



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 **June 2007**

Last Chance To Sign Up For Camp New Friends



Date: July 15-21, 2007
Camp Site: Bishop Claggett Center, Buckeystown, MD
Cost: \$650 Registration (\$100 non-refundable deposit)

Camp New Friends is a great place to renew old friendships, make new friends, learn new things and have great adventures! Anyone with NF1 or NF2 aged 7 to 16 years is welcome to apply.

The deadline for registering as a camper or counselor is JUNE 20, 2007. Keep in mind there are still camperships available. **For more information, call Sandy Weinstein, PT, LCSW-C, Camp Director at Children's National Medical Center, Washington, DC at 202-884-5142 or email: scushwei@cnmc.org.**

NF, Inc.-Mid-Atlantic is providing host families and coordinating the transportation to and from BWI airport in Baltimore. If you would like to help with transportation taking kids to camp or picking them up at camp after the awards program and getting them to the airport, call the NF office at 1-866-261-1271 (toll free) or email: nfmidatlantic@aol.com.

Allison's Snack Stop

For 9 Sundays, Allison Kempe, age 11, with the help of her family, sold all kinds of snacks to the soccer teams and spectators at the Jesup Blair soccer field in Silver Spring, Maryland. The funds raised have been donated to Boston Children's Hospital where she had brain surgery 3



years ago and to Camp New Friends where she attended for the past 2 years. We thank Allison for her terrific example of commitment to community service and to improving the lives of young people with NF.

RainbowKids Waiting Child

This little 4-year old boy in South Korea has NF1 and is looking for a family. If you are interested, contact Moti Irani at the Americans for International Aid and Adoption in Troy, Michigan at 248-362-1207 or email moti@aiaaadopt.org.



NF, Inc.-Mid-Atlantic Donates \$5,000 to NF Cure Project



The NF Project partners with pharmaceutical companies which produce drugs that may be effective in treatment of NF and with NF scientists to test these drugs. Currently, it is working with Indiana University in a Phase II study of Gleevec to investigate its effectiveness on plexiform neurofibromas in NF1 patients. For more information about the study, call Shannon Burke at 317-278-3395. More information about the NF Cure Project, visit the website at www.nfcureproject.org.

Good Summer Reading

The book is about a young woman with NF1, college life, and romance. The author lives with her husband, son and two cats in Fort Worth, Texas. You can purchase a copy of *Thirty Cats* on www.amazon.com.



Participate in NF Research

Health-Related Quality of Life for Pediatric NF1 Patients (Project 3) The purpose of this study is to develop a tool that will assist doctors and researchers understand how having NF1 affects how children and teens feel and act and recognize the kinds of things they are able to do. Young people between the ages of 8 and 17 years, and parent volunteers will fill out questionnaires taking between 45-60 minutes. Participants will be paid \$20 for their time.

This study is funded by the Department of Defense. **For more information, contact Drew Bradlyn, PhD, Principal Investigator, Health Behavior Research Center, West Virginia University, Morgantown, WV at 304-293-6218 or email: abradlyn@hsc.wvu.edu.**

Notes from Bev

Our NF Symposium in Norfolk, VA was a great success. Attendees heard from a variety of interesting speakers, ate good food, and had time to “meet and greet.” Our thanks to all our speakers. Thanks also to all those who made the day possible, among them: Sali Gear, Sharon Victor, Penny Freeman, Mary Ann Wilson, and Randy Bristow.

Our newly hired executive director has resigned for personal reasons. We have had to cancel our October 5th Golf Tournament. Due to the ongoing problem of water leaking into our office, we find ourselves to be a little behind right now both with paperwork and office finances.

Remember Camp New Friends July 15-21 at the Bishop Claggett Center in Buckeystown, Maryland. Visitors Day is scheduled for Saturday morning the 21st. Host families to provide transportation to and from BWI for out-of-town campers and counselors are needed. Call the NF office if you can help.

