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

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.

Advancing Research for Neurofibromatosis Type 2

Email: contact@advocurenf2.org
Web: www.advocurenf2.org

Advocure Brochure RSS Feed

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!

AdvocureNF2’s signature event the “Halloween Bash” was an overwhelming success! The goal of raising $100,000 was successful. For more details and photos please see page eight.

The Ninth Annual “Ohio Gathering” was held in Columbus in October. Lots of fun was had and lifelong friendships formed. Doctor Welling from Ohio State University also presented at the gathering. More details on page eleven.

Please note: all blue, underlined text are clickable links which lead to outside articles.

Disclaimer: The links and verbatim are excerpts of new and interesting NF2 relevant research. AdvocureNF2 did not write the following links or excerpts nor do we necessarily endorse them. They are to be interpreted using each reader’s discretion.

NF2 Cruise - Join the NF2 Crew on April 7-14, 2013 for a fun-filled 7-night Eastern Caribbean Cruise. Just $500 will hold a cabin (yes, that’s per cabin, not per person) on the Royal Caribbean ship Freedom of the Seas. Visit the NF2 Crew website for the full itinerary and more information on how to join in on the NF2 Cruise!
**NCIS Raises Awareness about NF2**

Chris Waild is a writer/producer for the hit show NCIS, the #1 drama on television. He also is a friend and supporter of Leah Manth, a 12 year old from the Buffalo, NY area with NF2. In an effort to raise awareness, he wrote an episode titled “Lost at Sea” that includes a sub-plot about a child with NF2. The episode aired on 10/23/2012 on CBS. If you missed it, you can watch the full episode on CBS.com (captioned). **AdvocateNF2 and the entire NF2 community would like to express their sincere appreciation to Chris Waild and the Manth family for making this amazing opportunity possible!**

**Children’s Tumor Foundation to Host 2012 Annual Benefit Gala “A Night to Celebrate Our Stars”**

The Children’s Tumor Foundation (CTF) is pleased to announce that its premiere event, the annual Benefit Gala, originally planned for November 1 but rescheduled due to Superstorm Sandy, will be held on **December 6, 2012** at Cipriani Wall Street in New York City...

**Blood Flow Changes, Not Hormones, Explain Growth of Benign Tumors in Pregnant Women**

Meningiomas are a common type of benign brain tumor that sometimes grows dramatically in pregnant women. A new study suggests that this sudden tumor growth likely results from “hemodynamic changes” associated with pregnancy...

**Long-term natural history of neurofibromatosis Type 2–associated intracranial tumors** - Neurofibromatosis Type 2–associated intracranial tumors most frequently demonstrated a saltatory growth pattern. Because new tumors can develop in NF2 patients over their lifetime and because radiographic progression and symptom...

**Intraorbital meningioma: resection through modified orbitozygomatic craniotomy** - Intraorbital meningiomas are challenging lesions to excise because of their location and the restricted surgical corridor available due to the presence of important neighboring structures. Lesions located in the posterior one-third of the orbit require skull base approaches for their exposure and safe resection...

**Interventional Neuroradiology** - Many vascular diseases that required surgical intervention just 10-15 years ago can now be diagnosed and treated with a precise, image-guided procedure and no surgical incision...

**Cannabinoid May Treat Brain Cancer** - Researchers at University of California, San Diego Moores Cancer Center are evaluating the safety and tolerability of a synthetic cannabinoid called dexanabinol (ETS2101). Delivered as a weekly intravenous infusion, the drug is being tested in patients with all forms of brain cancer, both primary and metastatic.

**European Medicines Agency Awards Arno Therapeutics, Inc. (ARNI) AR-42 Orphan Drug Designation** - Arno Therapeutics, a clinical-stage company focused on developing products for the treatment of cancer, today announced that its investigational compound AR-42 has been granted orphan-drug designation...

**NF Midwest > NF2 Resources** - Good listing of transcripts for past NF2 presentations and other resources.
NF Educational Brochures - The following neurofibromatosis educational materials were written and designed for our patients and families...

Europe approves high-price gene therapy - European officials have approved the Western world’s first gene therapy drug from a small Dutch biotech company, in a milestone for the novel medical technology that fixes faulty genes...

