



Neurofibromatosis, Inc.

M I D - A T L A N T I C

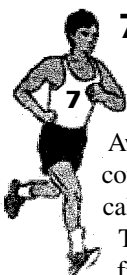
8855 Annapolis Road, Suite 110, Lanham, Md 20706-2924 • (301) 577-8984 • Fax: (301) 577-0016

Toll-free 866-261-1271

e-mail: nfmidatlantic@aol.com

www.nfmidatlantic.org

March 2008



7th Annual NF "Do It Yourself" Walk/Run

For the entire Month of May which is NF Awareness Month, you can choose your own course, set your own time and speed, keep physically fit AND raise funds for local NF activities!

Tell your friends and colleagues about it! Feel free to reproduce the entrance form. The entrance fee is only \$30 for individuals and \$45 for an entire family. Please send the NF office a photo of you or your family walking or running the race for publication in the summer newsletter. All who participate in the "Do It Yourself" NF Walk/Run will receive a certificate of completion. For more information, call the NF office 1-866-261-1271 or email nfmidatlantic@aol.com.

NF Family Day with the Washington Mystics

Join NF Mid-Atlantic for an afternoon of socializing and great WNBA basketball on **Saturday May 31, 2008 at 3:30 pm at The Verizon Center, 601 F Street, NW, Washington, DC.** We will be seated together on the handicapped accessible lower level. This event is to be the Camp New Friends May reunion activity. As an added treat 30 members of our group can give "high-fives" to the players as they come on the court to start the second half of the game! *Tickets are only \$18 each (\$6 goes to NF) with a savings of \$3.* **Help us reach our goal of 100 tickets!** Mail the enclosed form with payment to Washington Mystics, Attn: Maria Giovannetti, 627 No. Glebe Rd #850, Arlington, VA 22203 or fax to Washington Mystics, Maria Giovannetti at 202-266-2220.



First Sandra Blumberg Campership

Travis Glover of Chestertown, Maryland has been awarded the first Sandra Blumberg Campership to attend the 2008 Camper New Friends as a camper for the first time. Travis and his family have visited Camp New Friends in Buckeystown, Maryland on Visitation Day for the past two years – waiting until he turned 7 years so he could spend the entire week having fun and making new friends. Congratulations!

See page 2 for more on Camp New Friends.

See page 2 for more on Camp New Friends.

Neurofibromatosis Symposium*

"NF: Now & In the Future"
Saturday April 12, 2008

8:30 am – 4:30 pm

Holiday Inn Baltimore/Towson
1100 Cromwell Road
Towson, MD 21286

"Learning New Tricks from an Old Dog"

Douglas Stewart, M.D.

National Human Genome Research Institute,
Bethesda, MD

"NF and Learning Disabilities"

Laurie Cutting, Ph.D.

Kennedy Krieger Institute,
Baltimore, MD

"Getting the Most Out of Your Health Insurance"

Paul Mendelsohn, Ellicott City, MD

"Transitional Issues for Young People & Parents"

Panel Discussion

Carol Greene, M.D. Pediatrician

University of Maryland School of Medicine, Baltimore, MD

Howard Levy, M.D. Internist

Johns Hopkins Hospital – Greenspring Campus, Baltimore, MD

Jan Simpson, RN

Franklin Square Hospital Center, Baltimore, MD

Young Person Making the Transition

"The R-Files"

An Interactive Theatrical Program Helping

Young People Deal with Peer Pressure

Learn the 5 Steps to Personal Power from

Agents Sulky and Moldy of S.T.A.R.S.

Kaiser Permanente Educational Theatre Program

Exhibitors: Brain & Tissue Bank, NF Research Program at Kennedy Krieger Institute and others

***The registration fee for each person is \$20 (\$25 after April 9) which includes lunch and meeting materials.**

A limited number of scholarships is available.

Contact the NF office at 1-866-261-1271 (toll free).

Child care and a realtime captionist are not being provided.

FREE PARKING.

Notes from Bev

Congratulations to Travis Glover who was awarded our first Sandra Blumberg Campership. We know he will have a great time during his first experience at Camp New Friends in July.

We encourage you to attend our all-day symposium “NF: Now and in the Future” coming up at the Holiday Inn in Towson, MD on Saturday April 12th. It will be great fun participating in “The R-Files,” meeting others with NF, and learning about the latest NF research, how to maximize your health insurance, and deal with learning disabilities. There will be exhibits to visit too. Hope to see you there!

