling pathway that powers the growth of cancer in the head and neck. The investigation is presented Sept. 15 in *Clinical Cancer Research*, a peer-reviewed journal of the American Association of Cancer Research...

[Malay Folk Medicine points to Cancer Cure Tree](#) - A drug from a tree that belongs to the pomegranate family found here in Sarawak has shown promise in the fight against certain types of cancer. Known for hundreds of years to the Malay folk community, the plant grows in the highlands of central Borneo...

[An Immune System Trained to Kill Cancer](#) - "...Dr. June said his team hopes to use T-cells against solid tumors, including some that are very hard to treat, like mesothelioma and ovarian and pancreatic cancer. But possible adverse reactions are a real concern, he said, noting that one of the protein targets on the tumor cells is also found on membranes that line the chest and abdomen. T-cell attacks could cause serious inflammation in in those membranes and mimic lupus, a serious autoimmune disease..."

[Combining Curcumin \(Diferuloylmethane\) and Heat Shock Protein Inhibition for Neurofibromatosis 2 Treatment: Analysis of Response and Resistance Pathways](#) - The NF2 gene product,

merlin, is activated (dephosphorylated) by contact inhibition, and promotes growth suppression. We investigated the effect of curcumin (diferuloylmethane), a molecule with anti-inflammatory and anti-tumorigenic properties, on human schwannoma cell growth and the regulation of merlin by curcumin in both NF2 cells and neuroblastoma (non-NF2) cells. Curcumin inhibited the growth of HEI-193 schwannoma cells in vitro, and down-regulated the phosphorylation of Akt and ERK 1/2..... The combination of curcumin and a heat shock protein inhibitor synergistically suppressed schwannoma cell growth. Our results provide a rationale for combining curcumin and KNK437 in the treatment of NF2.

[Following A Path To A Potential Therapy For NF2, A Rare Tumor Disorder](#) - The proteins that provide cells with a sense of personal space could lead to a therapeutic target for Neurofibromatosis Type 2 (NF2), an inherited cancer disorder, according to researchers at The Wistar Institute. Their findings, which appear in the April 12 issue of the journal [Cancer Cell](#), could have profound implications for NF2...

[Definitive NF2 article by Dr. Gareth Evans](#) - In this GeneReview: Summary • Diagnosis • Clinical Description • Differential Diagnosis • Management • Genetic Counseling • Molecular Genetics • Resources • References • Chapter Notes. Last Update: August 18, 2011.

[Inhibitor: Nilotinib for neurofibromatosis type 2](#) - Nilotinib for neurofibromatosis type 2. Ammoun S, Schmid MC, Triner J, Manley P, Hanemann CO. "[Neuro Oncol. 2011 Jul](#)"... We recommend that therapy with nilotinib or combinational treatment that simultaneously inhibits PDGFR and the downstream Raf/MEK1/2/ERK1/2 pathway could stand for an effective treatment for schwannomas and other merlin-deficient tumors.

[Clinical research study at NIH, Protocol Number: 11-C-0115, Phase 2 Study of Bevacizumab in Children and Adults with Neurofibromatosis Type 2 and Symptomatic Vestibular Schwannoma](#) - Eligibility: Children, adolescents, and adults at least 12 years of age who have been diagnosed with vestibular





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schwannoma (caused by neurofibromatosis type 2) that has produced progressive hearing loss or whose tumor has increased in size in the past year; and who is not eligible for standard surgical treatment...

Neurocutaneous - Neurofibromatosis 2 (NF2) is a rare inherited neurocutaneous disorder that is characterized by vestibular schwannomas (tumours on the hearing and balance...

Neurofibromatosis 2 at Medical-dictionary.cc - An autosomal dominant disorder characterized by a high incidence of bilateral acoustic neuromas as well as schwannomas (NEURILEMMOMA)...

Multiple Cutaneous Plexiform Schwannomas as Initial Presentation of Neurofibromatosis 2 in a 9-Year-Old - Abstract of Multiple Cutaneous Plexiform Schwannomas as Initial Presentation of Neurofibromatosis 2 in a 9-Year-Old. TIEN V. NGUYEN B.A.1 ;; MARK R. MATTHEWS...

AccessMedicine | neurofibromatosis 2 (Paid access only) - 2. eFigure 142-6.3 Cutaneous schwannoma. Dermatology > Chapter 142. The Neurofibromatoses > Related Conditions > Neurofibromatosis 2...

Neurofibromatosis Type 2 Appears to Be a Genetically Homogeneous Disease - Robert L. Martuza, James F. Gusella, Guy A. Rouleau et al. - Neurofibromatosis type 2 (NF2) is an autosomal dominant syndrome characterized by the development of vestibular schwannomas and other tumors of the...

