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

Please join the NF Registry

WE NEED YOU! Have you joined the NF Registry? - The NF Registry’s mission is to identify people with NF who are interested in participating in clinical trials, as well as determining the commonality of specific characteristics of neurofibromatosis. Please help us reach our goal of 1,000 participants! See the thermometer graphic to the right to see the progress so far (392/1000). Registry sponsored by CTF.

Thank you for your support!

AdvocureNF2, Inc would like to thank Keith (featured in the “NF2 Compass” Winter 2013 edition), Lisa, and Tessa Kohnhorst for their generous donation. $1,234.00 was raised by the sale of the children’s book “The Brussels Sprout Man,” written by Keith Kohnhorst and illustrated by 11 year old Tessa.

If you would like to order a book, please contact: lisakohnhorst@att.net

Thank You For Your Support!
AdvocureNF2 is proud to announce funding towards five different NF2 projects this year. The majority of funds raised this year came from AdvocureNF2 Board member Roland Thoms’ very successful Halloween Bash – an annual event he has now held for nine years. The projects supported this year are:

A) SYNODOS

Synodos is a new Children’s Tumor Foundation (CTF) program designed to accelerate treatments for NF2. This is a first-of-its-kind NF2 research collaboration. This unique consortium brings together a multidisciplinary team of scientists from 7 world-class academic and medical centers of excellence, who have pledged to work closely together – sharing information, datasets, results – in real time, with the goal of speeding up the drug discovery process.

This group of researchers come to this project with a variety of backgrounds, from basic science to translational science to clinicians who will collaborate in real time, sharing successes and failures to avoid redundancy and save time and resources.

Advocure has funded $25,000 of the first year of the project, and will collaborate with CTF as needed. CTF is committed to funding $3 million in Synodos in the next three years. They are currently looking for additional funders interested in this transformative project. For more information please visit ctf.org/synodos.

Advocure will publicize their progress in future newsletters.

B) Long-Sheng Chang – Nationwide Children’s, Columbus, Ohio

Dr. Chang has been studying naturals as a treatment alternative for NF2 tumors. During this time, he found silvestrol to be most efficacious in shrinking tumors. The objective of Dr. Chang’s proposed study is to evaluate silvestrol and its related rocaglates, which target multiple converging oncogenic signals through translation inhibition, as potential therapies in NF2 schwannomas. Specifically, Dr. Chang’s group plans to compare how silvestrol, a potent anti-neoplastic natural compound from tropical Asian plant Aglaia foveolata, suppresses the growth of NF2-deficient schwannoma and normal Schwann cells and investigate its mech-
anism of action. Also, they have identified several silvestrol-related rocaglates that possess potent growth inhibitory activities similar to silvestrol but have chemical structures simpler (and smaller in molecular weight) than silvestrol. Therefore, these compounds will be easier to synthesize for clinical use. They plan to evaluate the anti-tumor activities of these silvestrol-related rocaglates in animal models for NF2-related tumors. Their ultimate goal is to develop an effective medical therapy that could significantly improve clinical care and long-term treatment outcomes for patients afflicted by NF2.

C) Chunling Yi – Lombardi Comprehensive Cancer Center, Georgetown University Medical Center, Washington, DC

Dr. Yi’s research will be to test the feasibility of establishing human schwannoma cell culture using Cellular Reprogramming technology. There is a critical need for this technology in NF2 as cells mutate and no longer reflect the original tumor that was surgically removed. If the cells from a tumor can be maintained in their original form, i.e., not mutate, testing of drugs on these tumors will be possible for personalized medicine for that individual’s specific tumor, thus increasing the chances of a positive response.

Two primary newly resected human schwannomas and adjacent normal nerve tissues will be subjected to culturing with various conditions according to Cellular Reprogramming technology. Once the cell lines are established, they will be stained with various markers to confirm their Schwann cell origin. The established lines will then be subjected to drug screening to identify drugs that preferentially inhibit the growth of schwannomas cells versus the normal Schwann cells.

D) Cristina Fernandez-Valle – University of Central Florida

NF2 Drug Discovery: Repurposing FDA Approved and Late Phase Clinical Trial Drugs for NF2 Therapeutics

Dr. Fernandez-Vallue will conduct a small scale in vivo mouse testing study for one to two drugs using an orthotopic nerve graft model. They will use a nerve graft mouse model, which takes 2-4 months to evaluate a drug rather than the 6-12 months it takes to evaluate drugs in a genetic NF2 mouse model. This model has recently been used and validated in other labs. They will then treat the mice with the drugs and test their ability to stop tumor growth or to shrink them.

