



Neurofibromatosis, Inc.

MID-ATLANTIC

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 February 2006

\$17 Million for NF Research

The Fiscal Year 2006 Department of Defense Appropriations Act authorized \$17 million for the Neurofibromatosis Research Program.

We especially want to express our appreciation to our champions in Congress who made this consistent avenue of funding NF research possible: *Congressman John Murtha (PA), U.S. Senators Tom Harkin (IA), Ted Stevens (AK), Daniel Inouye (HI), Congressmen Bill Young (FL), Jerry Lewis (CA), C.A. "Dutch" Ruppersburger (MD), Chris Van Hollen, Jr. (MD), Rush Holt (NJ), Donald Payne (NJ), Bill Pascrell (NJ), Senator Frank Lautenberg (NJ). We also thank all of the other Congressmen and Congresswomen and U.S. Senators who signed "Dear Colleague" letters encouraging their colleagues to support NF research and all who voted for the appropriation.*

Short summaries of the research accomplishments from the NF Research Program are posted on the Congressionally Directed Mandated Research Program (CDMRP) website under "Highlights." <http://cdmrp.army.mil>



ATTENTION RESEARCHERS: A New Funding Opportunity

The Investigator Initiated Research Award can receive up to \$1.4 million for a term of four years to focus on NF or Schwannomatosis basic and clinical research. **Deadline is March 14, 2006.**

For details, visit the CDMRP website: <http://cdmrp.army.mil> then click on neurofibromatosis.

NF Mid-Atlantic Receives Challenge Grant

A \$7,000 grant has been received from the E.C. Wareheim Foundation as a challenge to raise another \$7,000 in new money during 2006 for the NF Mid-Atlantic Outreach Program.

The Outreach Program consists of activities to inform families affected by NF and the health and education professionals who provide services for them. Conducting informational meetings with a realtime captioner, exhibiting, publishing newsletters and other educational materials, the new website and Camp New Friends are all components of the Program. Since NF can strike any family, informing the general public is an added component.

- Give what you can – any amount is appreciated.
- Solicit from your family, friends, associates, corporate and foundation contacts.
- Your donation is doubled in value.
- Your donation helps to expand NF activities in the Mid-Atlantic area.
- Send your donation to: Challenge Grant, 8855 Annapolis Road #110, Lanham, MD 20706-2924.
- Remember, you can make a donation on our website at www.nfmidatlantic.org
- THANK YOU.

2006 Camp New Friends



Camp New Friends is a specialty camp for children with NF1 and with NF2 from 7 to 15 years of age. It is sponsored by Children's National Medical Center in Washington, D.C. in collaboration with Neurofibromatosis, Inc. This is the third year the camp has been conducted. Camp New Friends is being held July 16-22, 2006 at the Bishop Claggett Center in Buckeystown, Maryland. Campers participate and choose from activities including hiking, arts and crafts, canoeing, sports, a low and high ropes course, camp

Olympics, swimming, yoga and drama. Support groups and educational programs promote knowledge, skill development and social connections. At Camp New Friends, children and teens gain a better understanding of their condition, strengths, and self-worth. They share the experience of being part of a team, learning, and having fun in a safe, exciting and supportive environment. *The cost is \$650 per camper which includes the \$100 registration fee. For more information, call Sandy Weinstein, PT, LCSW-C, Director of Children's Camps of the Department of Neurology, Children's National Medical Center at 202-884-5142 or email with your complete contact information to sandyweinstein@cnmc.org*

Much thanks for all donations given through the workplace campaigns, the Redskins Yards for Youth, and our 2005 Annual Appeal.

See our list on page 5.

WEBSITE: www.nfmidatlantic.org

Notes from Bev

Thank you to everyone who helped out last year – 2005. We also want to thank the M. Leo Storch Management Corporation for donating a Sharp copier to us and Best Buy in Bowie, Md for donating \$100 toward a new computer for the office.