Mesothelioma drug slows disease progression in patients with an inactive NF2 gene - Preliminary findings from the first trial of a new drug for patients with mesothelioma show that it has some success in preventing the spread of the deadly disease in patients lacking an active tumour suppressor gene called NF2.

First Gene Therapy Study in Human Salivary Gland Shows Promise - Gene therapy can be performed safely in the human salivary gland, according to scientists at the National Institute of Dental and Craniofacial Research (NIDCR), part of the National Institutes of Health...

Talk With Your Hands: Gloves Translate Sign Language Into Speech - Four Ukrainian tech whizzes have done the seemingly impossible: they’ve given a voice to the voiceless. Calling themselves QuadSquad, they created a product called “Enable Talk”—gloves that translate sign language into spoken word...

3D camera for brain surgery a big leap forward - The Toronto doctor who pioneered what has become an international standard in neurosurgery is once again breaking new ground, becoming the first surgeon in Canada to use a 3D camera to remove a brain tumour.

Transcripts from the May 2012 NF2 Weekend held in Sheffield UK - The Neuro Foundation hosted a Residential Weekend for all those affected by NF2 in Sheffield UK. A number of guest speakers shared their medical expertise on NF2 and transcripts of the presentations are now available for those who were not able to attend.

Targeting NF2 deficient meningiomas with combinations of small molecule inhibitors and radiation - Meningiomas are common tumors of the central nervous system and are the second most prevalent tumors in Neurofibromatosis type 2 patients...

Captioning Services - Many NF2 individuals who lose their hearing later in life and/or dexterity to sign with their hands find captioning as a more suitable method of...

NF2 loss is the initial step in malignant pleural mesothelioma: Research - Researchers have found that heterozygous loss of NF2 gene takes place early in the molecular alteration that is associated with the malignant pleural mesothelioma ...
UAB Medical Genomics Laboratory - The Medical Genomics Laboratory (MGL) is a CAP-certified nonprofit clinical laboratory at the University of Alabama at Birmingham, offering comprehensive testing for common and rare genetic disorders...

British, Japanese scientists share Nobel Prize for stem cell work - Two scientists who upended fundamental beliefs about biology by demonstrating that every cell in the body has the potential to grow into every other type of cell have won the Nobel Prize in physiology or medicine...

The Doctor Says Get a CT Scan. Should You? - An expert on radiation offers some insights on how much is too much...

Meningioma progression in mice triggered by NF2 and Cdkn2ab inactivation - Aggressive variants of meningiomas (WHO grade II and III) represent up to 30% of those tumors that are among the most common primary central nervous system tumors in adults...

Auditory Brainstem Implants: How Do They Work? This review covers the design, structure, and function of auditory brainstem implants. Auditory brainstem implants (ABIs) are auditory prostheses initially designed to treat deafness in patients with neurofibromatosis type 2 (NF2)...

Rac1 is required for Prkara1-mediated NF2 suppression in Schwann cell tumors - Schwannomas are peripheral nerve sheath tumors that often occur in the setting of an inherited tumor predisposition syndrome, including neurofibromatosis types 1 (NF1) and 2 (NF2), familial schwannomatosis and Carney complex...

Genome Sequencing Identifies a Basis for Everolimus Sensitivity - Cancer drugs often induce dramatic responses in a small minority of patients. We used whole-genome sequencing to investigate the genetic basis...

Clinical Research Awards Announced - Responding to the evolving needs of NF research, the Clinical Research Awards program is intended to support early stage pilot clinical trials of candidate therapeutics for the treatment of manifestations of NF1, NF2, and schwannomatosis...

Clinical Trial Award of Rapamycin for NF2 at NYU CTF recently announced funded Clinical Trial Awards, one of them being: a Phase II Trial of Rapamycin - for NF2 Tumors, by Dr. Matthias Karajannis, at NYU...

Neurogenetics DNA Diagnostic Laboratory: Testing for Autosomal Dominant Neurofibromatosis Type 2 - We currently offer linkage analysis of the NF2 gene using PCR amplification and flanking and introgenic markers. Linkage analysis is recommended when 1) the mutation screening and MLPA...

Determination of a facial nerve safety zone for navigated temporal bone surgery - Transtemporal approaches require surgeons to drill the temporal bone to expose target lesions while avoiding the critical structures within it, such as the facial nerve...