On July 23rd Dave Dobson and I will be exhibiting at the SHIP Convention in Turf Valley, Maryland. Our 8th “Italian Night for NF” is coming up November 10th to benefit 2008 Camp New Friends.

Look for details in this newsletter about our summer fundraiser with Glory Days Restaurants.

See you soon.

Bev

ACTIVE MEMBERS



American College of Medical Genetics *Debbie Copenhaver, M.S., genetic counselor at the NF Clinic at Children’s National Medical Center, Washington, DC, had one of two posters about NF at the ACMG annual meeting in Nashville.*

Alexandria Country Day School *Tim Laramy, Faculty Advisor to the Student Council, is with Walt Sanders who made a presentation on NF and Camp New Friends at the school assembly on April 26, 2007. Through various activities the school hopes to raise \$1,300 to send two kids to camp.*



Barbara Shaw, an occupational therapy student at Allegheny College of Maryland in Cumberland, made a presentation on NF to her class on April 17, 2007.



NBC 10 FitFest *Beverly Dobson, President of NF, Inc.-Mid-Atlantic, is with Terry Kane who assisted with the NF exhibit at the Philadelphia Convention Center April 14-15, 2007.*

Sali Gear *Sali spoke to the Board of the Southeastern Virginia Oncology Nurses Society on March 21, 2007 about NF and the May 5th NF Symposium in Norfolk. Sali is also coordinating the formation of an NF support group in the Hampton Roads area. If you are interested in the support group, call Sali at 757-679-4327.*



NF Walk/Run The “Do It Yourself NF Walk/Run” is an annual NF Awareness non-event fundraiser held throughout the entire month of May which is NF Awareness Month. Most people send in their “registration fee” donation but some actually run or walk their own course at their own time and speed at a location of their choice. Many THANKS to all who have participated in this fundraiser so far to increase the public’s awareness of NF:



James’s Team in Midlothian, VA



Sharon Victor’s Team in NJ

Mr. & Mrs. Robert Benzel, Mary Hammond, Peg & Rob McGratts, Robyn Porter, Clark Witte, The Rick Witte Family, and The Victor Family.

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 May 20, 2007.

In Honor of...

Diane Bark
 Claire Faben
 Andrew & Jeffrey Kummeth
 James Porter
 Nathaniel O’Dell
 Danny Shiff
 Sean Small
 Gail Spahn & Adrian Iosiesescu
 Sue

Contributor

Reba Nussbaum
 Beverly C. Faben
 Greg & Jean Kummeth
 Robert & Hope Williamson
 The Charles O’Dell Family
 Ben, Diane & Max Bark
 Bob & Kathy Small
 Ben, Diane & Max Bark
 Reginald A. Howard

In Memory of...

Elizabeth Kalinich
 Stephen Master

 Lisa W. Smith

 Charruth Tinsman
 Sherry Tinsman

Contributor

Russell & Marian Stickle
 Brooks & Lois Doyle, Elaine Doyle, Exercise Class at Nazareth Senior Center, Shirley Frey, GAF Co-Workers, Eva C. Happel, Linda & Ronald Jones, Richard T. Kropp, Jean Master, Jean Morgano, Wilson & Adele Roth, Janet & Keith Schlamp, Mr.&Mrs. Richard Simpson, Kirk & Loretta Smith Adolph M. Chwastyk, Dorothy W. Cousineau, Susan P. Divilio, Richard A. Safren
 Willard Tinsman, Sr.
 Willard Tinsman, Sr.

HELPFUL RESOURCES

CaringBridge is a free, non-profit webservice that connects family and friends to share information, love and support during a health care crisis, treatment and recovery. Sign up for this service or subscribe to the journal of a patient already registered, www.caringbridge.org.

Health Insurance Website: www.healthinsurance.org

Specialized shoes and socks for children who have to wear leg braces or have disabilities can be found at **KeepingPace, Inc.** www.keepingpace.com.