We have a lot of interesting things in the works for this year. Among them are our first golf tournament, an art show of illustrators of children's books, and a tribute of Dr. Susan Panny who has been on our Professional Advisory Board for many years. Please check the Calendar of Events and mark your calendar to participate in as many of our activities this year as you can. If you can help in any way with the fundraisers, please call the NF office toll free at 1-866-261- 1271.

Also Camp New Friends is moving to the mountains this year. Remember, you can donate to the NF Mid-Atlantic Camp Fund at any time.

Keep in mind your donation dollars will be doubled this year, thanks to the E.C. Wareheim Foundation Challenge Grant. Happy New Year!

Bev

Here's How You Can Help!

Volunteers are needed to help with many of these special events this year.

- Assist at the events
- Obtain silent auction items: trips, time share weeks, vacation weeks at personally owned resort property, artwork, jewelry, liquor and wine, restaurant and other gift certificates and services such as landscaping, plumbing, construction, housecleaning, etc.
- Engage members of the clubs you belong to in supporting NF activities.
- Pass on leads for new fundraisers, grants or donations.

Call the NF office if you can help 1-866-261-1271 or email: nfmidatlantic@aol.com.

Welcome 2006-2007 Board of Trustees

We are grateful to these men and women who have promoted NF and our organization and generated financial support for NF activities in our area. They have already agreed to take on even more responsibility this year. You will be hearing more from them in the coming weeks!

Diane Bark, owner of DNB Financial Services, Inc. in Baltimore, is the Chair of the Tribute to Dr. Panny.

Jim Daniel from Lusby, Md is Chair of our 1st Golf Tournament in September.

Shari Devlin, owner of Merino, Inc. in Severna Park, Md, raised considerable funds for NF with Matthew Freeman at the Shipley Elementary School year-end charity activities in May 2005.

NF Presentation to Georgetown Med Students

On January 13, 2006 Mary Ann Wilson participated on a consumer panel which discussed various aspects of living with a genetic disorder in the family. More than 100 first year med students and faculty attended the hour and a half session. Mary Ann talked about being a mother and a grandmother of individuals with NF1, as well as working with a support group and its partnership with the medical and research communities. Thanks to Elizabeth Kramer, M.S. a genetic counselor at Georgetown Hospital in Washington, DC and an alumnae of the Genetic Alliance, for including NF on the panel.

Meet Our New Board Members

Doug Albrecht is pictured at the 2005 Italian Night for NF telling about his experience as a counselor at Camp New Friends. Doug is Chief of the Training Division of the Spotsylvania County Fire Department and has family members with NF1.



Joe Billings is an attorney who heads his own firm in Bowie, Maryland. He has served as a Board member and officer of Neurofibromatosis, Inc.



NF Exhibits at the 46th Annual Convention of PACEC



Mary Ann Wilson is explaining NF to Sue Haney of Scientific Learning Fast ForWord of Pittsburgh whose niece had just been diagnosed with NF1.

The annual convention of the Pennsylvania Association Council for Exceptional Children provided training and certification for special educators in Pennsylvania. Mary Ann and her husband Chuck spent November 3-4, 2005 at the conference in Hershey, PA talking with teachers and student teachers in Special Ed about NF.

Teddy Bears for NF at NIH



Victoria and her mother Laura from Charlotte, NC just arrived at the Children's Inn at the National Institutes of Health where Victoria is a participant in an NF research protocol to slow or stop the grow of tumors. She received a Teddy Bear from the collection provided to NF Mid-Atlantic by Gillian

Anderson fans. If you know of a child with NF going into a hospital in the Washington, DC/ Baltimore area, please call the NF office at 301-577-8984 so he/she can also receive a Teddy Bear.

