



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: info@nfmidatlantic.org www.nfmidatlantic.org **October 2008**

NEW EXECUTIVE DIRECTOR



Barbra Levin, M.A., M.P.H.

The Neurofibromatosis, Inc.-Mid-Atlantic Board of Directors is pleased to announce the appointment of Barbra Levin, M.A., M.P.H. as the new Executive Director. This announcement signals the effort of NF, Inc.-Mid-Atlantic to expand and promote its services in the entire Mid-Atlantic region.

No stranger to the nonprofit sector, Ms. Levin has a background of working with health-related support and service organiza-

tions. She has held executive positions with the Sidran Institute, Baltimore Community Foundation, the Stulman Foundation, Baltimore REACH, Sunrise Community Health Center in Colorado, Jewish Vocational Services of Chicago and Refugee and Immigrant Health Services for Cook County, Illinois Department of Public Health. She specializes in management, board, and fund development.

A native of Illinois, Barbra began her professional career as a Peace Corps Volunteer in Thailand. She holds a B.A. from Goucher College, A Master's Degree from the University of Chicago and a Masters in Public Health from Harvard University.

"We are delighted that Barbra has chosen to work with our organization to take us to the next level of expanding our services in the Neurofibromatosis Community and educating the public about NF." Said Beverly Dobson, President of NF, Inc.-Mid-Atlantic.

Support 2009 Camp New Friends at 9th Annual **"Italian Night for NF"** November 15, 2008

Everybody come out to "Italian Night for NF" to benefit 2009 Camp New Friends, have a great Italian buffet dinner, great bargains in the silent auction, AND GREAT FUN.

The festivities begin at 7:00 pm at the Lantern Gardens, 7830 Philadelphia Road (Route 7), Baltimore, MD 21237.

Adults are \$35 and children 12 years and under are \$15.

The silent auction has a kids section, as it did last year.

The Bake Table proved to be such a hit last year that we are having a bigger one this year! Be sure and call Bev Dobson before

November 12th about the items you are donating 410-828-4138.

New this year is the "Change Jar." Be collecting your loose change and bring to the event. Help to make this fundraiser for camp bigger and better than last year! Mail in the enclosed ticket order form with your check or purchase tickets with a credit card and then fax the form to 301-577-0016 or call toll free 1-866-261-1271. See you there!

Neurofibromatosis Symposium*

"NF: Now & In the Future"

Saturday October 25, 2008

8:30 am – 4:30 pm

**Hershey Medical Center
Conference Center at
University Fitness Facility
Hershey, PA 17033**

"NF1, NF2, and Schwannomatosis"

Roger L. Ladda, M.D.

Department of Pediatrics/Genetics
Penn State Hershey Children's Hospital

"Removal of Small Tumors"

Rogério Neves, M.D., Ph.D.

Associate Professor of Plastic Surgery &
Dermatology
Penn State Hershey Medical Center

"Peripheral Nerve Tumors"

Kimberly Harbaugh, M.D.

Associate Professor of Neurosurgery
Penn State Hershey Medical Center

"NF Research at the National Institutes of Health"

Douglas Stewart, M.D.

National Human Genome Research Institute, NIH
Bethesda, MD

"Learning Disabilities and NF1"

Elana Farace, Ph.D.

Professor of Clinical Neuro-Psychology
Penn State Hershey Medical Center

"How to Make the Most of Your Health Insurance"

Paul Mendelsohn

Professional Advisory Board
Neurofibromatosis, Inc.-Mid-Atlantic

*A realtime captionist will be present for the hearing impaired. There is free parking. A registration fee of \$20 covers lunch and meeting materials. A limited number of scholarships is available. Contact the NF office at 1-866-261-1271 (toll free).

Notes from Bev

Hi, Friends!

Our big news this month is our new Executive Director, Barbra Levin. You will be reading more about her later. We are confident she will be a great addition to our NF Family. Please make her feel welcome when you talk to her.

I just want to express our sincere thanks to all of the people who made the 2nd NF Swim-a-thon such an overwhelming success this year. The Shipley's Choice Swim Club in Millersville, Maryland and Stacie Glover of Chestertown, Maryland engaged their entire communities in support of our local NF activities.

