

Arkansas NF

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QUARTERLY NEWSLETTER



2009 Annual Red Carpet for Research

Special points of interest:

- *2009 Annual Red Carpet for Research*
- *NF Endurance Team*
- *NF Research*
- *What is NF*
- *Learning Disabilities and NF*

The Second Annual Red Carpet for Research Gala to benefit the NF Clinic at Arkansas Children's Hospital was held on Thursday, September 24, 2009.

The event began with pictures on the Red Carpet, cocktail reception, and a silent auction. The Master of Ceremonies for the event will be Craig O'Neill with presentations by Teen NF Ambassadors and Dinner.

Entertainment for the night was provided by Jamileh Kamran, Arkansas Designer/Couturier and her students.

Dr. Paul H. Phillips, Pediatric Ophthalmologist, from Arkansas Children's Hospital was also honored for his outstanding care of children with NF.

This year's gala was held at the Chenal Country Club in Little Rock.

Watch the Arkansas CTF Chapter's website at www.ctfarkansas.org for information and photos from this event.



2008 Committee Members

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Facts about NF Research and the NF Endurance Team

Recent advances in NF research are moving us significantly closer to reaching the goal of FDA-approved treatments for neurofibromatosis (NF). Research grant monies are now being used to fund basic and translational research with an eye on developing drug therapies. Dr. Bruce Korf, one of the foremost NF research scientists states, "We now more or less understand the activity of the NF

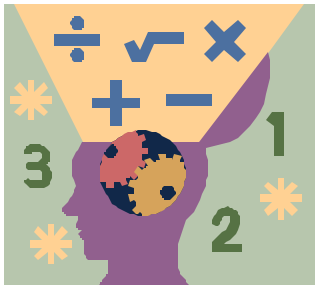
gene in the cell and are beginning to use that information to develop new treatments. I believe we're at a point where we can look forward to effective treatments for NF1, NF2 and Schwannomatosis in the reasonable near future."

The NF Endurance Team (NFET) is the largest Children's Tumor Foundation (CTF) program funding NF research; indeed all donations to the NF

Endurance Team are restricted for use in the CTF science and research programs. The NFET continues its commitment to advancing NF Research, now providing close to 1/3 of the funds to support the annual CTF research budget. Following last year's record \$1.2 million raised, we are pleased to

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NF1 and NF2 are called autosomal dominant genetic disorders. Half of all cases are inherited from a parent who has NF1 or NF2; half of all cases are not inherited but the result of a new or spontaneous mutation (change) in the sperm or egg cell. Each child of a parent with NF1 or NF2 has a 50% chance of inheriting the gene and developing NF1 or NF2.



Research has revealed that about 50-60% of school-aged children with NF1 are academic underachievers

What is NF?

Neurofibromatosis encompasses a set of distinct genetic disorders that cause tumors to grow along various types of nerves and, in addition, can affect the development of non-nervous tissues such as bones and skin. Neurofibromatosis causes tumors to grow anywhere on or in the body.

Types Of Neurofibromatosis

Neurofibromatosis (NF) has been classified into three distinct types: NF1, NF2 and Schwannomatosis.

Neurofibromatosis 1 (NF1): also known as von Reckling-

hausen NF or Peripheral NF. Occurring in 1:3,000 births, characterized by multiple cafe-au-lait spots and neurofibromas on or under the skin. Enlargement and deformation of bones and curvature of the spine (scoliosis) may also occur. Occasionally, tumors may develop in the brain, on cranial nerves, or on the spinal cord. About 50% of people with NF also have learning disabilities.

Neurofibromatosis 2 (NF2): also known as Bilateral Acoustic NF (BAN), is much rarer occurring in 1:25,000 births. NF2 is

characterized by multiple tumors on the cranial and spinal nerves, and by other lesions of the brain and spinal cord. Tumors affecting both of the auditory nerves are the hallmark. Hearing loss beginning in the teens or early twenties is generally the first symptom.

Schwannomatosis: a rare form of NF that has only recently been recognized and appears to affect around 1:40,000 individuals. It is less well understood than NF1 and NF2, and features may vary greatly between patients.

Learning Disabilities in NF1

Learning disabilities represent one of the most common and challenging complications of NF1. Research has revealed that about 50-60% of school-aged children with NF1 are academic underachievers, with many children experiencing marked difficulties in academic areas such as reading, spelling, arithmetic, and written expression.

Estimates of the incidence of learning disabilities in NF1 vary considerably, attributed to the use of different terms, diagnostic criteria, and biased study samples (e.g. participants obtained from learning disorders clinics). Despite these varying estimates, without intervention children with NF1 are at a far greater risk of academic under-

achievement and potential failure during their school years than children without NF1.