Peripheral Nerve Involvement in a Neurofibromatosis Type 2 Patient With Plexiform Neurofibroma of the Cauda Equina: A Sonographic Vignette - We report a 20-year-old man with cauda equina syndrome and neurofibromatosis type 2. We discuss the role of sonographic and electromyographic evaluations...

Bevacizumab treatment for 31 progressive NF2-related vestibular schwannomas: hearing and volumetric - Early studies suggest that bevacizumab treatment can result in hearing improvement in some neurofibromatosis 2 patients

who have progressive vestibular...

What is Neurofibromatosis-2? - RightDiagnosis.com - Overview of Neurofibromatosis-2 as a medical condition including introduction, prevalence, prognosis, profile, symptoms, diagnosis, misdiagnosis, and...

Search by condition | Cumbria Partnership NHS Foundation Trust - Neurofibromatosis type 2 (NF2) is the least common type of neurofibromatosis, occurring in about ... Read more about the symptoms of neurofibromatosis type 2.

Neurofibromatosis type 2 | Case | Radiopaedia.org - From the case: Neurofibromatosis type 2. Modality: CT. Close. Please Note: You can also scroll through stacks with your mouse wheel or the keyboard arrow...

Risk Facts, Complications and When to See a Doctor for Acoustic Neuroma - Neurofibromatosis 2 is often called autosomal dominant disorder since the defective chromosome is found on a non-sex chromosome known as an autosome...

Acoustic Neuroma: Tumor That Causes Hearing Loss and Vertigo - Half the cases of neurofibromatosis 2 is due to the defective chromosome 22 passed on by ... Neurofibromatosis 2 is an equally rare disease that forms on the...

Meningiomas in children and adolescents: a meta-analysis of individual patient data - ... Patients with neurofibromatosis type 2 (NF2) had worse RFS than those without neurofibromatosis (2•36, 1•23—4•51; p=0•010). There was a significant change...

NF2ers in the News

Mother with Neurofibromatosis Type-2 needs help for Daughters for Christmas - I am the single mother of 2 amazing daughters 16 and 3 years old. I was diagnosed with rare genetic disease Neurofibromatosis Type-2 in 2005...

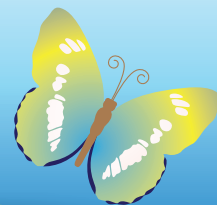
Ed Port to receive second surgery this week - Youngstown Vindicator - By Denise Dick - The second surgery for Ed Port,





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41, who suffers from neurofibromatosis Type 2, is scheduled for Wednesday at St. Joseph Hospital in Chicago...

[Brave little people - Manila Bulletin](#) - I was hospitalized due to dengue fever, typhoid fever, and finally Neurofibromatosis Type 2, a lifetime ill-health condition. A lot of people tell me...

[Calif. company to produce Ed Port documentary](#) - Youngstown Vindicator - Port has neurofibromatosis Type 2, a rare disease that causes large tumors. "They're going to film me Sunday at the [Boardman Rotary] Oktoberfest," said...

[Photo Gallery: Students Present Summer Research and Internship Experiences at Poster Sessions](#) By Nikolas Markantonatos, Summer Research Symposium: (go to page 8/19) Slide 8. Catherine Flynn '12 points to her poster as she explains her research project titled "The Role of the Protein Merlin in Neurofibromatosis Type 2."

[I'm Not Sick, Just A Little Bit Unwell](#) - Marketplace | NF2 Crew - Yvonne Foong's intent is to spread awareness of Neurofibromatosis Type 2, yet she offers so much more to the reader. Her compelling account of the challenges...

[Coulter still smiling, NF2 patient looks for others with disorder](#) The Daily Citizen ... Dalton High School, has had 10 surgeries on various parts of his body since he was diagnosed with a rare disease called neurofibromatosis 2 at age 14. ...

[What is Neurofibromatosis 2?](#) - Welcome to the Home Page of Neurofibromatosis 2. Home • About Us • What's Your Story? Contact Us. Share Your Story. Picture. We would love to post your...

[Rare disease, Ironman no match for Indiana man](#) - WGNtv.com - 14 years ago Hay was diagnosed with neurofibromatosis type 2, more commonly known as NF2. It's a debilitating disease affecting 1 out of every 40,000 people...

[I Can't Wait to See Where Life Takes Me Next](#) - House Calls (fall, 2011, Vol II, No. 2) - by Bryan Fulton "... I've learned that life doesn't stop because you can't hear. You can either choose to

let it hold you back or deal with it the best you can, move on and live life to the fullest..."