Participate in NF Research

Quantitative Phenotyping and Genotype-Phenotype Correlations in NF1 is a study aimed at identifying some of the genes that may influence the number of neurofibromas (tumors) a person with NF1 might develop. Adults 19 years and older who have been diagnosed with NF1 may be eligible for this study. Participants need to have an affected parent or sibling (other family members do not need to participate in this study). The principal investigator is Bruce Korf, M.D., Ph.D. at the University of Alabama-Birmingham. The study is funded by the NIH National Institute of Neurological Disorders and Stroke. **For more information, individuals and physicians are to contact Bambi Burns, BSN, RN toll free at 1-866-822-4362 or email bburns@genetics.uab.edu**

Early Identification of Cognitive Deficits in Children with NF1 is a study designed to learn more about how the brain works in infants and pre-school children with NF1. Children with NF1 less than 40 months of age may be eligible for participation. The participants will undergo regular developmental and/or neuropsychological testing over the course of 4 years. The results of the child's routine MRI scans will be included in the study. All developmental and/or neuropsychological testing will be free of charge. There are no costs for the research study and parking at the Children's National Medical Center, 111 Michigan Avenue, NW, Washington, DC 20010 is free. Families will be paid for their participation. The principal investigator of this study is Maria Acosta, M.D. This study is funded by the Department of Defense. **For more information, contact Leah Seldin-Sommer at 202-884-4236 or Dr. Acosta at macosta@cnmc.org**

NF2 Resources



www.nf2crew.org

**NF2
Advocure**
advocates for a cure

Advocure is a working advocacy group for the NF2 Crew. It is an international coalition committed to ensuring the rapid translation of the recent advances in our understanding of NF tumorigenesis and signal transduction into targeted therapy for the NF community. They monitor relevant research and drug developments world-wide and lobby to achieve their goal of expediting much-needed systemic therapy for this devastating disorder of the central nervous system. **For more information, write Advocure, P.O. Box 1273, McMurray, PA 15317 or email at contact@advocurenf2.org or visit their website at <http://advocurenf2.org/>**

New Online NF2 Support Group For Under 25 Years

This online support group is ONLY for individuals with NF2 25 years and younger. Membership has to be approved by the moderator of the group and the group is closed and private like the NF2 Crew support group. The address is http://health.groups.yahoo.com/group/NF2_Under25/ then click on the "join this group" button.

Professional Advisory Board Members & Volunteers



Robert Murray, M.D. of Howard University Medical School and Susan Panny, M.D., Chief of the Office for Genetics and Children with Special Needs, both members of the NF Mid-Atlantic Professional Advisory Board are flanked by Megan Skinner and Ania

White, University of Maryland genetic counseling students who have been working with the organization during the 2004-2006 academic years. Dr. Murray made a special presentation at the Maryland Advisory Council on Hereditary and Congenital Disorders at its November 2005 meeting.

Call for NF Research Proposals

Neurofibromatosis, Inc.-Mid-Atlantic is requesting proposals for research projects in neurofibromatosis (NF1 or NF2) which are initiated by investigators from the Mid-Atlantic area (Delaware, District of Columbia, Maryland, New Jersey, Pennsylvania, Virginia, West Virginia, North Carolina). The research must lead to a better understanding of the cause, treatment or prevention of NF or enhance the quality of life of those with NF1 or NF2.

Amount: up to \$30,000
Period: 1 to 2 years
Deadline: July 1, 2006

For an application, please call the NF, Inc.-Mid-Atlantic office at 301-577-8984 or email: nfmidatlantic@aol.com. A fax may be sent to 301-577-0016 or a letter addressed to NF Research Committee, NF, Inc.-Mid-Atlantic, 8855 Annapolis Road #110, Lanham, MD 20706-2924.

COMMENTS:

- The Board of Directors strongly encourages the principal investigator to include consumer input in planning the research project.
- Enclose with the application, a one-page abstract.
- Enclose a lay abstract of the project.
- Enclose a curriculum vitae of the principal investigator and the names of other investigators working on the project.
- Enclose a budget. No indirect costs will be funded.
- Enclose other sources of funding for this project.
- The proposals will be peer-reviewed.
- The NF, Inc.-Mid-Atlantic Board of Directors will make the award to the principal investigator's institution in September 2006.

6th Annual "Italian Night for NF"



Ilana Kowarski sang for the audience and was given a bouquet of roses by her uncle, Paul Mendelsohn, who is on the NF, Inc.-Mid-Atlantic Professional Advisory Board.