Mechanisms of Hearing Loss in Neurofibromatosis Type 2 - Patients with neurofibromatosis type 2 (NF2) develop bilateral cochleovestibular schwannomas (CVSs) that cause binaural deafness in most individuals. Hearing loss occurs in an unpredictable manner and the underlying mechanisms are not known...

House Research Institute and Children’s Hospital Los Angeles Partner with University of Verona Hospital to Bring Auditory Brainstem Implants to U.S. Children - House Research Institute and Children’s Hospital Los Angeles have
announced an international consortium with the University of Verona in Italy to collaborate on teaching and research to advance the use of the Auditory Brainstem Implant (ABI) in children worldwide...

**Children’s Tumor Foundation and Cenix BioScience Sign Framework Research Agreement to Accelerate Industrial Efforts on Neurofibromatosis**

“We are greatly excited by this opportunity to contribute our capabilities towards advancing the fight against some of the most devastating and, sadly, most common of so-called ‘rare diseases’,“ said Dr. Christophe Echeverri...

**Advocure NF2 Awareness Video!** - This excellent NF2 awareness video was put together for the annual Halloween Bash, a NF2 research fundraiser, which was held in October, 2012.

**Publications of Cannabis for medicine** - These are a range of selected publications on Cannabinoid compounds that provide further pharmacologic background within the fields of epilepsy, psychosis, metabolic syndrome and cancer.

**Reproductive Options for People with NF1, NF2 and Schwannomatosis** - People who themselves have been diagnosed with NF1, NF2 and schwannomatosis, or who have a child with one of these diagnoses, often wonder whether future children of theirs will be affected with the same condition...

**Phase II trial of lapatinib in adult and pediatric patients with neurofibromatosis type 2 and progressive vestibular schwannomas** - This single-institution phase II study was performed to estimate the response rate to lapatinib in neurofibromatosis type 2 (NF2) patients with progressive vestibular schwannoma (VS). Twenty-one eligible patients were enrolled...

**New Laser Targets Brain and Spine Tumors** - Lee Eric Tessler, MD, Chief of Neurotrauma and Chairman of the Neurosurgery Quality Improvement Committee at Winthrop, was recently among the first neurosurgeons in the New York Metro area to use a new advanced, hand-held CO2 (carbon dioxide) laser...

**Human stem cells partially restore hearing to deaf gerbils** - Scientists have partially restored the hearing of deaf gerbils with injections of nerve cells created from human embryonic stem cells...

**A paradigm shift in salvage surgery for radiated vestibular schwannoma** - Failed radiosurgery is an increasing indication for salvage surgery in patients with posterior fossa tumors. A conservative approach with a willingness to perform partial and near-total tumor removals leads to better facial nerve outcomes with no current evidence of treatment compromise...

**Tumor Suppressor Genes Vital To Regulating Blood Precursor Cells In Fruit Flies** - UCLA stem cell scientists have shown that two common tumor suppressor genes, TSC and PTEN, are vital to regulating the stem cell-like precursor cells that create the blood supply in Drosophila, the common fruit fly...

**Mayo, TGen close in on personalized gene therapy**
The right drug for the right person at the right time. The pioneers of medicine’s Genetic Age have long predicted that personalized drug treatments are inevitable as technology improves and costs plummet...

**MRC awards grant to design new drug for treatment of chronic pain** - Scientists at the University of Liverpool and the Royal Liverpool University Hospital have been awarded -1.4 million to design a new drug for the treatment of chronic pain...
Uncommon Ocular Manifestations of Neurofibromatosis: Case Report and Review - A 19-year-old woman diagnosed with type 2 neurofibromatosis visited our hospital with amblyopia of the right eye and mild visual disturbance of the left eye...

Topol: Get Rid of the Randomized Trial; Here’s a Better Way - In our series The Creative Destruction of Medicine, I’m trying to get into critical aspects of how we can Schumpeter or reboot the future of healthcare by leveraging the big innovations that are occurring in the digital world, including digital medicine...

Will Patients Bear the Burden for Developing Their Own Treatments? - Patients who take a close look at medical science in search of treatments are often appalled by what they discover...

Grapefruit juice lowers dose of cancer drug - A daily glass of grapefruit juice can boost the effectiveness of a cancer drug, allowing patients to take a much lower dose. The combination could help patients avoid side effects associated with high doses of the drug and reduce the cost of the medication...

