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THE NATIONAL NEUROFIBROMATOSIS FOUNDATION, INC.

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## New Medications for the Treatment of Attention Deficit Hyperactivity Disorder (ADHD) in NFI

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### Introduction

ADHD is a common problem in children with NFI, and is frequently the major management issue for parents of a child with NFI. The signs of ADHD are often first noticed by parents and are apparent before age 7: inattention, hyperactivity and impulsivity. Frequently, children with ADHD and NFI also have a specific learning disability (LD), which require its own specific treatment in the form of specialized educational services. Teachers often bring these problems to the attention of parents, with a request for the child to be evaluat-

**ADHD is a common problem in children with NFI, and is frequently the major management issue for parents of a child with NFI.**

ed by the school psychologist. The school psychologist will recommend a consultation with a physician if he or she feels the child should be treated with medication. Some pediatricians assess children for ADHD and prescribe medication, though more commonly they will refer the family to a specialist, usually a child psychiatrist or neurologist. An effective treatment plan for ADHD may involve medication, but should also include special education services and supportive counseling for the entire family. There is no evidence that ADHD is caused by too much sugar, TV, food allergies or inner ear problems.

### Stimulants

For many years the stimulant category of drugs has been used to treat ADHD: Ritalin (methylphenidate), Dexedrine, Dextrostat (dextroamphetamine) and Cylert (pemoline).

These drugs do not cure the disorder but improve the symptoms in 90% of children. Unfortunately, they also frequently produce side effects, including loss of appetite and insomnia. Less commonly they may

produce tics, or involuntary muscle twitches.

Most physicians believe that the benefits to be gained from taking stimulants outweigh the side effects. Adjustment of the timing and level of medication dose, in addition to providing drug "holidays" during vacation periods, may help manage side effects and allow children to catch up on weight gain.

In our experience, Adderall (mixed amphetamine products), a newer stimulant class drug, provides the best results with the least side effects. The extended release form (Adderall XR) will provide coverage for a 7-hour period and can be given once a day in the morning, which does away with the need of having your child going to the school nurse for medication. Adderall XR comes as a capsule which can be taken apart and the contents sprinkled on applesauce, yogurt or other foods.

### Strattera (atomoxetine)

Strattera is a non-stimulant drug for ADHD, which was introduced in the U.S.

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## NF PROFILE

### NASCAR Driver Inspired by a Child with NF

Carl Edwards, NASCAR racer, definitely felt different when he stepped on to the tracks at Daytona, last February. Indeed it was a momentous day for Carl; he went on to win the biggest race of his career. But to Carl, winning the race signifies more than just taking home the winning trophy.

Josh Baysinger of Futon, Missouri had his dream fulfilled when he was invited by Carl to Daytona to attend the races. The 12-year-old boy is battling with Neurofibromatosis. Josh struggles to live with continued growth of tumors on his back which are expanding and deforming his chest cavity. Josh told Dream Factory, a foundation in Missouri, that he wanted to meet a NASCAR driver; they contacted Carl Edwards and told him about the boy's everyday health struggle and his wish.

Before the race, Josh gave Edwards a good luck hat. Carl placed the hat on his truck and told Josh that he would give it

back to him in victory lane. True to his words, Carl not only returned the hat to Josh but also his winning trophy. "I was happy to give him the trophy. I just feel fortunate to have met Josh. I did not realize he had a battle going on in his life. Always a smile on his face, he inspires me," Edwards said.

It wasn't an ordinary race for Carl Edwards, a hero who reminded us of the true meaning of winning. Nor it was an ordinary day for Josh Baysinger, a little boy with strength and determination that can touch a crowd at Daytona. **NF**

**Craftsman Truck Series driver Carl Edwards celebrates his first Daytona Victory with 12 year old Josh Baysinger of Jefferson City, Missouri who has NF. (Josh, front with cap)**



# Teens with NF Play Scientists for a Day!!!

**The Day at the Lab program visited Cincinnati, OH on April 3, 2004 where teens with NF became scientists for a day.**

Neurofibromatosis is not a regular Saturday morning topic for most teenagers. However, for teens with NF, discoveries and breakthroughs on this topic are important for them to learn about so they can better understand the disorder.