Philadelphia’s NBC 10 FitFest scheduled in April has been cancelled. Dave Dobson and I will miss seeing all of you who have visited our NF exhibit over the years. Please plan to visit the 7th Annual Schnee Way NF Picnic June 28th in Salunga, PA.

Don’t forget to keep track of the Hike4NF. The hikers left Cape Henlopen State Park in Delaware on February 29th and passed through Bowie March 10th. A feature article about the hikers and NF was supposed to have been published in *The Bowie Blade*.

Watch, too, for more information about NF Family Day with the Washington Mystics on May 31st. Help us maximize our fundraising potential and surpass our goal of 100 tickets!!

Hope to see you soon.

Bev

2008 Camp New Friends



Date: July 13-19, 2008
Camp Site: Bishop Claggett Center,
Buckeytown, MD
Cost: \$650 Registration
(includes \$100 non-refundable deposit)

We are sad to report the passing of Nikirah Milbourne on February 29, 2008. She was quite extraordinary. While she was receiving chemotherapy in the hospital, she conducted a Read-a-Thon to raise money for the 2008 camp. Her mother wrote “Camp New Friends made such a big difference in her life. She really started blossoming after attending camp. Thank you so much for all that made Nikirah’s last two summers wonderful.” We extend our condolences to her family and our camp family who knew her.

Thanks to David and Jennifer Griggs of “Happy Tabs” for donating \$50 to the 2008 Camp New Friends. What is “Happy Tabs”? Visit www.happytabs.org.

NEXT CAMP NEW FRIENDS ACTIVITY

Bring the whole family and your friends for an afternoon of music, dancing, games and an Italian Supper at the CNMC Camps Family Reunion!

When: Sunday April 13, 2008 from 1-5 pm

Where: Old McLean Firehouse, 1440 Chain Bridge Road,
McLean, VA

Cost: \$20 per person – pay at the door

RSVP: Julz at jabate@cnmc.org by April 1, 2008

NF2

New NF2 Research Study at NIH: “A Prospective Natural History Study of Patients with NF2”

This project at the National Institute of Neurological Disorders and Stroke (NINDS) in Bethesda, Maryland will study NF2 tumor development and progression. Study participants will have a thorough clinical evaluation and how their tumors affect function (vision, hearing, walking, balance, etc.). All testing will be performed as an outpatient and repeated every 6 months. Eligible patients must have a diagnosis of NF2, be between 8 and 75 years old, and be able to have MRIs. There is no charge for the study-related tests and travel costs may be reimbursed. *For more information, call the NIH Patient Recruitment Office at 1-800-411-1222 or email: prpl@cc.nih.gov.*

2008 NF2con

Date: May 22-25, 2008

Place: The Sahara Hotel and Casino, Las Vegas, NV

Contact: Jodi Berlin at email: jodiber@gmail.com or visit www.nf2crew.org

New NF Program at St. Joseph’s Regional Medical Center, Paterson, NJ

St. Joseph’s Regional Medical Center is pleased to announce the opening of the Neurofibromatosis Diagnostic and Treatment Program, a multidisciplinary program for individuals with NF1, NF2 and schwannomatosis. The Program offers outpatient multidisciplinary care for children with NF who live in the tri-state area.

The NF Program offers the services of multiple specialists in one setting. Evaluations by a medical geneticist, a pediatric neurologist and a developmental pediatrician are completed in one session. The team will also coordinate care with a pediatric ophthalmologist, pediatric orthopedist; audiologist and any other necessary specialists. Patients and their families have the opportunity to meet in order to gain social and emotional support. Through a team approach, the NF Program provides a medical home for children and families affected by NF.

For more information or to make an appointment, contact Christina Flora, clinical coordinator at 973-754-3222 or email: florac@sjhmc.org.

What is Schwannomatosis?

Schwannomatosis is a relatively rare disease that presents with multiple schwannomas (a form of peripheral nerve sheath tumor) that develop on multiple nerves throughout the body. This is similar to NF2, however, patients do not develop vestibular schwannomas or other brain tumors. Patients often come to medical attention in adulthood due to nerve-based pain and the identification of “bumps” on their nerves. The quality of pain is highly variable but can be severe. Surgery may be indicated to remove schwannomas causing pain that is not effectively controlled by medications. Patients may also have weakness or sensory changes related to the tumors.

The first diagnostic criteria for schwannomatosis were published in 2005 and include:

- Age greater than 30 years AND
- Two or more schwannomas (proven with biopsy)
- AND no evidence of vestibular tumor on MRI scan of the brain

continued on next page

Honoring Loved Ones

We want to express our sincere gratitude to the following individuals, companies and organizations who have honored a loved one by making a donation to the NF Research activities of NF, Inc.-Mid-Atlantic through March 10, 2008:

In Honor of...