E) NF2 State of the Art Conference

Advocure has made a contribution as a Silver Sponsor of the 2014 NF2 State of the Art conference. This annual conference brings together international researchers in translational and clinical science to assess current knowledge and identify opportunities for improving treatment of NF2. The 2014 meeting will focus on areas of controversy in NF2 to stimulate productive conversation among experts within the field. Areas of focus include surgical, chemotherapeutic, and radiation treatment, as well as quality of life, mechanisms of hearing loss, and the use of model systems for research.
NF Federal Funding in Washington DC

John, Erin and Leah Manth (Leah has NF2) traveled to Washington DC with the National NF Network to advocate federal funding for NF research. They are from NY State and met with Staffers from both senators and 10 out of 27 representatives from the House Side. Additionally, they completed 17 walk-in appointments with the remainder of the NY Delegation, basically dropping off information packets and following up with e-mails. This is the Manth family’s 7th year going to the Hill with the NF Network. It is essential that the federal government continue to fund NF research through the National Institutes of Health and the Congressionally Funded Medical Research Program.

Did you know that May is NF Awareness Month?

May is NF awareness month, and May 22nd is “officially” National NF2 Day. Please consider raising awareness and organizing fundraising events for this occasion. As we all know, NF2 is in desperate need of funds to go towards research for treatments for this devastating disorder. If you would like advice, ideas, or assistance in planning a fundraising event, please contact Roland Thoms at: roland@varsitypainting.com. Roland is Advocure’s fundraising expert and encourages you all to help out. Roland is the founder and organizer of the extremely successful “Halloween Bash” events, which take place in California every October.
“I have what?”
Neurofibromatosis Type 2—that’s what the neurosurgeon called it. Now, if you’re reading this, you either have it or you know someone who does—or perhaps not. You could always look it up on the glorious world of the Internet. I have. I could even recommend several of the informative sites for you, but I’d rather not. Instead, I’m going to spare you the tedious medical blah, blah, blah, and just tell you my story—at least a portion of it anyhow.
I've got NF2. I’ve had it for 15 years now. I was diagnosed with Neurofibromatosis Type 2 in September 1999.

I started out just like most of you with the persistent ringing in my ears, my vision blurring in and out. Diagnosed at the age of 22, I saw a full of life before me; I was carefree as the wind. That all changed in the blink of an eye—literally. I couldn't hear very well anymore, and my vision would blur in and out so badly at times that I couldn’t drive after dark. Then I couldn’t smell aromas or taste food the way I used to and the headaches and sinus pressure—ugh! I visited three ENT specialists (Ear, Nose and Throat), and each one diagnosed my problem as allergies or some other simple matter. My symptoms continued to worsen and before I knew it my world was flipped upside down and seemingly taken from me. I would say that I was scared of what was happening to my health, but, honestly, everything happened so fast I never really got a good emotional panic in.

As luck would have it, I finally had my childhood eye doctor examine me. He was the one who “got the ball rolling” for me. In a single day, I saw two eye doctors and ended up face-to-face with a neurosurgeon who delivered my final diagnosis. I’ll never forget that day as long as I live. My parents, struggling to maintain sanity, had me propped up in a sterile bed, as they stared at my savior clad in sneakers, jeans and a scrub top.

“You have five brain masses—Neurofibromatosis Type 2,” he said. “I’ve got WHAT?” I fired back.

Since then I’ve weathered four brain surgeries, two Gamma Knife treatments, two shunt replacements and two eye surgeries. I’ll be totally honest, it’s been hell. It’s not fair, and I’ve felt weak and broken before. But my strength and spirit will never surrender to NF2; I won’t allow it. I have NF2, it doesn’t have me. I’ve had a tremendous setback in life, but I have accomplished and gained much more than I could have imagined when I received my initial diagnosis. I’ve discovered life does go on, it really does. Make the most of every second of every minute of every hour, month and year. Live it. Love it. I do, and I have NF2.
NF2 News and Research:

Children’s Tumor Foundation Announces Historic New Initiative in Neurofibromatosis Research - The Children’s Tumor Foundation, the leading non-governmental organization dedicated to neurofibromatosis (NF) research, announced today an important new research collaboration called Synodos, a first-of-its-kind initiative dedicated to defeating the rare genetic disorder neurofibromatosis type 2 (NF2)...

Johnson joins ‘Dream Team’ of scientists collaborating on rare pediatric cancer - UNC Lineberger member Gary Johnson, PhD, professor and chair of the UNC Department of Pharmacology, has been tapped to join Synodos, a team of scientists working together to defeat the rare genetic disorder neurofibromatosis type 2...