The NNFF in collaboration with the Neurofibromatosis Clinic at Cincinnati Children's Hospital and the University of Cincinnati hosted a recent Day at the Lab at the Vontz Center for Molecular Studies at the University. Dr. Nancy Ratner and her staff opened their laboratories and welcomed teens and parents from all over the state for a day of fun and learning. This was also the first concurrent program for parents where they had the opportunity to attend educational workshops and presentations conducted by scientists and physicians.

The Day at the Lab program is designed for students to learn about the genetic and cellular aspects of Neurofibromatosis. The program invites teens with NF to visit working laboratories, talk one-on-one with NF researchers and perform hands-on experiments. In previous years, the NNFF has hosted the



program at the University of Utah Eccles Genetics, Medical College of Wisconsin in Milwaukee, Massachusetts General Hospital Cancer Center and the House Ear Institute in Los Angeles. **NF**

**Feeling like true scientists! Teens had a wonderful time at Dr. Nancy Ratner's Lab in Cincinnati where they had the opportunity to make friends while learning at the same time.**

## How Can We Further Assist You Today?

As many of you know, NF can have a devastating effect on a family; physically, emotionally and financially. There are many organizations that work to help these families in their time of need. Two such organizations have asked the Foundation to let those families know that they may be eligible to benefit from their services: Make A Wish and Wings for Children. These are both worthy organizations that work to provide relief to those facing difficulty. The following describes the services that they offer and explains how to contact them for further information.

### **"Show The Power Of A Wish" Make A Wish**



#### **What is Make-A-Wish?**

Make-A-Wish is the largest nonprofit organization that grants the wishes of children with life-threatening medical conditions to enrich the human experience with hope, strength, and joy.

#### **What are the qualifications?**

The following are the three criteria that the child must meet:

- Child that is between the ages of 2 1/2 to 17.
- Child with a life-threatening medical condition.
- Child has not had a wish grant from another organization.

### **"Making A Difference In A Child's Life"**

#### **Wings For Children**

#### **What is Wings for Children?**

Wings for Children is an organization that provides free air transportation for seriously ill or disabled children so that they may reach medical care in distant cities. They fly children to and from Pittsburgh, as well as to or from any city within their service area.

#### **What are the qualifications?**

To qualify:

- The child must be in need of medical evaluation or treatment in another city.

- The family must demonstrate a need for the flight, either financial or medial. The need will be verified through a social worker, doctor's office, employer or clergy member.
- The child must be able to walk or be carried to the plane and board alone or with the help of a parent or guardian.
- The parent or guardian must be able to handle all care needs during the flight.
- The child must be able to sit up in a seat or travel in a car seat during the flight.

If you think that your child or someone you know, might qualify for these programs and would like to obtain additional information about the organizations and the services they offer, please contact them directly. For more information on Make-A-Wish, please visit their website [www.wish.org](http://www.wish.org) and for additional information about Wings for Children please call 1-800-743-5527 or visit [www.wingsforchildren.com](http://www.wingsforchildren.com). **NF**

# The 8th Annual NNFF International Summer Camp

**New Camp**  
SATURDAY, JULY 17TH –  
FRIDAY, JULY 23RD, 2004  
\$550 plus airfare

Send your child for a week of fun and learning at the NNFF Camp where they will visit Salt Lake City, UT. 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 baseball 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.

**Reunion Camp**  
SATURDAY, JULY 24TH –  
FRIDAY, JULY 30TH, 2004  
\$550 plus airfare

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.

**For details please contact the camp's "Mama" Jackie at [jmedina@nf.org](mailto:jmedina@nf.org) or 1-800-323-7938**

**HURRY!**  
**Spaces**  
**Are Limited!!** 



## ADHD

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approximately six months ago. It works by inhibiting norepinephrine reuptake in the brain. It controls the signs of ADHD without the insomnia caused by stimulant drugs, and with very little appetite suppression. In my opinion it offers the best combination of benefits with the least side effects and should be the first drug prescribed for children with ADHD. One pill will provide coverage for 24 hours. Some children may develop stomach upset and nausea; usually this goes away in the first week or two. Frequently, children become slightly drowsy 2-3 hours after taking a capsule. For this reason, we typically begin by giving a capsule on a full stomach, after dinner.


