

**NFCA**  
Neurofibromatosis Clinics Association  
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## 14th Annual NFWalk

With a chill in the air and coffee waiting, the 14th Annual NFWalk – **the Walk in the Wild** – was held at the Pittsburgh Zoo and PPG Aquarium on April 8, 2008. Quite a new look was sported by our walkers, clad in delightfully grrrrreat artwork by Mark Bender. Dressed in lions and tigers and bears: Oh, my! – the walkers meandered through the zoo, attempting to site all the animals big and small. Many were able to catch the polar bears taking an early swim, quite an awesome scene.

The wrap up was held back at the tent with the formal raffle – hey, who won those Steeler tickets? – and an extra drawing. Face painters and airbrush artists added their colorful designs to those desiring the temporary “tattoos” and AGAIN we were entertained by Franco Ledonne & Co., DJ and singer extraordinaire!

The 15th Annual Walk will again be a **Walk in the Wild**. Please plan to join in on the fun on April 25, 2009, registration 8:00 AM



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**15th Annual  
5K Walk in the Wild!  
for Neurofibromatosis**  
Saturday, April 25, 2009  
Pittsburgh Zoo and PPG Aquarium

*Dr. Kathy Gardner, Cornell McMullin, Founder & NFCA President (Ex-Officio) and Sinikka Davis, MSW*



# \$\$\$\$\$\$ MARCH TO A MILLION \$\$\$\$\$\$

Friday evening, October 10, was buzzing with excitement as guests participated in the **SECOND NEUROFIBROMATOSIS WINE TASTING AND AUCTION FUNDRAISER** held at Oakmont Country Club. Baskets galore adorned in numerous themes from exercise equipment, toys, entertainment, sports memorabilia, animal treats to holiday goodies filled the silent auction tables. While the live auction showcased private wine tasting in your home, golf at Muirfield Village Golf Club, bidding on luxury boxes for the Steelers and Pirates as well as a fabulous New York weekend to mention a few. You could even win a Rolex watch if your lucky key opened the Treasure Chest!

As many supporters exclaimed, it was a spectacular evening for wine tasting with great hors d'oeuvres and fabulous desserts stationed throughout the Club.

Under the direction of Lorna Irvin, the NF Challenge, which first began as a golf event over 12 years ago, raises money to support the salary of a social worker who serves as the most important link to the families who live with NF. This year's Challenge proved to be no exception.

The Pittsburgh community once again rose to the occasion and with the support of sponsors, auction donors, advertisers, the NF Challenge Volunteer Committee and

the wonderful attendees, the NF Challenge – **"March to a Million" grossed over \$78,000!**

## Definitely a reason to give thanks this season Congratulations Everyone!

Thanks to NF Challenge Director Lorna Irvin and the committee:

Ruth Alley	Barbara Marx
Kristin Bashforth	Shirley McElhinney
Patricia Bellows	Gerry Michanowicz
Ann Buechli	Lee Murphy
Sally Chontos	Lyn Null
M. A. Cooper	Nancy Pennell
Joan Dudreck	Shirley Phillis
Connie Fitzgerald	Diane Randolph
Mary Helen Fuhrer	Sallie Royston
Phyllis C. Hewitt	Donna J. Schano
Mitzi Hofmann	Nancy Succop
Sharon Jaynes	Patricia D. Thompson
Arlene Kaufman	Joyce Trew
Rebecca P. Keevican	Ann Vanzant
Adrienne Lear	Isabella Wagner

## Changing of the Guard

The NFCA Board of Directors is pleased to announce recently elected officers:

- > Mehran Arbab, Ph.D., President
- > Patrick Kane, Vice President.

Mehran replaces Lorna Irvin and Patrick fills an office which was vacant.

Pat has been a member of the board for 6 years. He is the Chief Investor Relations Officer, with Equitable Resources.

Mehran has been a member of the board for over 4 years. He is the Director of Glass Science & Technology at PPG Industries, Inc.

Sincere thanks to Lorna for serving as President. She will continue to serve on the Board of Directors.

Welcome gentlemen to your new positions. We know your leadership will be of benefit to the NFCA.

## Rusty Dory Pub Fundraiser

JoAnne Teti, Owner and DJ Mary held a Karaoke/Gong show night, the proceeds of \$140 donated to NFCA by the Patrons in the name of customer and friend, Amy Grundler. THANK YOU JoAnne and DJ Mary! How special you are to celebrate your friend!

## The Gift Wrap Chairladies

Shirley, Sarita, and Zondra, chairladies of a Gift Wrap Committee and friends of NFCA active volunteer Patty Schneider, included the NFCA in their list of charities last holiday season. One hundred dollars of the money they raised at the Holiday Gift Wrap Booth at Monroeville Mall was donated to the NFCA. We know you have many organizations which are dear to your hearts. THANK YOU for including the NFCA!

## 1st Annual M/C's Tiny Turkey Trot

There was running, skipping, hopping, galloping and, of course, WADDLING on November 21st and 22nd for this event sponsored by Son-Shine Preschool, Mercer United Methodist Church.

