

neuro·fibroma·tosis®

THE NATIONAL NEUROFIBROMATOSIS FOUNDATION, INC.

WINTER 2003

Volume 25, No. 1

Insurance Coverage for the Removal of Neurofibromas

By Sally Stuart, MSW, LICSW

Children and adults with NF1 and NF2 are at risk for developing tumors known as neurofibromas. Neurofibromas which may begin to appear before puberty or later and may require removal if the tumors cause excessive itching (pruritis), transient stinging, catch on clothing, or create discomfort because they are in a location like the belt line, on an ankle or foot and interfere with the comfortable wearing of shoes.

Normally, the removal of a skin tumor for cosmetic reasons is not covered by health insurance, however the situation is different for the removal of neurofibromas for persons diagnosed with neurofibromatosis. If you have health insurance, your insurance plan should cover the removal of neurofibromas. Medicare and Medicaid should also cover the removal of neurofibromas for persons with neurofibromatosis. The removal of neurofibromas is medically justified for the following reasons: 1) there is a small, but statistically significant possibility that the

individual tumors can become malignant, and 2) they can cause nerve damage when they grow or 3) they are causing pain or interfere with normal function.

The diagnostic codes for the neurofibromatoses are:

Neurofibromatosis
Unspecified Type—237.70

Neurofibromatosis Type One—237.71

Neurofibromatosis Type Two—237.72

The billing code for removal of neurofibromas from the face is CPT 64788. (There are other codes for removal of neurofibromatosis other than the face which your physician's office staff should know.)

Both diagnosis code and billing code must be on the insurance claim form.

If your insurance company denies your claim, check with your doctor's office to make sure the claim was fully documented. The lack of information may be the reason your claim was been denied. You may need to request reconsideration. Make sure that

If your insurance company denies your claim, check with your doctor's office to make sure the claim was fully documented.

your reconsideration makes it clear that you have neurofibromatosis and give the reasons above for removal (e.g., pain, loss of function, pre-cancerous, etc). Your insurance company may require that your physician submit the reconsideration. If you are denied again and have a private insurer write a letter to the State Health Insurance Commissioner. This number can be found in the blue pages of the telephone directory. If your insurance is through your employer, you should also let your company benefits coordinator know the problems you are having with the insurance plan. If you have Medicaid coverage, call your state Medicaid office. This number can also be found in the blue pages of the telephone directory. If you

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New York Knicks Star Kurt Thomas Launches "Rebounds for Research"

A National Fundraising and Public Awareness Campaign to Benefit NF Research

New York Knicks star Kurt Thomas will act as spokesperson and personally donate to the National Neurofibromatosis Foundation for every rebound he makes during the 2003-2004 NBA season. In addition the star forward for the Knicks will appear in a series of public service announcements to support NF research and is inviting children affected by Neurofibromatosis (NF) to watch the Knicks at Garden home games this year.

Kurt's involvement with children's tumor research began when his agent met the father of 8-year-old Katelyn Watkins from Cartersville, Georgia. Katelyn was born with a tumor behind her left eye and had her first surgery when she was five months old. The doctors tried but failed to remove the tumor that was causing pressure on her eye. Although she has had several other major surgeries and has lost the sight in her eye, Katelyn's spirit won over both Kurt and his agent and they resolved to do what they could for Katelyn and the Foundation.

Kurt, one of the league's leading rebounders, is personally donating \$15 dollars for



Kurt Thomas and Katelyn Watkins

every rebound he grabs to the National Neurofibromatosis Foundation. In addition he will supply seats for children at 3 home games this season and star in a PSA to support the Rebounds for Research program and bring attention to the plight of children like Katelyn. The PSA will air in the New York Metro region.

The National NF Foundation has launched a website: www.reboundsforresearch.org for those interested in learning more about Kurt's involvement with the Foundation or supporting the program through a matching donation program. Participants who join the matching donation program will be

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Research Report

Editors Note: Three major recent research papers, all authored by scientists whose laboratories that have been funded by the NNFF, demonstrate the ongoing progress in NF Research. Drs. Gutmann and Viskochil co-chair our Clinical Care Advisory Board, and serve on our Research Advisory Board. Dr. Clapp's laboratory is the recipient of a Young Investigator Award; he also plays a key role in the Foundation's NNFF International Consortium For The Molecular Biology Of NF1 and NF2.