Treatment Options for Neuropathic Cancer Pain - Neuropathic pain is related to abnormal somatosensory processes that directly affect the peripheral or central nervous system. Cancer can cause neuropathic pain by direct invasion, irritation, or external pressure on peripheral neural structures...

Development of drug treatments for neurofibromatosis type 2-associated vestibular schwannoma - PURPOSE OF REVIEW: To review the discoveries in molecular pathophysiology contributing to the development of neurofibromatosis type 2 (NF2)-associated vestibular schwannomas and the recent experiences with drug therapies for these tumors...

FDA approves first drug formulated for children with rare brain tumor - The U.S. Food and Drug Administration today approved Afinitor Disperz (everolimus tablets for oral suspension), a new pediatric dosage form of the anti-cancer drug Afinitor (everolimus) used to treat a rare brain tumor...

A Diet for Brain Cancer - There are two specific diets that should be considered for treating brain tumors, either separately or in combination...

Marijuana Fights Cancer and Helps Manage Side Effects, Researchers Find - Mounting evidence shows ‘cannabinoids’ in marijuana slow cancer growth, inhibit formation of new blood cells that feed a tumor, and help manage pain, fatigue, nausea, and other side effects...

Web TV needs to have captions starting next month, the FCC Rules - Deaf and hard-of-hearing web video viewers have long pressed for a faster adoption of closed captioning, and it looks like the FCC got their back: Content also shown on TV will have to have closed captions when streamed online starting next month, the commission recently ruled.

What is InnoCaption Service? - InnoCaption provides free real-time caption service for the deaf and HOH (Hard of Hearing) mobile user. It will function with any smart phone that utilize the Android or iPhone OS...

Specialist programmes for people with NF2 - Our friendly residential specialist programmes help people with Neurofibromatosis Type 2 and their families adapt to hearing loss and equip them with skills and information so they can cope...
Living With NF2:

These are some secondary complications from NF2 and care strategies. There are also NF2 patients’ weblogs, videos, and online memoirs. If you have an online NF2 story that you’d like to share, please contact us at contact@advocurenf2.org. Thanks!

NF2ers in the News:

Women’s Hoops Announces “3 For A Cure” Campaign - The Canisius College women’s basketball team has announced a “3 for a Cure” campaign during the 2012-2013 season to raise awareness for neurofibromatosis as well as raise funds for research toward a cure for the disease. The Golden Griffins developed the campaign after adopting North Tonawanda resident Leah Manth for the upcoming season.

NF Support group in the Philippines - When I was diagnosed with NF, I tried searching for NF support groups here in the Philippines. I wanted to meet a person with the same condition. I have joined NF groups online who are mostly based in the U.S and I told myself that someday, there would also be an NF support group in the Philippines to spread awareness in the country...

The glory of artificial hearing - Molly Brown, in an interview, talks about her hearing loss from NF2 which resulted in receiving a Penetrating Auditory Brain Implant (PABI) to help her hear again ...

Baraboo woman hopes to raise awareness about rare disorder - In September 2009, Heidi Schroeder Martin began to experience ringing in her ears. She initially thought it was an ear infection, and assumed it would go away. But it didn’t...

Levittown Board Honors Division Sophomore - Division Avenue High School Principal Dr. Francesco Ianni described sophomore Bailey Gribben as a true inspiration, one who makes the district a just a little more special each day...

Elchonon Hellinger and Thrifty Computer – The Rocky Road to Success - Sometimes entrepreneurs face extreme challenges that do not have their origins in the business world, but still manage to impact their business greatly...

Making the best of it: Streator man lives with tumor condition - Brandon Gotch has lost his ability to hear and balance and is losing his ability to see, use his arms and legs and is developing vocal cord paralysis...