Remember there is still time to register for our October 25th meeting at the Hershey Medical Center. You can call the NF office toll free at 1-866-261-1271. Remember also that Run4NF in the Philadelphia Marathon is coming up November 23rd.

This is the last newsletter before our annual "Italian Night for NF" in Baltimore on November 15, 2008 to benefit the 2009 Camp New Friends. Please send for your tickets and let us know if you are bringing baked goods and what you are bringing for the Bake Table. You can call me at 410-828-4138. We encourage you to support the event as the camp fee is going up in 2009 and we don't want anyone to be left out!

For those of you who can, please designate NF, Inc.-Mid-Atlantic in your workplace charity campaign. Mary Ann Wilson and Peter Childs have been providing NF materials at several of the campaign kickoffs in Maryland.

Our 2008 "Make A Difference Award" goes to Max Bark's teachers at The Weinberg Academy in Baltimore. The Award will be presented at "Italian Night." Looking forward to seeing you there or at the NF Symposium in Hershey October 25th.

Bev

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, Inc.-Mid-Atlantic through September 30, 2008.

In Honor of...	Contributor
Claire Faben	Beverly Faben
Kelsey Garner	LTC Clay & Cheryl Garner
Ana Kurland	Ieda Siqueira Wiarda
James Porter	Robert & Hope Williamson
Mark Tomlinson	Mark & Elizabeth Tomlinson
Shannon Yandell	Sara McMahan Yandell
In Memory of...	Contributor
Claire Cohen	Diane Bark
Tim Davias	Jeanette I. Davias
Samuel Mussoff	Diane Bark



2009 CAMP NEW FRIENDS

A Place Where Everybody Knows Your Name, And Worries Are All The Same"

"For most of my life I was made fun of, teased and degraded. When I came to Camp New Friends, for the first time I felt like I was at home. The fact that I have NF ceased to be a fact in my life. For once, I was normal. Everyone there was willing to be my friend." So says Niall Covington, 21 years old, Eagle Scout, College Student, 5-year veteran of Camp New Friends and 2008 Camp Counselor.

Camp New Friends provides such great opportunities to learn new skills, meet new friends and just have fun. No child with NF who wants to attend should be denied this life-changing experience. However, beginning this 6th year of conducting Camp New Friends in Buckeystown, Maryland, Children's National Medical Center is having to raise the camp fee to \$750 per camper for the week. This increase is necessary to continue providing the quality of activities and expert staff that have been characteristic of the camp for the past 5 years.

Campers, start saving your money now to make sure you have enough to attend camp July 12-18, 2009. You can start doing odd jobs, contacting service clubs such as the Rotary, Lions or Kiwanis clubs in your town, have your parents contact your state department of health respite program or the Developmental Disabilities Council about sponsoring you at camp next summer.

NF, Inc.-Mid-Atlantic provided 15 camperships last year. Help us increase that number in 2009 by attending "Italian Night for NF" November 15th or sending a donation to the NF Camp Fund, 8855 Annapolis Road #110, Lanham, MD 20706-2924. The Community Foundation of Frederick, Maryland by the direction of Jeff Robertson and Charles Cashour has already made the first donation to the 2009 Camp New Friends. Any amount is welcome and is a truly an investment in the lives of our young people with NF.

Double Your Donation to NF Mid-Atlantic!

During this past year, the following corporations have matched an employee's donation to NF, Inc.-Mid-Atlantic: *Abbott Laboratories, Choice International Hotels, Scitor Corporation, Verizon, Wachovia Bank.* Participate in your employer's Matching Program and double your contribution to assist individuals and families affected by neurofibromatosis. THANKS!

Helpful Resources

New Webpage to Help Caregivers

A wealth of information to help caregivers navigate Medicare, compare drug plans, get in-home services, obtain financial help and a Caregiving Exchange are found at www.medicare.gov/caregivers/

"Talking With Your Doctor" is an 18-minute video that teaches teens how to communicate effectively with healthcare providers. Teens will also learn how to prepare and give information to healthcare providers that will help them get the best possible medical care. The video was produced by the Institute for Child Health Policy at the University of Florida. To view the video visit their website at <http://video.ichp.ufl.edu/twyd.php>.

The League for Crippled Children, Inc. is a private nonprofit organization in Cumberland, Maryland that provides free clinics in orthopedics, orofacial, speech/language, physical therapy for children birth to 21 years of age in →

2nd Annual NF Shipley's Choice Swim-a-thon Breaks Records!