NNFF'S Director of Technology Transfers and Clinical Trials, Dr. Judy Small, provided the following summary of the papers.

In 2002, Dr. Luis Parada (a member of the NNFF Research Advisory Board, whose lab he has funded several times) and his colleagues published a paper describing the role of the tumor environment in the formation of plexiform neurofibromas in a mouse model of NF1 (1). In this paper, they showed that loss of both copies of the NF1 gene was necessary, but not sufficient, to cause tumor formation. In addition, the surrounding cells must contain one good and one bad copy of the NF1 gene. This hallmark paper has led to a number of studies that have provided important understanding of the biological conditions necessary for tumor growth.

In a December 2003 paper by Dr. Wade Clapp and his colleagues at Indiana University School of Medicine (2), they studied

the interaction Schwann cells and mast cells in neurofibroma formation. They showed that mast cells respond to signals from Schwann cells that did not have a functional NF1 gene, and that mast cells with one bad copy of the NF1 gene responded at a higher level than a mast cell with two good copies. Dr. David Viskochil of the University of Utah School of Medicine described the significance of these findings on the rational development of therapeutic agents that might work by altering the signals or response of these cell types (3).

In a separate series of experiments, Dr. David Gutmann and his colleagues at the Washington University School of Medicine and the University of Texas Southwestern Medical Center described experiments in a mouse model of NF1 where the gene was inactivated in astrocytes, as occurs in optic pathway tumors in NF1 (4). Again in these animals it was shown that the surrounding cells needed to have one good and one bad copy of the NF1 gene in order for tumors to grow. If the surrounding cells had two good copies, no tumors appeared.


These are very exciting findings, which will be important in the next year or so as scientists think about how to use this information to develop ways to control tumor growth. The mouse models are an important biological tool for learning about the mechanisms of tumor growth, and this understanding can lead to the appropriate

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interventions that may prevent or reduce the growth of neurofibromas. Because it would be very difficult to repair the gene responsible for NF1, having information that would allow treatment that bypasses this gene's role result in the improvement in quality of life for persons with NF1.

To see the abstracts for these papers, please go to The NF Website at: <http://www.nf.org/nfabstracts/>

The citations for the papers are as follows:

- (1) Zhu, Y. et al., Science 296: 920-922 (2002)
- (2) Yang, F-C, et al., The Journal of Clinical Investigation, 112: 1851-1861 (2003)
- (3) Viskochil, D. The Journal of Clinical Investigation, 112: 1791-1793 (2003)
- (4) Bajenaru, ML et al., Cancer Research, 63: 8573-8577 (2003) 

Jim Gavin, NF Fighter, Retires



Jim Gavin seated center, daughter Deanna Miyamoto left, granddaughter Tamra center, granddaughter Leah right and son-in-law Bob Miyamoto back right

One of the longest serving Chapter officers, Jim Gavin, is retiring as Treasurer of the NNFF Washington Chapter. Jim served his Chapter and the Foundation faithfully for more than eighteen years. Announcing Jim's retirement, the Chapter gave him a spirited send-off with a party in Seattle. Few eyes remained dry when the many tributes from friends far and near were read. The Foundation wished Jim long life and good health in his new position as "a civilian".

Long Term Giving Where There Is A Will, There Is A Way

Assuring the future of research into cures for the neurofibromatoses and their complications has never been more important.

Recent developments in biomedical research, technology, gene therapy and genetic engineering promise to create new knowledge at a speed that increases every day.

By donating to the National Neurofibromatosis Foundation we can keep pace with our researchers.

Have you recently reviewed your financial plans while preparing your tax returns? Think about fitting a Legacy Gift to the National Neurofibromatosis Foundation into your long-term plans.

Providing for loved ones and for NNFF does not have to be an either/or proposition.