MRI Without Magnet Removal in Neurofibromatosis Type 2 Patients With Cochlear and Auditory Brainstem Implants - MRI scanning without magnet removal is safe and well tolerated in NF2 patients with auditory implants. With appropriate MRI sequences, the image quality is not significantly impaired.

The role of NF2 gene mutations and pathogenesis-related proteins in sporadic vestibular schwannomas in young individuals - In this study, we evaluated clinical behaviors of 12 young sporadic VSs by the statistical comparison with a matched series of 145 adult cases. We found that young tumors were characterized by an earlier onset of initial symptom, shorter duration from the first symptom to diagnosis, and larger tumor size than adult ones...

Longitudinal evaluation of quality of life in 288 patients with neurofibromatosis 2 - The disease-focused NF2 impact on quality of life (NFTI-QOL) patient questionnaire was assessed as an outcome measure for treatment in a multi-centre study...

Surgeons perform first auditory brainstem implant operation in Northeast Ohio - Surgeons at University Hospitals Case Medical Center have completed the first auditory brainstem implant (ABI) operation in Northeast Ohio on a woman who has lost most of her hearing due to benign tumors on her auditory nerves...

Chemoprevention for neurofibromatosis 2: just over the horizon? - In the current issue of Neuro-Oncology, Dr Giovannini and colleagues report the effect of rapamycin on NF2-deficient schwannoma cell lines in vitro and in vivo. The data presented in the study provide further evidence that rapamycin can increase the time-to-progression of schwannomas in mouse models of NF2...

D. Bradley Welling, M.D., Ph.D., F.A.C.S., Named Mass. Eye and Ear/Mass General Otolaryngology Chief and HMS Chair of Otology and Laryngology - The Massachusetts Eye and Ear/Massachusetts General Hospital and Harvard Medical School communities welcome D. Bradley Welling, M.D., Ph.D., F.A.C.S., as the next Chief of Otolaryngology for the Massachusetts Eye and Ear / Massachusetts General Hospital departments...

In Vivo Functional Analysis of the Human NF2 Tumor Suppressor Gene in Drosophila - Here we describe experiments in which we used Drosophila as an in vivo system to test the functions of the normal human NF2 gene products and patient-derived mutant alleles...

Proteomic screening identifies a YAP-driven signaling network linked to tumor cell proliferation in human schwannomas - The goal of our study was to evaluate the expression and activity of these signaling pathways in human schwannomas in order to identify new potential therapeutic targets...
For Biology Professor, Cutting Edge Research ‘A Team Effort’ - Robert Bellin, associate professor of biology at Holy Cross, is currently researching the causes of neurofibromatosis type-2 in a laboratory setting with his junior and senior students, a project he refers to as “a team effort.”...

Axl/Gas6/NFκB signalling in schwannoma pathological proliferation, adhesion and survival - Research Highlight: Here, we demonstrated strong overexpression and activation of Axl receptor as well as its ligand Gas6 in human schwannoma primary cells compared to normal Schwann cells...

Patient-reported outcomes in neurofibromatosis and schwannomatosis clinical trials - Research Highlight: This article describes the PRO Working Group of the Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS) Collaboration, its main goals, methods for identifying appropriate PRO measures for NF...

Schwannomas and Their Pathogenesis - Merlin has multiple functions, including within the nucleus and at the cell membrane, and this review summarises our current understanding of the mechanisms by which merlin loss is involved in schwannoma pathogenesis, highlighting potential areas for therapeutic intervention...

CDMRP Neurofibromatosis Research Program for Fiscal Year 2014 (FY14) - The FY14 Defense Appropriations Act provides $15 million (M) to the Department of Defense Neurofibromatosis Research Program (NFRP) to support innovative, high-impact neurofibromatosis...

Wells Center researchers “build” a better mouse model for neurofibromatosis type 2 - Mouse models of human disease are often key parts of biomedical research since they provide scientists a chance to understand the origins and progression of a disease -- and begin testing potential therapies -- in ways that may not be possible with tests in cell cultures in the petri dish...

Inhibition of SIRT2 in merlin/NF2-mutant Schwann cells triggers necrosis - Mutations in the NF2 gene cause Neurofibromatosis Type 2 (NF2), a disorder characterized by the development of schwannomas, meningiomas and ependymomas in the nervous system. Merlin, a tumor suppressor encoded by the NF2 gene, modulates activity of many essential signaling pathways.

