



NF Inc. Minnesota E-News

From the NF Inc. Minnesota Chapter

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Making Sick Children's Wishes Come True

By Jason DeRusha
December 3, 2005

(WCCO) Waconia,
Minn. - On the court at
Waconia High School,
Jon Kalthoff looks like
any other freshman basketball player.



Jonathon Kalthoff, Waconia, MN

But on the inside, the 14-year-old has an incurable disease with a scary name: neurofibromatosis.

"It's a disease where you can grow tumors in your body anywhere you have a nerve, which is pretty much everywhere," said his mother, Barb.

"I don't feel them at all, unless I touch them," Jon said.

So this wannabe hoop star got the chance to make a hoop dream come true.

Jon has to spend his time on the court with freshman at Waconia High School so when it came time to make a wish, he wanted to see the professionals.

"I couldn't believe it at first when they said we're going to send you to the (NBA) All-Star game," Jon said.

The All-Star wish is right on Jon's very own Christmas tree in the Mall of America's Camp Snoopy.

He's one of 50 special kids with 50 important wishes.

"Sometimes this is the light at the end of the tunnel for

them," said Tom McKinney, Make-A-Wish Minnesota's Executive Director. "If they can make it through the treatment, they get a trip someplace or they get to meet somebody."

On Friday night, Make-A-Wish kicked off their Stories of Light campaign. From 4-year-olds who want to go to Disney World to a 14-year-old who may be biggest All Star at that game in February.

"I'm just counting the days until I go," Jon said. "I can't wait."

Jon is actually doing pretty well. He has a couple tumors inside him right now, but they're not cancerous. The danger is if a tumor pops up in the throat or on the brain.

He goes to Washington D.C. to the National Institutes of Health for treatment, so he's got the best doctors in the country working on his care.

Health Supervision for Children with Neurofibromatosis



From PEDIATRICS the official journal of the American Academy of Pediatrics

This set of guidelines is designed to assist the pediatrician in caring for the child in whom the diagnosis of neurofibromatosis has been made. Although the pediatrician's first contact with the child is usually during infancy, occasionally the pregnant woman who has been given the prenatal diagnosis of neurofibromatosis will be referred for advice. Therefore, these guidelines offer advice for this situation as well.

At least two distinct types are recognized – neurofibromatosis 1, or NF-1 (previously known as von Recklinghausen disease or generalized neurofibromatosis), and neurofibromatosis 2, or NF-2 (previously known as bilateral acoustic neurofibromatosis). This discussion addresses only issues concerning the diagnosis and management of NF-1.

For more information on this subject, [click here](#). To download Acrobat Reader, [click here](#).

UCLA Scientists Recreate 'Flowers for Algernon' With a Happy Ending; Discover Statins Overcome Gene

Mutation Linked to Learning Disabilities

In a surprise twist that recalls the film classic "Flowers for Algernon," but adds a happy ending, UCLA scientists have discovered that statins, a popular class of cholesterol drugs, overcome the mutation linked to the leading genetic cause of learning disabilities. The Nov. 8 issue of Current Biology reports the findings, which were studied in mice bred to develop the disease, called neurofibromatosis 1 (NF1).

The results proved so hopeful that the Food and Drug Administration approved the use of the drugs in three clinical trials currently under review to test the effect of statins in children and adults born with NF1. The findings could help the estimated 35 million Americans who struggle with learning disabilities.

For more information, [click here](#).

Pen Pal for Josh

Recently, Rosemary Anderson, President of the NF Support Group of West Michigan contacted NF Inc. Minnesota with a request for a pen pal. Rosemary writes: I have been in contact with a mother in the Michigan area (near Toledo). She has a son name Josh, who is 11 years old. He is having a tough go with NF1 and would like to talk with other kids who have NF. If you know some kids who would like a pen pal, his e-mail address is jariley@tc3net.com. Would you please pass the word around for this young boy. Thanks for your help with this.

The 10th Annual NF Summer Camp - 2006

New Camp (Ages 12-18)

**July 15th - 21st
2006**

Campers will spend a few days at Camp K, enjoying the ropes course, arts and crafts as well as fun day trips to see AAA base-ball games, visit 12,000 foot Snowbird mountain, lots of swimming,

hiking, horse back riding, camp fires, dances, a talent show, fishing and more. A unique feature of our camp is the visit to the University of Utah's Eccles Genetic Science Learning Center, take a tour of a working genetics lab, perform hands-on experiments and have the chance to talk one-on-one and ask questions of an NF researcher. The kids always enjoy being scientists for a day and learning about NF and genetics in a fun, interactive way. To sign up, [click here.](#)



Reunion Camp (for kids who previously attended Camp)

July 22nd - 28th, 2006

The purpose of this camp is to reunite old campers. Reunion camp gives an opportunity for friends to catch up. Campers will enjoy activities similar to those of the New Camp and also participate in new and revised program. To sign up, [click here.](#)