At school, many children with NF1 struggle to acquire the basic skills necessary for Literacy and Numeracy

LITERACY SKILLS IN NF1

To become a skilled reader, children need to learn a number of basic reading sub-skills such as letter recognition, whole word recognition, knowledge of letter-to-sound rules, and the ability to access meaning from the printed word. Recent findings suggest that a high percentage of children with NF1 experience difficulties with one or more of these reading sub-skills.

NUMERACY SKILLS IN NF1

Reading and language difficulties, even subtle ones, can make it difficult for the child with NF1 to acquire numeracy skills. Mathematics has its own language and this can cause a number of problems, particularly for children with reading difficulties. While some children who experience reading difficulties are good at math, a large number of children with reading difficulties also experience problems in at least some areas of math, such as those that require many steps or place a heavy load on working memory (e.g. algebra or long division). The effects of math failure throughout schooling can lead to math illiteracy in adulthood, impacting upon daily living and vocational prospects.

NF Endurance Team

Local members of the NF Endurance Team have participated in the LR Marathon for the last 4 years. Our team presence on the course has increased to numbers we never dreamed we would reach. We went from having 4 runners on the team to almost 100 runner/walkers last year. In addition to the large number of runners and walkers that participate in the marathon events, we have also increased our presence in volunteers. The NF Endurance Team took on the job of hosting a water stop at mile 18 in the Little Rock Marathon. Over the last 3 years, we have had over 180 volunteers who came to help; not only their NF Team members but all those participating in the marathon. We have help from the community: The

Delta Zeta Sorority from UCA, the UCA Nursing students, and nursing instructors from UCA have all sent members to help the NF Endurance Team.

When you put that many people in our bright yellow shirts, you get noticed – which is one of our goals in participating as a runner, walker, or volunteer. We want people to ask us what that “NF” stands for on our shirt. It’s funny, sometimes people say “NF, what’s that stand for, not finished,?” My response to them is, NF can mean a lot of things, depending on the day. . . NF can mean, not fun, not finished; which is also relative to neurofibromatosis (NF). We are out there wearing our bright team colors because we are Not Finished; as long as there is no cure and no good treatment options for those

with NF, we will continue to run, walk, and volunteer to raise awareness.

We are grateful for all those that have come out to help and hope they come away from the experience feeling fulfilled by knowing they have made a difference. We want everyone to know they can join the team in any capacity. We have runners, walkers, cheer support, volunteers, etc. We are not a group of elite runners, but rather group of people hoping to make a difference for those with NF. For more information on the NF Endurance Team go to www.ctf.org/endurance or contact loslica@gmail.com



Facts about NF Research and the NF Endurance Team

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continue with this level of projected funding and to apply team donations to partially fund promising and top-priority CTF research initiatives in 2009.

For more specific information please go to our Team Fundraising Dollars at work section on our Team web page. Our Team’s fundraising success is an investment that can offer a world of possibilities to some-

one with NF. We are helping solve the NF Puzzle one mile at a time, one clinical trial at a time, one potential drug therapy at a time.

“We now more or less understand the activity of the NF gene in the cell and are beginning to use that information to develop new treatments.”

Ending Neurofibromatosis
Through Research

QUARTERLY NEWSLETTER

Arkansas Chapter of the Children's Tumor Foundation
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RED CARPET FOR
RESEARCH

PHOTOS FROM 2008



Information on upcoming Arkansas events
can be found on our website:

<http://ctf.org/Chapters-Affiliates/arkansas-affiliate.html>



Mission Statement

The Children's Tumor Foundation is a non-profit 501(c)(3) medical foundation, dedicated to improving the health and well being of individuals and families affected by the neurofibromatoses (NF).

The mission of The Children's Tumor Foundation, is to:

- Encourage and support research and the development of treatments and cures for neurofibromatosis types 1 and 2, schwannomatosis and related disorders (hereafter collectively referred to as "NF");
- Support persons with NF, their families and caregivers by providing thorough, accurate, current and readily accessible information;
- Assist in the development of clinical centers, best practices and other patient support mechanisms (but not including direct medical care) to create better access to quality healthcare for affected individuals; and,
- Expand public awareness of NF to promote earlier and accurate diagnoses by the medical community, increase the non-affected population's understanding of the challenges facing persons with NF, and encourage financial and other forms of support from public and private sources.

The Neurofibromatoses are genetically-determined disorders which affect more than 100,000 Americans; this makes NF more prevalent than Cystic Fibrosis, hereditary Muscular Dystrophy, Huntington's Disease and Tay Sachs combined.