NF Symposiums or Conferences With an NF2 component:

- **December 6, 2012** • New York, NY, USA
  **2012 Annual Benefit Gala**
  Hosted by CTF

- **April 18 - 21, 2013** • Nashville, TN, USA
  **2013 NF Forum**
  Hosted by CTF

- **June 08 - 11, 2013** • Monterey Bay, CA, USA
  **2013 NF Conference**
  Hosted by CTF
The Eighth Annual Halloween Bash Recap:

For the eighth consecutive year, Roland Thoms and his family had two very successful “Halloween Bash” events held in Oakland and San Diego California. On behalf of Varsity Painting, a special thank you to all of the Sponsors for their extraordinary efforts and partnership in The 8th Annual Halloween Bash. Also, a huge thank you to everyone that attended to make this very special event unforgettable. The Halloween Bash is the signature event of Advocure NF2, an organization advancing research for Neurofibromatosis (NF2) to raise awareness of the disease and funds for important research. All funds raised are awarded to research projects aimed at controlling tumor growth. Varsity Painting is pleased to announce this year’s goal of raising $100K was achieved! We could not have done this without all of your support and generosity. THANK YOU SO MUCH! To view more pictures from The Halloween Bash, please log on to: 2012 So Cal Halloween Bash.

AdvocureNF2 and Varsity Painting would like to express our sincere thank you to all of the generous sponsors of the “Halloween Bash” events:

Varsity Painting • Shermin-Williams • All Seasons Roofing & Waterproofing Inc. • Arlengroup Employee Benefits • Del Conte’s Landscaping, Inc. • Dean Coney Emery Financial • Roofworks & Construction • True Wireless • American Asphalt • Aquatic Environments • BSM Facilities Services • Collins & Co. • Dunn Edwards Paints • Kelly Moore Paints • Hughes Gill Cochrane P.C. • Jean Bates & Associates • Mutual of Omaha Bank • Reply.com • Valley Community Bank • P.W. Stephens Environmental • TransAmerica Retirement Services • United Trustee Services • Stout Insurance • Kimball, Tirey & St. John. LLP, • Uncle’s Loft Graphic Design • Rodent Pest Technologies Inc. • DM Construction Services • Har-Bro • Mission Association Financial • Park West Landscape Management • Silldorf & Levine • TVRI • Prendiville Insurance, Comex Group • Pacific Green Landscape • New Way Landscape & Tree Service
Potential Chemotherapeutic Agents for the Treatment of NF2-associated Schwannoma and Meningioma

D. Bradley Welling and Long-Sheng Chang
The Ohio State University and Nationwide Children’s Hospital

Using various cell culture and animals models to test effective drug treatments for NF2-associated tumors, we previously reported that AR-42 (formerly named OSU-HDAC-42), a pan-histone deacetylase (HDAC) inhibitor, potently inhibited the growth of schwannomas and meningiomas. We further investigated the molecular mechanism underlying AR-42-mediated growth arrest in these tumor cells. A human Phase I clinical trial for AR-42 in advanced or recurrent solid tumors, including vestibular schwannomas and meningiomas, has been initiated at The Ohio State University.

In addition, we have tested six additional small-molecule inhibitors, including MK-2206 (an AKT inhibitor), three Aurora kinase inhibitors (PF-03814735, MLN8237, and VX-680), ICG-001 (an inhibitor of Wnt/β-catenin signaling), and JNJ-26481585 (a pan-HDAC inhibitor). We found that the HDAC inhibitor, JNJ-26481585, efficiently inhibited proliferation of schwannoma and meningioma cells with the IC50 (50% inhibitory concentration) values of ~40-50 nanomolars. The three Aurora kinase inhibitors also suppressed schwannoma cell growth at sub-micromolars of concentration. The Wnt/β-catenin signaling inhibitor, ICG-001, moderately reduced tumor cell proliferation, while the AKT inhibitor, MK-2206, was not effective.

Another approach to identify novel medical therapies that we have undertaken is to screen a library of pure, structurally-defined natural compounds for potent growth inhibitory activity in schwannomas and meningiomas. Previously, we identified several natural compounds that effectively reduced schwannoma and meningioma growth, including silvestrol, a rocaglate derivative from the tropical Asian plant Aglaia foove-lata. We also found that silvestrol induced cell cycle arrest at G2 phase in schwannoma and meningioma cells. In addition, we investigated antitumor effects of two other plant-derived natural compounds, cucurbitacin D and goyazensolide, in schwannoma and meningioma cells. We found that cucurbitacin D inhibited proliferation of schwannoma and meningioma cells at sub-micromolars of concentration. Goyazensolide also suppressed schwannoma and meningioma growth at about 1 micromolar of IC50. Both cucurbitacin and goyazensolide induced G2 arrest in NF2-deficient meningioma cells. Presently, we are investigating the growth-inhibitor mechanisms of drug action of these compounds.