Penny Freeman, NF, Inc. Secretary/Treasurer at NF Exhibit



Registration Table with Severna Park High School Volunteers



Matthew Freeman, the 9-year-old inspiration of the event, with his friends and Rod McCullum, co-chairman of the event, as he finishes his 111 laps breaking his last year's record.



Shari Devlin, Member of the Shipley's Choice Swim Club and of the NF, Inc.-Mid-Atlantic Board of Trustees, presented Matthew with a \$6,600 check being the largest single sponsor.



Champion Swimmer Tony Marchetti who swam 601 laps this year breaking his last year's record pictured with young swimmers and Camp New Friends campers Maddie Gorham, Travis Glover and Matthew Freeman

In the 12-hour event held on Labor Day Weekend 14,511 laps were logged and nearly \$20,000 were raised which doubled last year's proceeds. The Annapolis Capital featured an article about the swim-a-thon with pictures on September 4th and The Severna Park Voice published an article with a picture of Matthew Freeman with the principal of his school on September 11th.

Special Thanks...

Swim-a-thon Organizing Committee: Lynn Harmeyer (PR and photos), Rod McCullum, Tammy Turner, Ann Jobmann, Susan Koussouris, Shari Devlin, Melissa McCullum and Penny Freeman

Sponsorships: Dawson's Liquors, Long Fence, Kendall Miller, D.D.S, Seaway Coatings

Multiple Sponsors: Dave Fredriksson, Stacie Glover, The Killpatrick Family, Tony Marchetti, Charlie Markham, The Toth Family

All 120 swimmers, all donors, the Shipley's Choice Swim Club and the entire Millersville, Maryland community.



Shipley's Choice NF Swim-a-thon Committee



Stacie Glover, Member of the NF, Inc.-Mid-Atlantic Board of Trustees, swam 42 laps in honor of her son, Travis. She raised \$2,286 in sponsorships.

Maryland, West Virginia and Pennsylvania. The League also provides financial assistance to families traveling to appointments and surgery. The assistance includes lodging, transportation and food. Properly fitting shoes, medical supplies and special devices and equipment including crutches, braces and wheelchairs are also purchased as necessary for the children.

For more information, call 301-758-5200 or email

leagueforcrippledchildren@yahoo.com.

Parents' Guide to Learning Disabilities associated with NF1 booklet is available at no cost to NF families, thanks to the Katie Ridder Memorial Fund. To obtain a single copy, call NF, Inc.-Mid-Atlantic at 1-866-261-1271 or email info@nfmidatlantic.org.

Calendar of Events*

October 25, 2008	NF Symposium, Hershey Medical Center, PA 8:30 am
November 2008	Annual Appeal
November 12-14, 2008	NF Exhibit American Society of Human Genetics, Philadelphia
November 14, 2008	Whalen Dinner/Dance, Telford, PA
November 15, 2008	9th Annual Italian Night for NF, Baltimore 7:00 pm
November 23, 2008	Philadelphia Marathon, www.run4nf.org
March 22, 2009	Shamrock Marathon, Virginia Beach, VA

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

NF Research Receives \$10 Million – More than Last Year!



Many thanks to Members of the U.S. Congress who supported the \$10 Million for FY2009 for the Department of Defense NF Research Program administered by the Department of Army! Our champions are Congressmen John Murtha (PA), Bill Young (FL), John Carter (TX), Luis Gutierrez (IL), Peter Roskam (IL) and Senators Tom Harkin (IA) and Daniel Inouye (HI). *NF Community, write letters to our champions in Congress and to your state's Congressmen and Senators for supporting NF research and investing in our young people's future.*

Give to Neurofibromatosis, Inc.-Mid-Atlantic In Your Workplace Charity Campaigns



Please continue to support local NF families by designating your donation to Neurofibromatosis, Inc.-Mid-Atlantic and encourage your friends, family and colleagues to also designate our local NF organization.

Combined Federal Campaign permanent #51268
Maryland Charities #1235
United Way of the National Capital Area #8851

THANKS!

Support NF

Run in
Philadelphia
Marathon
November 23,
2008

Contact Debbi
Hanlon:
debbi@run4nf.org

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
Program 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.

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