[Determined to Make it Work](#) - House Calls (fall, 2011, Vol II, No. 2) In his early 20s and heading a company with sales approaching \$900,000, Elchonon Hellinger was on his way to success as an online entrepreneur when a series of setbacks caused him to retrench. Elchonon is no stranger to overcoming adversity. At the age of two, he developed tumors that resulted in a diagnosis of neurofibromatosis type II (NF2)...

[Living with NF2](#) - House Calls (SPRING 2008 Vol. 8 No. 2) - Losing all hearing in his right ear at 16 and in his left ear at 22 are only two of the ordeals Dan Knodel has experienced in his ongoing battle with NF2...

[Student Copes with NF2](#) - House Calls (FALL 2009 Vol.9 No.1) - As his hearing gradually diminished, Mark Pyeatt finds ways to compensate that allow his college and career goals to remain unchanged...

[Candice Patterson, who has Type-2 neurofibromatosis, to speak of overcoming challenges at Great American Teach-In](#) - Candice Patterson awoke feeling woozy, tired and in pain. Her head was bandaged and she couldn't see...

[Division Students Walk in Battery Park for Classmate Afflicted With Neurofibromatosis](#) - Patch.com - The walk at Battery Park raised awareness for neurofibromatosis types 1 and 2, schwannomatosis and related disorders.

[I Have a Benign Brain Tumor - Neurofibromatosis Type 2](#) - I was told i had a small defenseless brain tumor when i was 15 years. As time kept passing it kept getting slightly bad. I have 3 children now im 25 years old...





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2011 Halloween Bash Raises \$100,000 for children's tumor research!!

By: Roland Thoms, Advocure NF2, Inc.

The 2011 Halloween Bash has come and gone and it was a huge success. On Saturday, October 22nd, 300+ people packed the Redux Lounge in downtown Walnut Creek to attend the 7th annual Bash, a benefit through Advocure NF2 to fund children's tumor research. Over \$40,000 was raised that night and with contributions from Varsity Painting and the Thoms family, the total amount raised for research is \$100,000.

Many thanks go out to the corporate sponsors and the attendees and many non-attendees who continue to support this event and cause year after year.



The evening started out on the sidewalk as those entering the venue were entertained by the unusual musical stylings of "Dirty Cello" (www.dirtycello.com). Think classical cello meets Guns N Roses.

A walk past the silent auction featuring \$15,000 worth of items that people typically picked up for half their value. Entering the club, everyone had their photo taken by our favorite photographer, Kevin Walters of Blue Iris Arts (www.blueirisarts.com). Photos will be posted online soon.

The intimate club soon hosted "Haberdasher" as its first musical act. With Brian Teal of Varsity Painting on the keyboard, they set the tone that this was going to be a pretty cool party.

Soon afterwards, and for the 4th consecutive year, STUNG (www.stunglive.com) came out and ran through a 1 hour set of Police covers that had everybody in the club dancing.

I got up on stage and spoke briefly about why we were there. After a description of Neurofibromatosis 2, the condition my daughter has, I asked people to help me reach my fundraising goal. Many people opened their hearts and wallets to support the cause. Two vacation rentals in Costa Rica were auctioned off for over \$10,000.



Finally, Lovefool (www.lovefoollive.com) brought people back to the 80's and 90's with an energizing 2 hour set of dance tracks that kept the party going until 12:30 before a DJ rounded it out into the wee hours.

The outpouring of generosity was the hallmark of this year's event. Random checks keep showing up in our mailbox and in our PayPal account. I got teary-eyed on more than one occasion.

HOSTED BY: PRIMARY SPONSOR:



SHERWIN WILLIAMS

SPONSORS:

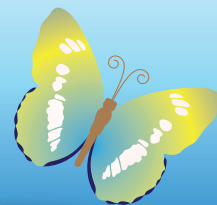
All Seasons Roofing & Solar, ArlenGroup Employee Benefits, Del Conte's Landscaping, Inc., EBCO Print & Promotions, Hughes Gill Cochrane P.C. Attorneys at Law, Roofworks & Construction, True Wireless and Uncle's Loft Graphic Design





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Extraordinary NF2er — Devon Payette

By: Kim Gillet (Devon's mother)



This photo was taken after the big competition in October of this year when Devon qualified for his schools cross-country team. In a group of 200 boys from grades 4 and 5, he was the last out of the gate but not the last to finish! Huge accomplishment for him!