The silent auction's election was bigger and better than in previous years.



Jim Daniel, a member of the NF, Inc.-Mid-Atlantic Board of Trustees, was the auctioneer for the evening and brought in the biggest proceeds for the NF Camp Fund than ever before. Ricky Dobson, a counselor at Camp New Friends, got a good deal and fellow camp counselor Jenny Hill looked on.

Everyone had a great time with plenty to eat, renewed friendships, and helping a significant program that will benefit children with NF for many years.



Sandy Cushner-Weinstein, PT, LCSW-C from Children's National Medical Center, Washington, DC and Director of

Camp New Friends, announced the plans for the upcoming 2006 NF camp. Introduced were Ania White, a genetic counseling student at the University of Maryland, and Rose Storaska, a high school teacher in Stafford County, VA who were counselors at the 2005 camp. Jennifer Janusz, Ph.D. conducted the NF research at the camp and Debbie Copenhaver, M.S. of Children's National Medical Center, was the genetic counselor.



The big winners of the raffles were Joylene Kuhn and Matthew Freeman.

Beverly Dobson, President of NF, Inc.-Mid-Atlantic, was the emcee for the successful event in Baltimore held November 12, 2005 to benefit Camp New Friends.



**Our Special Thanks for Making
2005 Italian Night for NF Possible**

*Diane Bark
Jim Daniel
Beverly Dobson
Penny Freeman
Joe Waynick
Sandy Weinstein*

American Visionary Art Museum, Baltimore
Annapolis Symphony Orchestra, Annapolis, Md
Baltimore Orioles
Baltimore Ravens

Baltimore Symphony Orchestra
Diane Bark
Jerry Bark

Benjamin Carson, MD
CenterStage, Baltimore

Jim & Judy Daniel
Dave & Busters
Shari Devlin
Karen Kuhn

Beverly Dobson
DSW Shoes

Estate of David Abelow
Mary Louise Kolb

L.A. Designs, Baltimore
Allene Lyons

Marketpro Show
Medieval Times

National Aquarium, Baltimore
Patrick's Restaurant, Cockeysville, Md
Megan Skinner

Southwest Airlines

Sports Legends Museum at Camden Yards, Baltimore
Sterling Caterers, Baltimore

Tri-County Hearth & Patio, Waldorf, Md

Tydings & Rosenberg, Baltimore
Melissa Walden

Joe Waynick
Ania White

Williamsburg Inn, White Marsh, Md

Mary Ann Wilson
Windsor Peak Press
Workman Publishing

**& Everyone Who Made a Donation
& Everyone Who Attended the Event**

Thanks For Your Generous Support

Through the workplace campaigns



Through the Redskins Yards for Youth



Through our 2005 Annual Appeal

The following people made donations in honor of loved ones to support the NF Mid-Atlantic educational activities for NF families and professionals, the website, and support activities:

In Honor of

Thaddeus Clark
The Dobsons
Derick Forney
Matthew Freeman

Michael Glasscock, MD
Stephen C. Hemler
Jeffrey Kummeth
Kathie Lee
Stanley C. Lumb
James Porter, Jr.
Terra L. Sherrer
Evan Schneider

In Memory of

John Ahern
Antaine Apaucio
John Chambers
Fritz Cramer
Wes Fox
Charles A. Jacobson
Gertrude B. Mendelsohn
Sherry Tinsman

Contributor

Eleanor C. Clark
Berniece I. McMullan
Edgar & Lois Forney
Elspeth Feldman
Mary Lynn Fisher
Katherine Roth
John Woodman
Craig & Kathy Hemler
The Kummeth Family
Linda Ryan
Elizabeth A. Lumb
Robyn Porter
John & Bonnie Abbott
Sherrill Canobbio

Contributor

Michael Ahern
June Sweeney
John Woodman
John Woodman
Mildred Fox
Jeff Pardo
Helen Mendelsohn
Charruth Tinsman

HONORING LOVED ONES

We want to express our sincere gratitude to the following individuals who have honored a loved one by making a donation to the NF research activities of NF Mid-Atlantic through January 2006.