Antiangiogenic agents for nonmalignant brain tumors - Research Highlight: During treatment (range 4 to 21 months, mean 9.1) with antiangiogenic agents, two patients with an atypical meningioma and radiation necrosis had dramatic partial response, the six NF2 patients...

REiNS collaboration seeks common outcome measures for neurofibromatosis clinical trials - As potentially effective new treatments for neurofibromatosis (NF) are developed, standardized research approaches—including outcome measures specific to NF—are needed...

Ipsilateral cochlear implantation after cochlear nerve preserving vestibular schwannoma surgery in patients with neurofibromatosis type 2 - Research Highlight: To investigate the outcomes from ipsilateral simultaneous or sequential cochlear implantation in patients with neurofibromatosis type 2 (NF2) after vestibular schwannoma removal with cochlear nerve preservation...

Natural history of vestibular schwannoma growth and hearing decline in newly diagnosed neurofibromatosis type 2 patients - To determine the rate of growth in vestibular schwannomas and the rate of hearing decline in neurofibromatosis type 2 (NF2) patients not undergoing active treatment...

A deletion causing NF2 exon 9 skipping is associated with familial autosomal dominant intramedullary ependymoma - Research Highlight: Intramedullary ependymomas are rare and benign tumors in the adult. Little is known about their physiopathology, but the implication of the NF2 gene is suspected because of their presence in a third of patients with type 2 neurofibromatosis...
mTORC1 inhibition delays growth of neurofibromatosis type 2 schwannoma - We found that treatment with the mTORC1 inhibitor rapamycin reduced the severity of NF2-related Schwann cell tumorigenesis without significant toxicity...

Changes in gene explain more of inherited risk for rare disease - Changes to a gene called LZTR1 predispose people to develop a rare disorder where multiple tumors called schwannomas form near nerve pathways, according to a study published today in the journal Nature Genetics and led by researchers from the University of Alabama...

Brain Tumor Research:

Brain Tumor News Update on Medicare Part D Changes - The ABTA (American Brain Tumor Association) is pleased to share that within 24 hours of commenting on the proposed changes to the Medicare Part D and the Medicare Prescription Drug Benefit Programs...

World's First Noninvasive Brain Tumor Treatment with Focused Ultrasound Thermal Ablation - For the first time, focused ultrasound was successfully used in the treatment of a brain tumor. The adult patient had a recurrent glioma, a portion of which was thermally ablated using InSightec’s Exablate Neuro system...

Image-guided stereotactic radiotherapy for patients with vestibular schwannoma - Local tumor control and functional outcome after linac-based stereotactic radiosurgery (SRS) and fractionated stereotactic radiotherapy (FSRT) for vestibular schwannoma (VS) were assessed...

Fishing rod reels brain tumour cells to their death
Let's go fishing... for cancer cells. A tiny rod has been developed that reels in brain tumor cells and guides them out of the brain to their death. Rather than engineer ever more toxic drugs to kill glioblastoma cells deep in the brain, Ravi Bellamkonda...

Adding chemotherapy following radiation treatment improves survival for adults with low-grade gliomas, a slow-growing type of brain tumor - Adults with low-grade gliomas, a form of brain tumor, who received a chemotherapy regimen following completion of radiation therapy, lived longer than patients who received radiation therapy alone...

How a simple injection could help shrink a brain tumour - University of Leeds scientists are exploring whether a simple injection could help shrink a brain tumour as part of groundbreaking research...

Neurocognitive function in patients with recurrent glioblastoma treated with bevacizumab - Neurocognitive decline is a frequent adverse effect of glioblastoma. Antitumor therapies that are efficacious, as measured by traditional endpoints such as objective response..

New research funding for pioneering MRI technique - The Brain Tumour Charity and children’s charity Action Medical Research are co-funding Professor Andrew Peet at the University of Birmingham to develop Magic Angle Spinning Nuclear Magnetic Resonance Spectroscopy...

Aspirin Intake May Halt Growth of Vestibular Schwannomas/Acoustic Neuromas - Researchers from Massachusetts Eye and Ear, Harvard Medical School, Massachusetts Institute of Technology and Massachusetts General Hospital have demonstrated, for the first time, that aspirin intake correlates with halted growth...

Misc. News and Research:

Goggles help surgeons ‘see’ tumours - Scientists are continually seeking new ways of targeting cancer - and the latest is high-tech goggles. “The technology is quite amazing - almost like having a microscope to guide your surgery in the operating room,” says Dr Ryan Fields, a surgeon involved in a pilot study of the device...
Researchers add gene therapy to cochlear implants in deaf animals, aiming to improve hearing - Australian researchers are trying a novel way to boost the power of cochlear implants: They used the technology to beam gene therapy into the ears of deaf animals and found the combination improved hearing....