Devon was 5 years old in 2007 when he developed pneumonia and was admitted to our local hospital. During that time, he developed a staggering gait and a kinked neck, which no one seemed

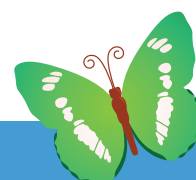
too concerned about. I thought that maybe he had an ear infection, but several days after leaving hospital this had not resolved and he was falling for no apparent reason. A CAT scan revealed a large tumour in the posterior fossa of his brain. We were quickly transferred to the regional children's hospital and after a battery of tests it was revealed that he actually had 4 other tumours in his little body, including one on the (R) optic nerve that had already rendered him blind in that eye (no one knew). Hindsight is 20/20 and looking back there were several symptoms that we now knew were a result of that tumour. He had two surgeries in 3 weeks and they removed about 80% of the tumour that had compressed his brainstem to the point that it was no thicker than a sheet of paper. After the first surgery, they told us it was a benign meningioma. The topic of NF2 was not brought up until after his second surgery. He had genetic testing but that came back negative so he was diagnosed by the traditional criteria. Within 9 months, that tumour had grown back to its original size and he was referred to a larger center in the city of

Toronto. He had his third surgery just over a year after the first two. Again, they were unable to remove his entire tumour. Because it graded as an aggressive tumour, the opinion of two teams was to radiate, so with great trepidation we traveled 2 hours daily for six weeks for radiation therapy.

Each surgery left Devon having to relearn to walk and use his right arm and hand. He has (r) sided hemi-paresis and his (r) vocal cord is paralyzed so he does have episodes of choking. He has always persevered to do everything everyone else is doing. He would tell his father "Never give up, right Dad?" before we even knew about the NF2 motto!

Since 2008, Devon's MRIs have always been "no growth" until this October when we were advised that his (R) VS and a tumour at L3 in his spine have grown. Thankfully, he is not experiencing any symptoms at this time.

Devon likes to run; a sport he can participate in alone as his doctors have banned contact sports. He continues to exhibit his fighting spirit and never gives up. He inspires me and many other people in his life. He never worries about winning the race. Just to participate and finish gives him a tremendous amount of joy and a feeling of accomplishment. He has an old soul and a sunny spirit and I feel truly blessed by God to be his mother.





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It's Not About Me: Coping with NF Stigma

by: Sondra E. Solomon, Ph. D.

A few months ago, John Manth asked me to write an article for the Winter Advocure NF2 Newsletter. He mentioned that his 10-year-old daughter is living with an advanced case of NF2 and noted that many people with NF2 have to cope with hearing impairments, facial paralysis, and a decline or loss of physical mobility. John heard me speak at the 2011 NF Forum this past summer in Minneapolis about living with neurofibromatosis and he thought that I might share some of my insights with you about coping with NF stigma. I am honored to do this.

First, let's define some terms. In 1963, Irving Goffman wrote "Stigma: Notes on the Management of Spoiled Identity." He said that a stigma is a feature that an individual possesses which is discrediting, dishonorable or shameful. Since Goffman wrote his book researchers have been wondering why certain groups or individuals face social exclusion, prejudice, and discrimination based on how they appear to others and how people with a stigma cope with this exclusion.

I use the term "distinction" when talking about abnormal, aberrant, disfigured or deformed attributes. "Distinction" is a relatively neutral word and is a neutral word for a culturally devalued attributes. Physical distinctions, such as those that can occur in NF, are particularly stigmatizing because the true worth or identity of a person with a distinction does not meet society's expectations for that person. We all know that physical perfection is the gold standard for social inclusion and social exclusion may be inevitable if the stigma is visible and particularly if it involves the face.

As you read my words, I would like for you to say to yourself, "It's not about me." One of the reasons I am a psychologist, professor, researcher and clinician is that I enjoy stories. Other people's stories offer insight into whom and what they are. So, here is a story about me that may help you as you manage a life that is affected by NF.

During the second year of my graduate training, I took a course in Community Clinical Psychology. On the first day of class, the professor asked us to answer a question. "What is the most important thing to know about you?" All the students in the seminar told their stories and when it was my turn, I told the class my story:

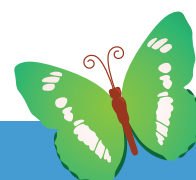
I grew up in a housing project in New York City, in the northeast Bronx. At that time, the projects were not at all like the projects that we see today. It was truly transitional housing for the working class. The upwardly mobile working class of the late 50s early 60s. The Bronx River Housing Project was a diverse community of Europeans, African Americans, South Americans, Pacific East Islanders, and Asians. Of course, we did not call ourselves by those names back then (we were Negro, Jew, Oriental, Irish, Italian, Greek, French, German, etc.)