A Parent's Guide to Medical Research helps parents decide whether or not to allow their child to participate in research. It can be obtained from the Boston Children's Hospital website www.bostonchil.vitalcon-sent.com.

Successful NF Symposium in Norfolk



Attendees lined up to ask questions following Dr. Stewart's presentation.

Medical Airlift had an exhibit of their services in providing air transportation for

patients needing specialized medical care within a 1,000 radius of their headquarters in Newport News, VA. Clara Benjamin informed us that they will also provide air transportation for campers attending specialized camps such as Camp New Friends. www.angelflight.com



Our special thanks to the speakers: Doug Stewart, M.D. from NHGRI at NIH in Bethesda, MD; Carrie Shilyhansky of the Dr. Alcino Silva Lab at UCLA; Paul Mendelsohn, NF, Inc.-Mid-Atlantic Professional Advisory Board; Jonathan Schreiber, M.D., Ph.D. of Advanced Dermatology Associates in Norfolk; Matthew Frank, M.D. of Children's Hospital of the King's Daughters in Norfolk; and Barbara Cohoon of the National Military Family Association in Alexandria, VA most of whom stayed the entire day.

We are grateful to the E.C. Wareheim Foundation for making this symposium possible; Merz Pharmaceuticals for the free samples of Mederma ointment; Sali Gear for picking up the tab for the audio-visual equipment; and the Lions Charity Foundation #24-D of Portsmouth, VA for partially funding the realtime captionist, Beverly Early of Manassas Park, VA.

Dr. Stewart's General Recommendations for Adults

- Educate your doctor about your disorder
- Be aware of the horse/zebra problem (common symptoms might be serious for a person with a rare disorder)
- Know your medical and family history
- Keep a copy of your own records
- Be pro-active – do not assume “the system” will always work
- Ask questions
- Use common sense
- Do not smoke!

For a copy of the handouts from the “Transition” Workshop, call the NF office at 1-866-261- 1271 (toll free) or email nfmidatlantic@aol.com with your name and address.



What to Expect When You Visit the NF Clinic

The NF clinic within the Division of Genetics & Metabolism is held on the 1st, 3rd and 4th Tuesday mornings of each month. Our multidisciplinary clinic includes services of geneticists, a genetic counselor, pediatric neurologists, pediatric ophthalmologists, neuropsychologist and pediatric developmentalist and a neuroradiologist.

When you come to Children's National Medical Center's NF Clinic for the first time, you will meet with a genetic counselor. A detailed pregnancy, birth, developmental and medical history will be taken as well as a family history. General questions and concerns about NF can be answered and discussed. If you have medical reports from other doctors you have seen recently or reports from MRIs, please bring those with you.

Every time you are seen at the NF Clinic, a height, weight, head circumference and blood pressure reading will be taken. We will also ask about your child's schooling and if there are any educational issues. We will discuss any new medical concerns that may have presented, such as headaches, blurred vision, new café-au-lait spots, freckling or neurofibromas (bumps). If your child had any appointments to other medical specialist since the last time we saw you, we will discuss those appointments and follow-up that is needed.

A geneticist will do a physical examination, looking for new café-au-lait spots, freckling or neurofibromas (bumps). They will look in the child's ears, eyes, nose and mouth. They will also feel the child's skin to see if they can feel any neurofibromas underneath the skin.

A neurologist will do a neurological examination, testing the reflexes and looking for any new changes that could be associated with NF1 complications, like brain tumors or plexiform neurofibromas. A neuro-

logist will also review and discuss with the family any learning difficulties or current developmental concerns.

The geneticist and neurologist are able to discuss each patient together and decide if any follow-up care is needed. Children's National Medical Center has many different research protocols involving NF patients. If the doctors feel your family may be appropriate for any of these protocols they will discuss it with you. All of these protocols are voluntary and your decision to participate or not does not affect the overall care that you will receive. The doctors may wish to refer your child for developmental or neuropsychological testing. Both kinds of testing (which are based on your child's age) help point out your child's strengths and weaknesses. Imaging, in the form of MRIs or x-rays, may be recommended also. It may be necessary for the patient to be sedated during the MRI. Being sedated is painless and ensures that the patient does not move during the exam.