Imbalanced hearing is more than a mild disability
Researchers at Washington University School of Medicine in St. Louis have received a five-year, $3 million grant from the National Institutes of Health (NIH) to study the effects of asymmetric hearing loss in adults and children...

UK to fast-track some drugs under early access scheme - Britain is to accelerate access to ground-breaking drugs for serious conditions under a new early-access plan that the government hopes will benefit both patients and pharmaceutical companies...

NIH announces recruitment for clinical trial to test new tinnitus treatment device - Researchers supported by the National Institutes of Health are launching a clinical trial to test a device that uses nervous system stimuli to rewire parts of the brain, in hopes of significantly reducing or removing tinnitus, a persistent buzzing or ringing sound in the ears in the absence of any real sound...

The future of brain implants - Brain implants today are where laser eye surgery was several decades ago. They are not risk-free and make sense only for a narrowly defined set of patients—but they are a sign of things to come...

First device to prevent migraine headaches wins FDA approval - The US Food and Drug Administration has given its first approval for the marketing of a device for preventing migraine headaches...

Cornerstone Pharma demonstrates ability to disrupt growth of cancer cells - Cornerstone Pharmaceuticals, Inc., a leader in the growing field of cancer metabolism-based therapeutics, today announced that its first-in-class cancer metabolism targeted therapeutic, CPI-613, demonstrated the ability to inhibit tumor cell growth in the published studies...

On Data Sharing, Pharmaceutical Companies Finally Open Up - Over the past few years, the pharmaceutical industry has been embroiled in controversy over access to clinical trial data. At issue is the ability for researchers to independently verify study results...

Challenges remain before docs use whole-genome sequencing - Before doctors use technology to evaluate every “letter” in a person’s DNA to detect or diagnose medical conditions, several hurdles must be overcome, according to a new study.

Researchers Increase and Decrease Pain Sensitivity Using Light - Right now these mice are helping scientists study pain — how and why it occurs, and why some people feel it so intensely without any obvious injury...

NIDCD Researchers Find Strong Link between Hearing Loss and Depression in Adults - Researchers from the National Institute on Deafness and Other Communication Disorders (NIDCD), part of the National Institutes of Health, have found a strong association between hearing impairment and depression among U.S. adults of all ages...

Scientist Urges Withdrawal of His own ‘breakthrough’ Stem Cell Research - A Japanese scientist called on Monday for his own headline-grabbing study on stem cells to be withdrawn from publication, saying...

Visual Information Restoration and Rehabilitation via Sensory Substitution Technology - Richard Hogle of Wicab, Inc. led a team of interdisciplinary scientists at Wicab, University of Pittsburgh Medical Center, Lighthouse International, and Carnegie Mellon University to further develop the BrainPort V100 device...
New therapies raise hope for a breakthrough in tackling cancer - In the summer of 2012, a year after his wife had died of lung cancer, Michael Harris scraped open an old mole on his back and it would not stop bleeding. The doctors said he had stage 4 melanoma...

Cochlear implants — with no exterior hardware - A cochlear implant that can be wirelessly recharged would use the natural microphone of the middle ear rather than a skull-mounted sensor...

Fighting cancer with light-activated drug delivery by nanoparticle - A new type of treatment called “light-activated drug delivery” is showing promise as a way to give doctors control over precisely where and when drugs are delivered inside the patient’s body...

Lab on a Chip Features Drug Delivery Device that Could Restore Hearing - Draper Laboratory has demonstrated new advances miniaturizing in a drug delivery device that could help patients recover from hearing loss. The lab’s progress on the intracochlear drug delivery device...

X-Ray Glasses Help Surgeons See Cancer - A team of researchers from Washington University School of Medicine in St. Louis have developed a pair of high-tech glasses that could help surgeons visualize cancer cells...

Could One Cancer Test Find Unrelated Tumors? Researchers looked at 12 major types of cancer and identified 127 repeatedly mutated genes that seem to drive the development and progression of a range of tumors. The discovery sets the stage for devising new diagnostic tools and more personalized cancer treatments...

Detecting and targeting tumor relapse by its resistance to innate effectors at early recurrence - Tumor recurrence represents a major clinical challenge. Our data show that emergent recurrent tumors acquire a phenotype radically different from that of their originating...