In honor of...

Dawn Boyer
Robert Burge
Arlene Der
Claire Faben
Paula Jaeger Fanusn
Elaine Gates
Elizabeth Kalinich
Jeffrey Robert Kummeth
Vivian McEady Lindsey
Kyle & Greg Mills
Nathaniel O'Dell
Samuel Pauken
James Porter

Camille K. Simonetti
Diedra Maher Stabler
Mary Ann Wilson

Contributor

Lori Boyer
Ada Burge
David & Brenda Pauken
Gerry Jacobs
Judy Thompson
Judy Thompson
Marion J. Stickle
Greg & Jean Kummeth
VM Lindsey
Ruby E. Barkhimer
Chuck & Dabney O'Dell
David & Brenda Pauken
Robyn Porter
Robert Williamson
Ron & Jennifer Simonetti
Frances J. Maher
Susan Stine, M.D.

In Memory of

Ruth S. Adoff
Barbara Acors Coleman

Ralph Faulkner
Helen Mendelsohn
Beverly C. Myatt
Miriam Schloss
Robert Schloss

Contributor

Faith Steinberg
Virginia & William Motley, Jr.
Minnie Reeve
Gina M. Mauldin
Faith Steinberg
Ernest G. Myatt
Faith Steinberg
Faith Steinberg

During 2005, the Charles O'Dell Family and the George L. Shields Foundation made donations of \$1,000 and more to the NF Mid-Atlantic Research Fund. Their names are engraved on the plaque in the NF office. We are very grateful for their continued generous contributions to find better treatments for NF and hopefully a cure.

Calendar of Events*

February 23, 2006	Maryland Advisory Council on Hereditary & Congenital Disorders, 201 West Preston Street, Room L-1, Baltimore, 6:00 pm
March 14, 2006	DEADLINE for Army Grant
March 30, 2006	Maryland Advisory Council on Hereditary & Congenital Disorders, Baltimore, 6:00 pm
March - June 2006	Booz Allen Birdies for Charity
April 20, 2006	Maryland Advisory Council on Hereditary & Congenital Disorders, Baltimore, 6:00 pm
April 22-23, 2006	NF Exhibit at NBC 10 FitFest, Pennsylvania Convention Center, Philadelphia, PA
MAY IS NF AWARENESS MONTH	
May 1-31, 2006	NF Walk/Run (nonevent fundraiser)
May 9, 2006	“NF Night at BJ’s” BJ Pumpernickel’s Deli, Olney, Md 5-9pm
May 18, 2006	Maryland Advisory Council on Hereditary & Congenital Disorders, Baltimore, 6:00 pm
May 20, 2006	NF Informational Meeting, Germanna Community College, Fredericksburg, VA
July 1, 2006	DEADLINE for NF Mid-Atlantic Grant Proposals
July 16-22, 2006	Camp New Friends, Bishop Claggett Center, Buckeystown, Md
September 8, 2006	1st NF Golf Tournament, Chesapeake Hill Golf Club, Lusby, Md
September 14-October 12	“Dine for Charity,” Seibel’s Restaurant, Burtonsville, Md
September 17, 2006	Tribute to Susan Panny, MD, Baltimore
October 19, 2006 (tentative)	Arts for Healing Children Event, National Press Club, Washington, DC
October 26, 2006 (tentative)	Arts for Healing Children Event, Philadelphia, PA Area
November 11, 2006	7th Annual Italian Night for NF to benefit Camp New Friends, Baltimore 7:00 pm
November/December 2006	Annual Appeal

*Items in bold are fundraisers.

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, Walt Sanders	(703) 642-0849
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, Peter Childs	(301) 650-5926
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
Spanish Consultant, Susana Escola	(410) 821-7453

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.

REMEMBER – Dues can be paid at any time.

RETURN SERVICE REQUESTED

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

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