Diane Bark

Rob Burge

Ellen Kahan

Megan Kingsley

John Kivarr

Laurie Marshman

Mike Marshman

L. Content McLaughlin

Jonathan C. Neiswende

James Porter

The Felix Spinelli Family

Dawn Strumsky

In Memory of...

Margaret Bates

John Dobson

Judith Ann Hatfield Gee

Theresa H. Haasz

Elizabeth Kalinich

Marjorie Keefe

Stephen J. Master

John J. Serafinas

Contributor

Ruth & Bob Davidson

Ellen Z. Goodman

Sandy Guttenberg

Ada O. Burge

Sara Sutherland

Jacqueline & Brittney Kingsley

Penny Freeman

Sara Sutherland

Sara Sutherland

Diane Bark

Tonya Neiswender

Robert Williamson

Daniel Engeljohn

Penny Freeman

Contributor

Diane Bark

Thomas P. Walton, Jr.

VHI Transport Employees

Colleen A. Bennett

Connie Whitley, First Source

Publishing

Denise Galloway

Ryland Martin

Melissa Keeman Proffitt

John R. Smith

William & Anna Becker

Henry E. Haasz

John & Waltraud Haasz

Paul & Beryl Haasz

William W. Haasz, Jr.

Martin C. Kenig, OD

Ronald & Edith Murphy

Shirley A. Reitz

Marian J. Stickle

Jean R. Kennedy

John A. Knepper

Mr.&Mrs. Harry Nestler

John H. Nestler

Lynne C. O'Connor

Deborah & Andrew Sharkey

Jean E. Master

Diane Bark

NF Research Needs \$20 Million in FY2009



This year we are asking Congress to appropriate \$20 million for the NF Research Program of the Department of Defense Congressionally Directed Medical Research Program (CDMRP). These funds, administered by the Department of Army, will bring the NF research appropriations back to the level of funding 4 years ago when the NF investigators were beginning to make significant progress in finding insights into the cause of NF, developing treatments, and enhancing the quality of life for all who are affected by NF. For more information about the NF Research Program, visit the U.S. Army Medical Research and Materiel Command at <http://cdmrp.army.mil>. **Please contact your United States Congressman/Congresswoman and your Senators; tell them your story about NF; and ask them to support the \$20 million for the NF Research Program in the Department of Army appropriations.**

Hike4NF Across America



A great send-off dinner at TGI Fridays in Rehoboth Beach, Delaware on February 28, 2008 was held the night before beginning the 4,000+ mile hike to raise awareness of neurofibromatosis and \$100,000 for NF, Inc. Pictured are left to right: Christy next to her brother Jeremy Eby, the inspiration for the hike, Travis Glover;

middle row: hikers Kevin and Jodi with Debbi Hanlon coordinator of the NF, Inc. event and Stacie Glover from NF, Inc.-Mid-Atlantic; back row: hiker Dustin and Jeremy's father Scott. The *Cape Gazette* reported on changes in the hikers plans in the March 7th article. Kevin and Dustin are biking and hiking and Jodi is hiking with Josh Howell along the northern route of the American Discovery Trail. Special thanks to the Glover family and the Freeman family who provided overnight accommodations for them March 6th and 7th. To find out precisely where the hikers are or to offer overnight accommodations along the way, call Jodi Harrington at 419-265-5634 or email Debbi Hanlon at debbi@rn4nf.org. To make a donation visit www.firstgiving.com/adt.

NF Support Contacts

Hampton Roads, Virginia

Richmond, Virginia

West Virginia

Sali Gear

Robyn Porter

Steve Jarrett

757-679-4327

804-794-7376

304-744-8875

REMEMBER

... Neurofibromatosis, Inc.-Mid-Atlantic permanent CFC #51268

... Neurofibromatosis, Inc.-Mid-Atlantic United Way of National Capital Area #8851

... When making a donation to NF, Inc.-Mid-Atlantic on www.nfmidatlantic.org using the GiveDirect form, your credit card statement will show GiveDirect.

Melissa Receives a Husky



Melissa Schoppet received a Husky from Laurie's NF Menagerie after surgery and a week's stay in the new tower at Children's National Medical Center in February. *If you know of a child with NF who is in the hospital or will be going to the hospital, please call the NF office at 1-866-261-1271. We would love to send or hand-deliver one of Laurie's special friends.*

Schwannomatosis, continued from page 2

- AND no known NF2 mutation
- OR a pathologically confirmed non-vestibular schwannoma plus a first-degree relative who meets the above listed criteria.