Exon Skipping: Borrowing from Nature to Treat Rare Genetic Diseases - For decades researchers have been trying to co-opt nature’s way of copying only some of a gene’s information into messenger RNA (mRNA) to bypass harmful mutations as if they are typos. The strategy, called exon skipping, is finally nearing the clinic...

Scientists Make Artificial Muscles - Fishing line and sewing thread can create powerful artificial muscles that could be used to help disabled people or to build incredibly strong robots, a new study says...

We Are Giving Ourselves Cancer - DESPITE great strides in prevention and treatment, cancer rates remain stubbornly high and may soon surpass heart disease as the leading cause of death in the United States...

Give the Data to the People - LAST week, Johnson & Johnson announced that it was making all of its clinical trial data available to scientists around the world. It has hired my group, Yale University Open Data Access Project, or YODA, to fully oversee the release of the data...

NIH, industry and non-profits join forces to speed validation of disease targets - The Accelerating Medicines Partnership (AMP) aims to distinguish biological targets of disease most likely to respond to new therapies and characterize biological indicators of disease...

Fixing a body’s broken genes is becoming possible It sounds like science fiction, and for years it seemed as though it was just that: fiction. But the idea of gene therapy—introducing copies of healthy genes into people who lack them, to treat disease—is at last looking as if it may become science fact...

DNA Editing may spell the end for genetic diseases such as cystic fibrosis and sickle cell anaemia - Diseases caused by genetic mutations could be consigned to history after scientists found a way to edit human DNA one letter at a time...
The PRMRP Fiscal Year 2014 Appropriation Announcement - The Fiscal Year 2014 (FY14) Defense Appropriations Act provides $200 million to the Department of Defense Peer Reviewed Medical Research Program (PRMRP).

N.J.'s Merck, J&J team up with NIH in $230M research partnership - New Jersey pharmaceutical giants, Merck & Co. Inc. and Johnson & Johnson, are teaming up with eight other drug companies, the National Institutes of Health and several nonprofits in an unprecedented $230 million, five-year research partnership to speed the search for promising biological targets of disease and discover ways to combat them...

Using the human genome to customize medicine for patients - Every illness is its own story — a 30-year-old man with kidney failure but no clear diagnosis, a paraplegic woman with a bowel problem doctors can’t heal, a young woman with aggressive late-stage breast cancer. A new way to treat such patients is developing in which their very individuality is part of the cure...

Hearing Loss and Brain Shrinkage With Age - Older adults with impaired hearing may have a faster rate of brain shrinkage as they age, a new study suggests. A number of studies have found that older people with hearing loss...

Scientists discover a new, simpler way to make stem cells - A team of Boston and Japanese researchers stunned the scientific world Wednesday by revealing a remarkably simple and unexpected way to create stem cells able to give rise to any tissue in the body...

Some supplements might fuel tumors - Antioxidant vitamins are widely assumed to be cancer fighters, though research in smokers has found high doses may actually raise the risk of tumors. Now a new study helps explain the paradox...

Researchers turn adult cells back into stem cells - The future of medicine got a giant step closer Wednesday with the publication of new research showing what may be a much easier way to turn regular cells into flexible stem...

New computer model may aid personalized cancer care - Scientists have developed a mathematical model to predict how a patient’s tumor is likely to behave and which of several possible treatments is most likely to be effective...

New Truths That Only One Can See - The fear that much published research is tainted has led to proposals to make replication easier by providing more detailed documentation, including videos of difficult procedures. A call for the establishment of independent agencies...

Not all FDA-approved drugs get same level of testing - Patients might assume that all approved drugs are created equal. Yet new research finds that there can be big differences in the amount of testing that drugs and medical devices go through...

Omega-3 fatty acids could prevent and treat nerve damage, research suggests - Research from Queen Mary, University of London suggests that omega-3 fatty acids, which are found in fish oil, have the potential to protect nerves from injury and help them...

International deal to screen potential cancer drugs using DNA ‘barcodes’ - An innovative screening technology that tags compounds with unique strands of DNA – like barcodes – will be used to assess up to a billion prototype drug molecules for anti-cancer activity...

Frankincense Superior to Chemotherapy in Killing Late-Stage Ovarian Cancer Cells - Like the Magi, carrying myrrh, frankincense, and gold, researchers from the University of Leicester have, for the first time, demonstrated the potential of treating ovarian cancer using the Christmas gift frankincense...
The first 3D printed organ -- a liver -- is expected in 2014 - Approximately 18 people die every day waiting for an organ transplant. But that may change someday sooner than you think -- thanks to 3D printing...