1) What are the next anticipated steps with your studies? With AR-42, how long will it be before the phase 1 trials show measurable results?

The clinical trial of AR-42 that is ongoing in Dr. Welling’s clinic at The OSU Eye and Ear Institute is a Phase 1/2b clinical trial. The study is designed to recruit 20 patients with NF2-related vestibular schwannoma, sporadic vestibular schwannoma, NF2-related meningiomas, and/or sporadic meningiomas. The primary objective is to determine whether AR-42 hits the targets (e.g., AKT kinase and cell cycle regulators). The secondary objectives include (1) assessment of any audiometric changes pre- and post AR-42 administration, (2) evaluation of any volumetric tumor reduction after 10 doses of AR-42, (3) further assessment of the biological effects of AR-42 on the AKT pathway, tumor cell proliferation, cell cycle, cell death, and angiogenesis, (4) exploration of a potential biomarker, (5) the status of the NF2/Merlin and treatment, and (6) determination of the steady-state plasma and intra-tumoral concentrations of AR-42. The study is planned for three years.

2) With Silvestrol, at what point could that be recommended, if ever, as a supplement worth taking?

In our cell culture study, silvestrol potently inhibited proliferation of both NF2-deficient schwannoma and meningioma cells. Our OSU collaborator (Dr. A. Douglas Kinghorn) have shown anti-tumor efficacy of silvestrol in multiple cancer models, including ALL. Silvestrol is presently under preclinical development by the NCI. Dr. Kinghorn has been able to obtain sufficient quantity for us to study the in vivo effects of silvestrol in an animal models of schwannoma and meningioma. Also, the toxicity and tolerability profile of silvestrol is being evaluated at OSU. After all these studies are completed, we may be able to assess whether silvestrol is beneficial as a supplement.
Extraordinary NF2er: Jodi Berlin

The long and winding road of dealing with NF2 is not for the faint-of-heart. I feel humbled to be sharing my story while there are so many others “in the trenches” with me. I don’t feel extraordinary, I’m just a fighter like so many others who battle NF2.

My NF2 trail begins with my mom who passed-away from NF2 complications at age 40 in 1974. Back then, very little was known about NF2. I was five when my mom died leaving me to be raised by my dad and my three older brothers. The shattering toll that NF2 would have on my family had just begun and would continue on to present-day.

As a child, I was active and athletic. I did not have any symptoms of NF2. In 1980, my oldest brother collapsed at his job. This is when the NF2 legacy that my mom unknowingly left started to creep in to our suburban life. After a series of tests, it was discovered my oldest brother had NF2 just like my mom did. Then in 1981, it was discovered one of my other brothers had NF2 also. My dad decided to have me checked for NF2. I was 12 when tiny bi-lateral acoustic neuromas were revealed.

In November 1981, my brother who had recently been diagnosed with NF2 unexpectedly died at age 19 from Von Willebrand disease. His death was a crushing blow to my family. During this time, my dad gave me the choice of having surgery or not to remove the acoustic neuromas. It was a big decision for me to make, but I decided to go for it.

In 1982, at the age of 13, I had my first surgery in February, then the other done in June. Both operations were successful; my hearing was saved.

In 1994, my oldest brother died from NF2 complications. He was 34 and his death shook me to the core. I went on to graduate from college that year and tried to maintain a normal life.

I noticed my hearing getting bad when I was in college in the early 1990’s. I started wearing hearing aids then.

Skipping ahead to today, I have been completely deaf since September 2001. In 2004, I had my third acoustic neuroma surgery where the auditory nerve was removed and an ABI was implanted. The surgery was a success and my ABI has improved my quality of life. Hearing the barks of my four dogs is music to my ears!

Also in 2004, I felt the challenges of NF2 were too insurmountable to maintain the desk job that I had. Even though my supportive and understanding coworkers adapted to my limitations; I no longer had the stamina for the job. I then went on Long Term Disability, capping off 15 years of working at JPL/NASA.

The biggest NF2 hurdle was losing my right facial nerve during surgery in August 2005. Luckily for me, the nerve graft that was done has regenerated my smile.