One day my father announced to our family that he had bought a home and we were going to move from the northeast Bronx to Riverdale, an upscale community in the northwest Bronx. To this day, I do not know how my father managed to buy a home on his meager salary. He worked for the City of New York. He worked on the Staten Island Ferry and he did not make a lot of money. My father never said these words to me explicitly but the implicit message that my father's inspired behavior taught me was:

**AS LONG AS YOU ARE ALIVE YOU CAN DO,
SHAPE OR CHANGE ANYTHING.**

As long as you have a goal, a dream and a neuron firing in your skull you can achieve that vision. It does not matter what your life condition is or how rich, poor, pretty or fat you are. As long as you can move and think you can develop and implement a plan to achieve your goal.

That night when I returned home, a friend and fellow graduate student called. He said he was baffled about the story I told in class. He asked why I told the story that I did and wondered why I didn't talk about my NF. I thought I was answering the question "What is the most important thing to know about you." What my friend and most everyone else I meet for the first time want to know is, "What are those things on your skin?" "Why do you look like that?" "What is wrong with your eyes?" I imagine





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that happens to you as well. For the parents of children who have NF you may have to cope with similar questions about your children. These are legitimate questions but is it the most important thing to know about me or you? Probably not.

Sometimes answering other people's question about your appearance by telling a story about your experience with NF is telling a story that reduces their anxiety or personal curiosity about you. I have been living with NF my entire life. I do not think of myself as being particularly inspiring but I know who I am, where I am and I know that I have NF. I know that my place and path is to help others and to reduce suffering when I can and do as much as I can not to cause any suffering for other people. I put one foot in front of the other and pay attention to what is happening in the present moment. I also know it's not about me. Maybe I can explain what I mean about that.

When the stranger asks, "What are those things on your face" or a number of other intrusive questions I used to respond in a way that placed them at ease. I answered their questions. They walked away satisfied but I felt awful.

I understand it's not about me because my face, body or appearance may cause anxiety and make other people feel vulnerable, confused, and fragile. Many of you will understand what I am saying. Maybe some of you may consider that there is a different way to respond to the uncomfortable social situations we face every day.

When someone approaches me and says, "I don't know how you do it." I smile and say, "I imagine you don't." I respond in a way that is welcoming but is crafted in a way that establishes an alliance with the person who is asking the question. I recognize that it is their anxiety and not my NF that is pushing them to behave that way towards me. I have learned to cope with NF stigma through compassionate engagement and a recognition that it's not about me!

Brief Bio:

Dr. Sondra Elice Solomon is an Associate Professor of Psychology in the College of Arts and Sciences and a Clinical Associate Professor of Psychiatry in the College of Medicine at the University of Vermont. She is a

licensed clinical psychologist. Her research, clinical and teaching interests are related to stigma, chronic illness, facial distinction, disability, and genetic anomalies. She is engaged in curricular transformation across all educational domains. She is curious about resilience and is exploring the mechanisms of adaptive coping among those whose physical appearance departs from mainstream norms of acceptance. She is developing clinical interventions to provide support to affected individuals and their families. Dr. Solomon lives with Neurofibromatosis.

You can write to Dr. Sondra Solomon at Sondra.Solomon@uvm.edu or call her at 1-802-656-3034

NF Symposiums or Conferences With an NF2 component



- **Nov 30, 2011 • 8:00 p.m. Eastern Time - Online**
[NF2 webinar with Scott Plotkin, MD](#)
Hosted by NF Network
- **Dec 5, 2011 • Borden Auditorium, Monmouth Medical Center, 300 Second Avenue, Long Branch, NJ, USA**
[Brainstorm: Psychosocial Support for Brain Tumor Families](#)
Brought to you by the [National Brain Tumor Society](#).
- **May 21-22, 2012 • Manchester Conference Centre, Weston Building, Sackville Street, Manchester, UK**
[Third NF2 State of the Art conference](#)
Hosted by the Manchester NF2 Multidisciplinary Team
- **June 8-10, 2012 • New Orleans, LA, USA**
[2012 NF Forum \(Information to be announced\)](#)
Hosted by the Children's Tumor Foundation (CTF)





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NF2 Phase 2 Trial of Nilotinib: Update

by: Dr. Abhijit Guha



A new **NF2 Phase 2 clinical trial has commenced using Nilotinib**, the second generation of Gleevec, which has been used for decades in a variety of other human tumors. This trial will be through University of Toronto, Western Hospital in Canada: **PI- Dr. Abhijit Guha**, Professor of Neurosurgery. Dr. Guha studied sporadic and NF2 schwannomas cell lines and found they over-expressed and had activated PDGF and c-Kit Receptors, which are inhibited by Gleevec and Nilotinib. Gleevec and Nilotinib inhibited schwannoma viability, proliferation and growth, as well as induced apoptosis or cell death. The Gleevec results are reported in **Cancer Research** in 2009, with the Nilotinib pre-clinical data recently submitted.