There are many ways to provide for loved ones while supporting NNFF and providing significant estate tax savings.

For more information or a confidential discussion about a Legacy Gift to the NNFF contact:

Nancy DeNatale, Director of Development, The National Neurofibromatosis Foundation, 95 Pine Street, 16th Floor, New York, NY 10005-4001 (800) 323-7938 or (212) 344-6633 Email to: ndenatale@nf.org 

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.

**Deadline for all applications will be
May 1, 2004.**

**For details please contact the camps
"Mama" Jackie at jmedina@nf.org
or 1-800-323-7938**



Insurance Coverage

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have Medicare, follow the instructions for filing appeal that are included in your denial letter.


There are several health care cover options for uninsured children and adults. The State Children's Health Insurance Program is a federal/state program that covers uninsured children under 19 in families whose income is too high for Medicaid. Health insurance coverage through this program is free or low cost. To determine whether your child qualifies and what is available in your state call 1-877-543-7669.

For uninsured adults, contact your state's Medical Assistance Administration agency to see if you qualify for other state programs or if you can purchase private health insurance that may meet your needs. Their number can be found in the Blue pages of the telephone directory.

For additional information, contact the National Neurofibromatosis Foundation. Their telephone number is 1-800-323-7938. They can provide you with the name and contact person in your area. Peer support groups provide practical advice and assist you with advocating for your needs.


Inquiries regarding Medicare and Medicaid should be directed to Ms. Janet Miller, Health Insurance Specialist, Centers for Medicaid and Medicare Services, 7500 Security Boulevard, S2-25-14. Baltimore, MD 21044.

Paul D. Mendelsohn is a private consultant on disability issues. He retired from the Centers for Medicare and Medicaid Services, formerly the Health Care Financing Administration.

Sally Stuart, MSW, LICSW, is a Social Worker at the Center on Human Development and Disability, University of Washington. 



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 anti-oxidants. 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 may imply, a portion of the proceeds will be donated to benefit the Foundation. Chari-Tea is now on sale on the McNab's Tea Room website, www.mcnabspremiumteas.com, or you can contact them directly at 1-800-884-7222. 

Rebounds for Research

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eligible to receive various rewards depending on the giving level chosen. For example, participants who donate \$1 for every rebound Kurt grabs during the season receive a personally autographed basketball by Kurt; participants who donate \$5 dollars per rebound, receive a personally autographed basketball and seats to a Knicks home game.

To find out more about the Rebounds for Research program, visit www.reboundsforresearch.org. 

neuro-fibroma-tosis[®] NF Marathon Team *racing for research*



Upcoming Marathons

- 3/20/04 Shamrock Sports Fest
Virginia Beach, VA
- 4/4/04 Sprints of St. Louis
St. Louis, MO
- 4/24/04 County Music
Nashville, TN
- 5/23/04 Cellcom Green Bay
Green Bay, WI
- 6/6/04 Suzuki Rock N Roll
Marathon
San Diego, CA
- 6/19/04 Mayor's Midnight Sun
Anchorage, AK
- 9/5/04 Rock N Roll
1/2 Marathon
Virginia Beach, VA

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Latest NF Research Developments

We are very pleased to start the New Year with the comment that NF research continues at a productive and brisk pace, as indicated by the four major, recent articles. These papers are all authored by scientists whose laboratories we have funded with your support, and scientists who play significant leadership roles in the Foundation.

The citations for the papers are as follows:

- Zhu, Y. et al., *Science* 296: 920-922 (2002)
- Yang, F-C, et al., *The Journal of Clinical Investigation*, 112: 1851-1861 (2003)
- Viskochil, D. *The Journal of Clinical Investigation*, 112: 1791-1793 (2003)
- Bajenaru, ML et al., *Cancer Research*, 63: 8573-8577 (2003)

To see the abstracts for these papers, please go to The NF Website at: <http://www.nf.org/nfabstracts/>

See inside for detail. 

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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 NF1 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.

CORRECTION: Due to an error, Volume 24, No. 4 was mislabeled. It should have been labeled Fall 2003, not Winter 2004.