If the child needs an ophthalmologic examination (eye exam), the family will go upstairs at the hospital to the eye clinic following the genetics and neurologic examinations. The ophthalmologist needs special equipment to conduct a proper eye exam. The child's eyes will need to be dilated. Often, they will put the drops in the child's eyes and then ask if you want to get lunch or a snack since it takes ~30 minutes for the eyes to dilate.

Our approach to having a family seen by multiple specialists in one day allows the doctors to discuss patients and the patients' care as well as minimizing the number of times a family needs to come to the hospital.

If you have any questions about the NF Clinic at Children's National Medical Center, Washington, DC, please contact Debbie Copenheaver, M.S. at 202-884-4167.

Calendar of Events*

June 1- September 30, 2007 June 8, 2007	Glory Days Grill "Dine for Dollars" Send receipts to NF Office Julie Ann Robertson Cashour Memorial Golf Tournament for NF, Mt. Airy, Maryland
June 30, 2007	Schnee Way 6th Annual PA NF Picnic www.schneeway.info/nfpapicnic.php
July 13, 2007 July 15-21, 2007 July 23, 2007	NF Swim-a-thon Call Penny Freeman at 410-729-0878 Camp New Friends, Buckeystown, Maryland NF, Inc.-Mid-Atlantic Exhibit at School Health Interdisciplinary Program, Turf Valley, Maryland
August 4, 2007	"River to Sea" Relay in New Jersey debbi@run4nf.org
November 10, 2007	8th Annual "Italian Night for NF" to benefit Camp New Friends, Lantern Gardens, Baltimore, MD 7:00 pm
November 18, 2007	Philadelphia Marathon Deadline Nov. 14 debby@run4nf.org
November 29, 2007	"Magical World of Children's Book Illustration" Elizabeth Stone Gallery, Alexandria, VA 6:00 pm

*For more information call 1-866-261-1271



"There are Days and there are Glory Days"

MARYLAND AREA LOCATIONS

Pasadena • Towson • Bowie • Germantown • Frederick

VIRGINIA AREA LOCATIONS

Burke • Broadlands • Centreville • Fairfax • Fredericksburg • Gainesville • Herndon • Lorton • Manassas • Richmond • Sterling • Stone Ridge • Winchester • Woodbridge

Neurofibromatosis, Inc.-Mid Atlantic "Dining for Dollars" Fundraiser
A Great-Tasting Fundraising Event!

June 1 – September 30, 2007 *Sunday – Thursday Only, 11:30 AM – 11 PM*
Glory Days Grill in Your Neighborhood

When you dine at a Glory Days Grill on Sunday, Monday, Tuesday, Wednesday, and Thursday, the restaurant will contribute 10% of your total food purchases to *Neurofibromatosis Mid-Atlantic*.

Bring your neighbors, friends, and relatives, because the 10% applies to the total food bill.

Simply ask your servers for a copy of your guest check (not credit card receipt), and mail it to:

David Dobson, NF, Inc.-Mid-Atlantic, 8855 Annapolis Road #110, Lanham, MD 20706.

Questions? Call David at 410-828-4138 or email: nfmidatlantic@aol.com.

Not combinable with any other promotions, offers or discounts. This 10% donation cannot apply to sales tax, alcoholic beverages, or to any guest check that receives any other type of discount, coupon, offer or promotion. See Fundraiser Rules for full details.

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, Doug Albrecht	(540) 786-7020
Member-at-Large, Joe Billings	(301) 860-1011
Member-at-Large, David Dobson	(410) 828-4138
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	(202) 479-2494

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
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NF
June 2007

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