Novartis developed Nilotinib, by slightly modifying the structure of Gleevec, to address the problem of tumors which become resistance to Gleevec after a period of treatment. This targeted biologic also offers lower toxicity and increased tissue penetration – thus potentially having even better results with less side effects. Nilotinib is an oral drug, and in the trial will be taken twice a day. To date, Nilotinib only has been given to adults who have developed a resistance to Gleevec with very satisfactory results. There have been no similar studies in children and its potential use in schwannomas has not been tested.

The trial consists of adult patients with growing vestibular schwannomas, i.e., as seen in serial MRIs showing volumetric growth greater than 15% over past 18mths. The cohort will include both sporadic and NF2 patients. Nilotinib will be administered for 12 months, with follow up for another two years. The key exclusion are vestibular schwannomas which due to compression of the brainstem or hydrocephalus is already causing symptoms such as ataxia and headache. The main objectives is to determine if the drug can stabilize the growth of the vestibular schwannomas or cause shrinkage of the tumors as defined by 20% or more reduction by MRI volumetric measurement. In addition to tumor growth, other parameters related to hearing, quality of life are also measured and compared to historical and concurrent patient groups who are managed with current standard treatment strategies which include

observation, surgery or radiosurgery.

It is Dr. Guha's intention to also track other NF2 associated tumors, such as meningiomas and other schwannomas during the trial. While Dr. Guha is excited about the potential of this drug, he, like many others, believes NF2 may have to be treated with a combination of current treatment strategies (surgery, radiosurgery) and likely multiple biological therapies aimed at different biological properties of the tumor cells such as increased proliferation, vascularization etc.

The treatment strategies will likely not be the same for all patients, but must be individualized and altered as the tumor and patient characteristics change with time. He pointed out that schwannomas are not driven by just one genetic alteration, but rather multiple pathways and thus, monotherapy will not be the holy grail.

Dr. Abhijit Guha is a professor of Neurosurgery at University of Toronto, Western Hospital in Canada, and co-director of the Arthur & Sonia Lobb Brain Tumour Research Centre at the Hospital for Sick Children's Research Institute in Toronto.

The previous story on the NF2 Nilotinib Trial is by Barbara Franklin, and can be found in our **2010 Fall issue of NF2 Compass** on pg 16.

Fundraising:



• Zazzle™ - Cups & Stuff

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

• Magazine Subscriptions

Need to renew a magazine or gift idea for the upcoming holidays?

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 [click here](#).

• Adam Goodkind NF2 Research Fund

c/o Children's Tumor Foundation
95 Pine Street, 16th Floor, New York, N.Y. 10055

• Another easy way to contribute to NF2 is to visit us and donate on **Facebook**.





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NF2 and Other Relevant Clinical Trials and Studies:

NIH 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).

Location: National Institutes of Health Clinical Center, Bethesda, MD, USA.

• **Using Positron Emission Tomography (PET) to Predict Intracranial Tumor Growth in Neurofibromatosis Type II (NF2) Patients**

ClinicalTrials.gov Identifier: NCT01222728

This study is currently recruiting participants.

Objectives - To use magnetic resonance imaging and positron emission tomography to better understand the growth of brain tumors in people with **neurofibromatosis type II (NF2)**.

Location: National Institutes of Health Clinical Center, Bethesda, MD, USA.

RAD001:

• **A Single Arm, Monocenter Phase II Trial of RAD001 as Monotherapy in the Treatment of Neurofibromatosis Type 2 - Related Vestibular Schwannoma**

ClinicalTrials.gov Identifier: NCT01345136

This study is ongoing, but not recruiting participants.

The purpose of the study is to determine if RAD001 treatment

will shrink or slow the growth of the vestibular schwannoma(s) in Neurofibromatosis 2 (NF2) patients. Secondary objectives include determining if RAD001 treatment will improve hearing ability in NF2 patients.

Location: House Research Institute, Los Angeles, CA, USA.

• **Phase II Study of Everolimus (RAD001) in Children and Adults With Neurofibromatosis Type 2**

ClinicalTrials.gov Identifier: NCT01419639

This study is not yet open for participant recruitment.

Primary Outcome Measures - Radiographic Response: To estimate the objective response rates to RAD001 in patients with **NF2**-related tumors including cranial nerve schwannomas, meningiomas and ependymomas. Radiographic response for study purposes = greater than or equal to 15% reduction in tumor volume in any of the target tumors (partial response). Complete disappearance of any of the target tumors = complete response. MRI of the brain and spine will be performed every 3 months. If an objective response (15% reduction in tumor volume compared to baseline) is observed in any target tumor or stable disease, drug will be continued.