Researchers Uncover Why Combination Drug Treatment Ineffective in Cancer Clinical Trials
Medical researchers at the University of Alberta have discovered that combination drug therapy didn’t work well in clinical trials for cancer patients because one drug was making the other drug ineffective...

New Coalition Draws Attention to Plight of Those With Rare Diseases - New Jersey pharmaceutical companies, healthcare providers and patient advocates are working together -- in a newly-formed group called NJ Rare -- to solve the vexing challenge of finding treatments for diseases that affect relatively few people and therefore are the focus of less research.

Senators Franken and Kirk Introduce Cancer Treatment Parity Act - On December 19, Senators Franken (D-MN) and Mark Kirk (R-IL) introduced the Cancer Treatment Parity Act (S. 1879) in the U.S. Senate. The bills would require any health plan that provides...

Contrast Agent Linked with Brain Abnormalities on MRI - For the first time, researchers have confirmed an association between a common magnetic resonance imaging (MRI) contrast agent and abnormalities on brain MRI, according to a new study published online...

Adaptive cell therapy: Honing that killer instinct
Genetically altered immune cells are helping to push life-threatening cancers into remission and generating a buzz...

NF2ers in the News:

Wellston graduate publishes book - A local author is proud to announce the upcoming release of his first book entitled, “When You Leave This Way”...

John Christensen Weblog - Two and a half weeks ago to this day, I underwent surgery, and came out fine. It is my belief that I came out more than fine, and no pessimistic doctor can change my mind otherwise...

Man sees wife’s dying message - Ontario, N.Y. -- After a week of trying, a local man was finally able to view a video his wife left him before she died. Charles Wachal’s wife, Shannon, died on Valentine’s Day at age 26 after a lifelong battle with neurofibromatosis type 2 (NF2)...

FB is 10: Strong support for survivors - Finding out that you have an illness or genetic disorder is tough on anyone, what more when you or your loved one has a rare condition that many don’t understand.

PHOTOS: Cupid’s Undie Run in Boston - On Saturday, February 15, hundreds gathered at Who’s On First on Yawkey Way for the sold-out inaugural Boston edition of Cupid’s Undie Run, a national fundraiser for the Children’s Tumor Foundation. Steve and Anne Noble (pictured to the left - Anne has NF2) participated in Cupid’s Undie Run in memory of Shannon Wachal, a friend who recently passed away after a life-long battle with NF2.
Fundraising:

• **Order a SMARTBucket**
  A SMARTbucket is a re-purposed paint can that has been re-labeled and uniquely decorated to make it a “one of kind” flower pot. Add dirt and water and watch a healthy life blossom! Each bucket comes with flower seeds. The label is recyclable plastic. It can be used inside or outside. All art on the SMARTbucket created by NF2 families.

  **Order The Brussels Sprout Man” Book**
  Written by NF2 patient Keith Kohnhorst and illustrated by his 11 year old daughter, Tessa. Proceeds go to AdvocureNF2, Inc.
  Contact: lisakohnhorst@att.net

• **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**
  100% of these funds go towards NF2 research
  c/o Children’s Tumor Foundation
  95 Pine Street, 16th Floor, New York, N.Y. 10055

NF Symposiums, Conferences, Gatherings and Webinars with an NF2 Component:

• **May 14, 2014 • Online Webinar**
  Goodman Campbell Brain & Spine Methodist Hospital
  Microsurgical Removal of Acoustic Neuromas: What Patients Need to Know

• **May 22, 2014**
  NF2 Awareness Day

• **June 4-5, 2014 • Boston, MA**
  NF2 State of the Art Conference (Medical Community Only)
  The NF2 State of the Art conference will bring together international researchers in translational and clinical science to assess current knowledge and identify opportunities for improving treatment of NF2.

• **June 6-8, 2014 • Washington D.C.**
  Children’s Tumor Foundation NF Forum 2014
  The NF Forum is a weekend-long patient and family support meeting open to all people living with NF and their families. Hosted by the Children’s Tumor Foundation.

• **June 7 - 10, 2014 • Washington, D.C.**
  (Doctors Only)
  2014 NF Conference
  Held in conjunction with the NF Forum. Hosted by CTF.