The manufacturer recommends dosage according to weight. In my experience the sensitivity of children to Strattera and the stimulant drugs varies enough that I recommend starting treatment with the lowest dosage capsule and increasing the dose as needed. The manufacturer does not recommend that the capsule be sprinkled on food, as the contents can be very irritating if it gets into the eyes. Some parents whose children cannot swallow capsules do break the capsule apart and sprinkle it on food, though the contents are more tightly packed than that of Adderall. If you do sprinkle, I recommend that you wear eye-glasses and wash your hands if you touch the contents.

### Conclusion

The use of stimulant drugs for the treatment of ADHD has created a substantial, on-going controversy about their benefits and side effects, which have created anxiety in many parents for whom this category of drugs has been prescribed for their children. While stimulants do not cause children to get "high" or become addicted and do not lead to drug addiction later in life, we hope that the availability of a new category of non-stimulant drug for ADHD will help to defuse this controversy and will reduce the anxiety many parents have about ADHD treatment.

Some of the comments made in this article reflect my own experience, which may not be the same as that of your pediatrician or specialist. I recommend that you always follow the recommendations of your own physician, and to seek a second opinion if you feel uncomfortable with them.

### References

1. Attention Deficit Hyperactivity Disorder; NIH Publication 96-3572, 1996
2. Manufacturer's Prescribing Information, Adderall. Shire Pharmaceuticals.
3. Manufacturer's Prescribing Information, Strattera, Lilly Pharmaceuticals. 

## Viva Las Vegas

The Las Vegas NF2con is an opportunity for people with NF2 and their families and friends to meet and share friendship and support. The Sahara Hotel and Casino was the chosen

venue for the 2004 Las Vegas NF2con, held April 1 through April 4. This year also marked the 10th anniversary of the annual event, and was dedicated to the playful memory of former co-hostess Caren Miller, who passed away in October of 2003. [www.nf2crew.org](http://www.nf2crew.org)



## Crisci Brothers Fine Italian Coffee Extract

Crisci Brothers would like to introduce you to **THE ULTIMATE CUP OF COFFEE**. We offer a cold brew extract that is 99.9% acid free. Which means no bitter taste. This smooth cup of coffee is made by putting one ounce of coffee extract into seven ounces of water. Because the extract is acid free the coffee can be reheated over and over with no change in flavor. This means no waste! And it is perfect for camping trips! Crisci Brothers' Coffee is now on sale on the NF website at [www.nf.org](http://www.nf.org).



## Chari-Tea

This new tea, produced by MacNab's Premium Teas of Boothbay, Maine, was specially chosen for the Foundation and cleverly entitled, "Chari-Tea". It is a blend of black tea and Rooibos. Tea is a wonderfully healthful beverage high in antioxidants. Rooibos, also high in antioxidants, is an herb from the "red bush" in South Africa. It is slightly sweet, which adds to the wonderful flavor of the tea created for Chari-Tea. The delectable taste, antioxidants, and minerals are not the only benefits of Chari-Tea. As its name implies a portion of the proceeds will be donated to benefit the Foundation. Chari-Tea is now on sale on the MacNab's Tea Room, [www.macnabspremiumteas.com](http://www.macnabspremiumteas.com) or you can contact them directly at 1-800-884-7222.

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## NF Address Updates!!

### **Our California Field Office has been moved to:**

National Neurofibromatosis Foundation, California Chapter  
HEROES FOR A CURE  
8939 S. Sepulveda Blvd. Suite 516  
Los Angeles, California 90045-3616  
Toll Free: (888) 314-6633  
Phone: (310) 216-9570  
Fax: (310) 216-7789  
Email: [NFCAL@AOL.COM](mailto:NFCAL@AOL.COM)

### **Out Massachusetts Field Office has been moved to:**

NNFF Massachusetts Chapter  
75 McNeil Way, Suite 201  
Dedham, MA 02026  
Toll Free: (888) 585-5316  
Phone: (508) 879-5638  
Fax: (781) 326-4940  
Email: [nfne.ed@verizon.net](mailto:nfne.ed@verizon.net)

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The purpose of the National Neurofibromatosis Foundation, Inc. (NNFF) is to improve the well-being of patients and families affected by NFI and NF2. The Foundation therefore sponsors scientific research aimed at finding the causes and cures for the neurofibromatoses, promotes the development of clinical activities, works to create public awareness and provides patient support services.

*The National Neurofibromatosis Foundation is a founding member of the International Neurofibromatosis Association.*