Location: New York University Medical Center, New York, NY, USA.

• **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 ongoing, but not recruiting participants.

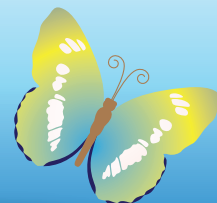
For patients with malignant pleural mesothelioma that has grown despite treatment with standard chemotherapy, no treatment has yet proven beneficial. The purpose of this study is to find out what effects, both good and bad, that everolimus has on the cancer. Everolimus works by blocking a protein that 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.





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*Locations: Dana Farber Cancer Institute, Boston, MA, USA.
Memorial Sloan-Kettering Cancer Center, New York, NY, USA.
University of Pennsylvania, Philadelphia, PA, USA.*

BEVACIZUMAB (Avastin™):

Phase 2 Study of Bevacizumab (Avastin™) in Children and Adults With Neurofibromatosis Type 2 and Symptomatic Vestibular Schwannoma

ClinicalTrials.gov Identifier: NCT01207687

This study is ongoing, but not recruiting participants.

This study is exploring whether a drug that is approved by the FDA and is currently used to treat other tumors might also work to treat VSs. Based on people who have taken this drug to treat VSs already, there is some reason to think that it might be helpful to certain people with **NF2**. People enrolled in this study will receive the drug one time every three weeks for one year by infusion. This study will follow subjects over the course of the year that the person is taking the drug and for six months after the drug is stopped. This study is recruiting people who have **NF2** and are currently having symptoms of tinnitus, dizziness, and/or hearing loss from their VSs. If you have **NF2** and are currently having symptoms caused by your VSs, you may be eligible to participate.

Locations: Johns Hopkins Comprehensive Neurofibromatosis Center, Baltimore, MD, USA. National Cancer Institute, Bethesda, MD, USA. Massachusetts General Hospital, Boston, MA, USA.

A Phase II Trial of the Combination of Bevacizumab (Avastin™) and Everolimus (Afinitor™) in Patients with Refractory, Progressive Intracranial Meningioma

ClinicalTrials.gov Identifier to NCT00972335

This study is currently recruiting participants.

In this multi-center, Phase II trial, the investigators plan to evaluate the activity of the combination of bevacizumab (Avastin™) and everolimus in patients with recurrent, progressive meningioma following maximal treatment with surgical resection and local radiation therapy. Although these patients are relatively rare, there is currently no established

standard of treatment for a disease that causes a great deal of morbidity, and that is eventually fatal.

Locations: Florida Hospital Cancer Institute, Orlando, FL, USA. Northeast Georgia Medical Center, Gainesville, GA, USA. Nebraska Methodist Cancer Center, Omaha, NB, USA. University of Pittsburgh Medical Center, Pittsburgh, PA, USA. Tennessee Oncology, PLLC, Nashville, TN, USA.

Phase II Trial of Bevacizumab (Avastin™) in Patients With Recurrent or Progressive Meningiomas

ClinicalTrials.gov Identifier: NCT01125046

This study is currently recruiting participants.

RATIONALE: Monoclonal antibodies, such as bevacizumab (Avastin™), 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 (Avastin™) works in treating patients with recurrent or progression meningiomas.

Location: Northwestern University, Chicago, IL, USA.

NILOTINIB:

Phase II Study of Nilotinib in Growing Vestibular Schwannomas

ClinicalTrials.gov Identifier: NCT01201538

This study is currently recruiting participants.

The primary objective of this study is to evaluate the efficacy of Nilotinib in the treatment of patients with progressing sporadic and **NF2** VS. Secondary objectives of this study is to evaluate the toxicity profile, quality of life and symptom management of Nilotinib in the treatment of patients with progressing VS.

Location: Toronto Western Hospital, University Health Network, Toronto, ON, Canada.

LAPATINIB:

Concentration and Activity of Lapatinib in Vestibular Schwannomas

ClinicalTrials.gov Identifier: NCT00863122

This study is currently recruiting participants.





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This phase 0 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.

Locations: House Ear Institute, Los Angeles, CA, USA. Johns Hopkins Hospital, Baltimore, MD, USA. New York University Medical Center, New York, NY, USA. Ohio State University Medical Center, Columbus, OH, USA.

• **Phase II Study of 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.

The purpose of this study is to determine if Lapatinib has any effect on tumors found in patients with Neurofibromatosis 2 (NF2).

Location: New York University School of Medicine, New York, NY, USA.