Other operations I’ve had were a cervical laminectomy in 1999; thoracic/lumbar laminectomies in 2002; mid-brain meningioma removal in 2010 and thoracic spine tumor removal in 2011. In case you’re wondering, I have become quite the hospital food connoisseur, obviously not by choice.

Today, at 43 years of age, I have been happily married to my wonderful husband for 15 years. I feel blessed to be alive, despite all the hardship I’ve endured. Life is good!
**Fundraising:**

- **Zazzle™ - Cups & Stuff**
  Let us customize a product for you; T-shirts, cups, hats with logos, family photos, pet photos, etc.

- **Magazine Subscriptions**
  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
  For more info, please contact Barbara Franklin at barbarafranklin144@gmail.com

- Another easy way to contribute to NF2 is to visit us and donate on [Facebook](#).

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**Thank You For Your Generous Donations!**

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**Ninth Annual Ohio Gathering:**

The Ninth Annual “Ohio Gathering” was held October 5-7, 2012. The Ohio Gathering brings together NF2ers and their loved ones for a weekend spent with those who know exactly what they go through. The “theme” for the event was Halloween/Autumn. In addition to fun activities and meals, Brad Welling MD, PhD spoke to the group with the latest breaking info on NF2 research and developments since last year’s Gathering. Dr. Welling is a highly respected doctor known internationally in the world of NF2. The NF2 community thanks Dr. Welling for taking the time to speak at the Ohio Gathering! Lots of fun and friendship was shared at the Gathering. We hope to see you all next year!
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.

**BEVACIZUMAB (Avastin™):**

- **Bevacizumab (Avastin™) in Treating 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 intreating patients with recurrent or progression meningiomas.
  Location: Northwestern University, Chicago, IL, USA.

**LAPATINIB:**

- **Concentration and Activity of Lapatinib in Vestibular Schwannomas**
  ClinicalTrials.gov Identifier: NCT00863122
  This study is currently recruiting participants.
  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.
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

SORAFENIB:

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

Adults who have Neurofibromatosis 2 (NF2) and at least two skin tumours (nerve tumours under the skin also referred to as ‘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. Professor Gareth Evans is the Principal Investigator in Manchester.

Location: Plymouth & Manchester, UK.

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.

Location: 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.

**MISCELLANEOUS STUDIES:**

**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.

**NF2 Patients Needed for New Vestibular Study at Harvard Medical School / Massachusetts Eye and Ear Infirmary**

The general clinical goal for our study is to quantify motion perception for a range of vestibular disorders. A long-term goal is to develop new clinical tests to provide early diagnosis for vestibular disorders. These clinical research efforts are part of a broader basic science investigation of vestibular thresholds. At this time, we are seeking NF2 patients who have complete loss of vestibular (i.e., “balance/equilibrium organ”) function in both ears following surgical removal of tumors from both ears. Travel reimbursement would be paid for all qualifying volunteers. Contact: Adrian Priesol, M.D., or phone: (617) 573-4148

Location: Massachusetts Eye & Ear Infirmary, Boston, MA, USA.
**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.

**Other Pharmaceuticals of NF2 interest:**
- Sorafenib (Nexavar™)
- Erlotinib (Tarceva™)
- Dasatinib
- Vandetanib (Zactima™)
- Malatinib
- Lapatinib (Tykerb™)
- RAD001 (Everolimus, Afinitor™)
- BEZ-235
- **Valproic Acid**
- **Rapamycin**
- **Cetuximab**
- **Trastuzumab** (Herceptin™)
- Seraphinib
- **Nilotinib** (Tasigna™)
- OSU-HDAC42 (AR-42™)
- OSU-03012 (AR-12™)

**Some Botanicals & Natural Compounds of NF2 interest:**
- Caffeic Acid Phenethyl Ester (CAPE (Bio30™ liquid propolis)
- **Curcumin** (with bioperine)
- Boswellia / 5-LOXIN
- Omega-3
- Zyflamend
- Episilvestrol
- Cucurbitacin D
- Honokiol
- Resveratrol
- Silvestrol
- Bruceantin

For more trials and/or studies, please see: ClinicalTrials.gov. When there, please try inputting “neurofibromatosis type 2”, or a NF2 tumor tissue type, such as; “Vestibular Schwannoma”, “Schwannoma”, “Meningioma”, “Glioma”, “Ependymoma”, or “Astrocytoma”, within the relevant search field. Thank you.