• **October 10-12, 2014 • Columbus, OH**
  NF2 Crew Ohio Gathering
  A social gathering for NF2 patients and their family, friends, and/or caretakers.
NF2 and Other Relevant Clinical Trials and Studies:

RAD001:

• Exploring the Activity of RAD001 in Vestibular Schwannomas and Meningiomas (RAD001 Phase 0)
ClinicalTrials.gov Identifier: NCT01880749
This study is currently recruiting participants.
The primary objective is to estimate the proportions of vestibular schwannomas (VS) and meningiomas after 10 days of exposure to the study drug RAD001 at a dose of 10 mg daily, as determined by immunohistochemistry. This is a “phase 0” PK (pharmacokinetic) and PD (pharmacodynamic) study of RAD001 in patients with Neurofibromatosis Type 2-related and sporadic VS and meningiomas. Enrolled patients will take RAD001 prior to a scheduled VS or meningioma surgery, and blood and tissue samples will be obtained for further analysis.
Location: New York University School of Medicine, New York, New York, USA.

• Study of RAD001 for Treatment of NF2-related Vestibular Schwannoma
ClinicalTrials.gov Identifier: NCT01345136
This study is currently recruiting participants.
The purpose of the study is to determine if RAD001 treatment will shrink or slow the growth of the vestibular schwannomas 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.

BEVACIZUMAB (Avastin™):

• Phase 2 Study of Bevacizumab in Children and Young Adults with Neurofibromatosis 2 and Progressive Vestibular Schwannomas (NF-2)
ClinicalTrials.gov Identifier: NCT01767792
This study is currently recruiting participants
RATIONALE: To determine the hearing response rate at 24 weeks after treatment with bevacizumab for symptomatic vestibular schwannomas (VS) in children and young adults with NF2.
Locations: Children's Hospital Los Angeles - Los Angeles, CA, USA
Children's National Medical Center - Washington, DC, USA
University of Chicago - Chicago, IL, USA
Indiana University - Indianapolis, IN, USA
National Cancer Institute - Bethesda, MD, USA
Children's Hospital Boston and MGH - Boston, MA, USA
Washington University - St Louis, St. Louis - Missouri, USA
New York University Medical Center - New York, New York, USA
Cincinnati Children's Hospital Medical Center - Cincinnati, Ohio, USA
Children's Hospital of Philadelphia - Philadelphia, PA, USA
University of Utah - Salt Lake City, Utah, 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.

AR-42:

• Phase 1 study of AR-42 for adults with Vestibular Schwanomma (More information to be determined).
Location: Ohio State University (OSU) Medical Center, Columbus, OH, USA

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.

ENDOSTATIN:

- **Endostatin Study for Patients With Neurofibromatosis Type 2 (NF2) and NF2-Related Tumors**
  ClinicalTrials.gov Identifier: NCT02104323
  This study is currently recruiting participants.
  1) Preliminarily evaluate the treatment effect of continuous vein injection of recombinant human endostatin on NF2;
  2) Preliminarily evaluate the safety and the patient’s tolerance of the treatment of endostatin;
  3) Provide an objective basis for an enlarged randomized double-blind trial.
  Location: Beijing Tiantan Hospital, Beijing, China.

OTHER STUDIES:

- **Neurofibromatosis (NF) Registry Portal**
  ClinicalTrials.gov Identifier: NCT01885767
  This study is currently recruiting participants.
  Primary Outcome Measures: to determine the natural history of NF1, NF2, and schwannomatosis patients will input medical information and treatment information about their NF and update at least yearly.
  Sponsors and Collaborators: The Children's Tumor Foundation
  New York, NY, USA. Principal Investigator: Pamela B Knight, M.S.

DONATE

William Hitselberger M.D. – 1930 - 2014

William E Hitselberger, neurosurgeon with House Research Institute, died February 13, 2014. In conjunction with William House MD, Dr. Hitselberger developed innovative approaches to skull base tumors. He performed more than 6,000 surgeries to remove acoustic neuromas. He was a pioneer in developing the auditory brainstem implant (ABI), which has benefitted NF2 patients who would otherwise have remained profoundly deaf. The ABI is the first successful prosthetic device that stimulates neurons in the human brainstem. While more than 1,000 adults have received the ABI worldwide, House alone has implanted more than 300 ABIs.

In neurosurgery for acoustic neuromas, aka vestibular schwannomas, neurosurgeons originally performed this surgery alone, and the approach was suboccipital. Doctors House and Hitselberger showed them how the best approaches to these tumors were through ENT approaches such as middle fossa. As a result, they had better results in terms of protecting the facial nerve, a better chance for hearing preservation and less post-surgery complications with smaller tumors. In addition, they explored the safer translabyrinthine approach for larger tumors, thus reducing morbidity and mortality rates associated with this surgery. He directly or indirectly helped train most neurotologic surgeons in this country.