SORAFENIB:

• **Sorafenib in a NF2 study, in the UK**

Adults who have Neurofibromatosis 2 (NF2) and skin tumours (schwannomas) are invited to participate in a research study being undertaken in Plymouth and Manchester; **Professor C. Oliver Hanemann**, a consultant neurologist at the Peninsula College of Medicine and Dentistry in Plymouth is the Chief Investigator...

SUNITINIB:

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

ClinicalTrials.gov Identifier: NCT00561665

The recruitment status of this study is unknown because the information has not been verified recently.

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.

Locations: Dana-Farber/Harvard Cancer Center at Dana-Farber Cancer Institute, Boston, MA, USA. Memorial Sloan-Kettering Cancer Center, New York, NY, USA. UPMC Cancer Centers, Pittsburgh, PA, USA. University of Virginia Cancer Center, Charlottesville, VA, USA.

• **Phase II Trial of Sunitinib (SU01248) 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.

Locations: Dana-Farber/Harvard Cancer Center at Dana-Farber Cancer Institute, Boston, MA, USA. Memorial Sloan-Kettering Cancer Center, New York, NY, USA. UPMC Cancer Centers, Pittsburgh, PA, USA. University of Virginia Cancer Center, Charlottesville, VA, USA.

PTC299:

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

ClinicalTrials.gov Identifier: NCT00911248

This study is ongoing, but not 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. This Phase 2 study is designed to test the hypothesis that PTC299 will be tolerable and will show evidence of VEGF reduction, anti-tumor activity, and hearing improvement when administered orally to patients with **NF2**.





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Location: Massachusetts General Hospital, Boston, MA, USA.

• **Oncology – PTC299**

SOM230:

• **Phase II Study of Monthly SOM230C for Recurrent or Progressive Meningioma**

ClinicalTrials.gov Identifier: NCT00859040

This study is ongoing, but not 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.

Locations: Cedars-Sinai Medical Center, Los Angeles, CA, USA. Northwestern University, Chicago, IL, USA. Dana-Farber Cancer Institute & Massachusetts General Hospital & Beth Israel Deaconess Medical Center, Boston, MA, USA. Duke University Medical Center, Preston Robert Tisch Brain Tumor Center, Durham, NC, USA. Wake Forest University Baptist Medical Center, Winston-Salem, NC, USA.

• **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.

Location: Huntsman Cancer Institute. Salt Lake City, UT, USA.

MISC. STUDIES:

• **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.

Location: Massachusetts Eye and Ear Infirmary, Boston, MA, USA.

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

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.

Location: Ohio State University Medical Center, Columbus, OH, USA.

Current NF2 Drug List:

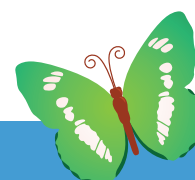
This list is provided by: NF2 New York City Support Group. If you have additional information, please contact Lori Davila (lori@nf2nycsupport.org). Thank you.

Current as of November 3, 2011.

Italicized wording on each listed item below is status on how to get access to the specified medication.

1. **Everolimus (RAD-001, Afinitor)** - *Newest Open Trial*
2. **Sirolimus Rapamycin**
3. **Lapatinib** - *Ongoing Trial*
4. **Bevacizumab Avastin** - *Available as Trial and Public*
5. **Erlotinib Tarceva**
6. **Sunitinib SU011248**
7. **Imatinib Gleevec (or Glivec)**
8. **Sorafenib**
9. **Nilotinib**
10. **PTC 299**
11. **Pasireotide SOM230** - *Ongoing Trial - Not Accepting New Patients*
12. **Hydroxycarbamide Hydroxyurea** - *Not Specifically NF2-*

Treatment for Meningiomas





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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*.*



• **PTC124 (Ataluren™)**, investigational new drug designed to enable the formation of a functioning protein in patients with genetic disorders due a nonsense mutation. *".....Though there may be applications in all forms of NF, it is considered that there may be most relevance initially to NF2 where nonsense mutations account for a significant proportion of sporadic cases."*

• Bevacizumab (**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.

- Sorafenib (**Nexavar™**)
- Erlotinib (**Tarceva™**)
- OSU-HDAC42 (**AR-42™**)
- OSU-03012 (**AR-12™**)
- **PTC299**
- **Lapatinib** (Tykerb™)
- Caffeic Acid (**BIO30™**)
- **RAD001** (Everolimus)
- **BEZ-235**

- **Valproic Acid**
- **Rapamycin**
- **Cetuximab**
- **Trastuzumab** (Herceptin™)
- Vandetanib (**Zactima™**)
- **Nilotinib** (Tasigna™)
- **Curcumin**
- **Dasatinib**
- **BIBF 1120** (Vargatef™)

For more trials and/or studies, please see: ClinicalTrials.gov. 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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