(Neurology (2005) 64:1838-1845)

In addition, there is a subset of patients who have schwannomas limited to a single limb or to adjacent sections of the spine that have a form of the disease called "segmental schwannomatosis." Although these criteria are helpful in recognizing the disease, they are not all inclusive and patients who are suspected of having schwannomas would likely benefit from an evaluation at an NF clinic that sees adults.

Jaishri Blakeley, M.D.

Johns Hopkins NF Clinic, Baltimore

Calendar of Events*

<i>Month of March 2008</i>	<i>Hike4NF Across America in MD, DC, VA, WV</i>
March 19, 2008	NF Presentation, Institute of Management Accountants, Holiday Inn, Roslyn, VA 6 pm
April 12, 2008	NF Symposium, Holiday Inn, 8:30-4:30 pm, Towson, MD \$20
April 13, 2008	CNMC Camps Family Reunion, 1-5 pm, McLean, VA \$20
<i>May 2008</i>	<i>NF Awareness Month</i>
May 1-31, 2008	NF Walk/Run Non-Event Fundraiser
May 8-18, 2008	NF, Inc. Doodle Day Celebrity Auction on eBay
May 16, 2008	NINDS Nonprofit Forum 2008 at NIH
May 20, 2008	NF Presentation at Town Hall, Denville, NJ 7:00 pm
May 31, 2008	NF Family Day with the Mystics, 3:30 pm game, Verizon Center, Washington, DC \$18
June 1, 2008	NF Exhibit, Rotary Street Fair, Denville, NJ
June 13, 2008	JARC Memorial Golf Tournament for NF, Mt. Airy, MD
June 28, 2008	7th Annual Schnee Way NF Picnic, Salunga, PA
July 13-19, 2008	Camp New Friends, 5th Anniversary, Bishop Claggett Center, Buckeystown, MD
Oct. 25, 2008	NF Symposium, Hershey, PA
November 2008	Annual Appeal
Nov. 13-15, 2008	NF Exhibit, American Society of Human Genetics, Philadelphia
Nov. 15, 2008	9th Annual Italian Night for NF, 7 pm, Baltimore, MD

*For more information, call 1-866-261-1271 or visit www.nfmidatlantic.org.

NF, Inc.-Mid-Atlantic Presents Check for 2008 Camp New Friends

At the March Camp New Friends Planning Committee meeting Beverly Dobson, President of NF, Inc.-Mid-Atlantic, and Dickson Kendrick, member of the NF, Inc.-Mid-Atlantic Board of Directors, presented Sandy Weinstein, PT, LCSW, Director of Camp New Friends, with a \$5,000 check for 2008 camperships.



NF CHAPTER READY REFERENCE

Mid-Atlantic Chapter	(301) 577-8984
Toll-free	1-866-261-1271
President, Beverly Dobson	(410) 828-4138
Immediate Past President, Brenda Duffy	(703) 765-6914
Vice President, Peter Childs	(301) 650-5926
Secretary/Treasurer, Penny Freeman	(410) 729-0878
Member-at-Large, Joe Billings	(301) 860-1011
Member-at-Large, David Dobson	(410) 828-4138
Member-at-Large, Dickson Kendrick	(301) 840-5988
Administrative Director, Mary Ann Wilson	(301) 577-8984
Genetic Counselor, Debbie Copenheaver, MS	(202) 884-4167
Genetic Counselor, Sandra Yang, MS	(202) 884-4168
Advocacy Consultant, Paul Mendelsohn	(410) 461-2245
Social Work Consultant, Joan O. Weiss, LCSW	(301) 656-4370
Legislative Consultant, Walt Sanders	(703) 836-6403

The current financial statement of Neurofibromatosis, Inc.-Mid-Atlantic is available upon request by contacting NF, Inc.-Mid-Atlantic, 8855 Annapolis Road, Suite 110, Lanham, Md 20706-2924; (301) 577-8984. For the cost of copies and postage, documents and information relating to NF, Inc.-Mid-Atlantic are available from the Maryland Secretary of State.

Mission Statement: NF, Inc.-Mid-Atlantic is to be the major resource for neurofibromatosis in the Mid-Atlantic States.

RETURN SERVICE REQUESTED

Neurofibromatosis, Inc.-Mid-Atlantic Chapter
8855 Annapolis Road, Suite 110
Lanham, Md 20706-2924
(301) 577-8984

NF
March 2008

Non-Profit Organization
U.S. Postage
PAID
Permit No. 5375
Glen Dale, Md. 20769