Edie Krofcheck worked with sons Miles Krofcheck and Curtis Esquibel to develop this event. Miles is a student at Son-Shine and Curtis is a scholarship student at Theil College. Being unable to attend Pittsburgh fundraisers regularly, they have been "scratching" their heads for an idea on an event to hold in their area: Mercer, PA. They created the 1st annual M/C Tiny Turkey Trot and successfully raised in excess of \$400.

**GREAT JOB!!!!!!!!!!!!!!!**



## Sandy Koluder Volunteers at Sam's Club

Sandy is a great friend of NF due to her daughter Danielle's diagnosis years ago. The good news: Danielle is doing SUPER and Sandy participated in a Sam's Club volunteer program, earning and donating \$250 to the NFCA. We are so grateful that people as busy as they can make TIME to GIVE to others. GREAT job Sandy and Danielle!

## Join us in support of Pitt Women's Basketball

**ENJOY WINTER GET OUT AND JOIN the NFCA OUTING ON January 10: Pitt Women vs DePaul 2PM start, Petersen Event Center, Oakland**

Why? Because in the words of the University of Pittsburgh: "Coach Agnus Berenato has been exactly what the University of Pittsburgh and the Pittsburgh community needed.

In just five seasons, she has taken a Panther team from complete anonymity and turned them into a program that is not just winning, it is making a nation-wide impact. In 2007-08, Pitt became just the 10th school in the last 20 years to advance to the Sweet 16 in just its second ever appearance in the NCAA Tournament.

Also last season, the team tied the school record for wins in a season with 24, reached the semifinals of the Big East Tournament by defeating No. 9 Notre Dame, and received a No. 6 seed in the NCAA Tournament.

Berenato's impact on the program has reached far beyond the court and the win/loss column, however, as she has put Pitt women's basketball on the map.

Last season, Pitt was on national, regional or local television 18 times and received unprecedented coverage on the national scene. The Panthers earned their highest-ever ranking in the top 25 polls with a No. 14 Associated Press mark and No. 15 in the USA Today/ESPN Coaches Poll.

The success is a credit to Berenato's character and the fact that she practices what she preaches to her team. Her passion for women's basketball has helped make her players better students and better people."

**Join us in a GREAT SUPPORT EFFORT for the Pitt Women Basketball Team. Admission, food and fun!!!!!!!!!! Must contact Sinikka Davis 412-795-3029 or [info@nfsocialworker.org](mailto:info@nfsocialworker.org) by 1/2/09.**

## SCHOLARSHIPS AVAILABLE

### ATTENTION: Graduating High School Seniors

If you are pursuing further education, either college or a trade school, you may qualify for the Cornell McMullin Academic Scholarship. Applications must be submitted by APRIL 1, 2009. For further information, including applications, contact Sinikka Davis, MSW, 412-788-1503 or [nfsocialworker@nfpittsburgh.org](mailto:nfsocialworker@nfpittsburgh.org) after January 1, 2009.

### ATTENTION: Parents Interested in Student Tutoring

The Ann Kramer Scholarship Fund can provide the monies for your child to receive tutoring help, enhancing his/her academic performance. For further information including applications, contact Sinikka Davis, MSW, 412-788-1503 or [nfsocialworker@nfpittsburgh.org](mailto:nfsocialworker@nfpittsburgh.org).

### ATTENTION: Students Interested in Summer Camp Adventures

If you are interested in NF Camp in the summer of 2009 in Maryland (Camp NewFriends, see [www.nfinc.org](http://www.nfinc.org)) or Utah (Camp K, see [www.ctf.org](http://www.ctf.org)), you can apply for a scholarship with the NFCA. Think about it over the winter and, if interested, contact Sinikka Davis, MSW, 412-788-1503 or [nfsocialworker@nfpittsburgh.org](mailto:nfsocialworker@nfpittsburgh.org) after January 1, 2009.

## SCHOLARSHIPS GRANTED

### ACADEMIC:

- > Curtis Esquibel, Theil College
- > David Gray, Liberty College
- > Andrew Morgart, University of Pittsburgh, Titusville
- > Carrie Sydow, Tri-State Business Intstitute

### CAMP:

- > Megan Weise, CTF's Camp Lostopolus, Utah
- > Brianna Schmid, NF Inc.'s Camp New Friends, Maryland

## Camp K Report

My name is Megan Weise and I am 16 years old. I was diagnosed with NF when I was 2 ½ years old. I have had chemo, radiation, brain surgery and tumors removed from my arm. It is not a fun disease.

In August I had an amazing opportunity to attend Camp Kostopolus in Salt Lake City, Utah. I had to fly for the first time in my life by myself. I was a little scared but the trip was well worth it.

Throughout the week we took many amazing trips. We went to a Bees game (the minor league baseball team), to the movies and to Park City, and boy was that ever fun. My favorite thing about camp was when we rode the alpine coaster and a zip line. We also went to a really fun water park.

At camp, all the counselors were so nice and I got to meet so many new amazing friends and have memories that will last a lifetime. I highly recommend that if anyone has a chance to attend camp, they should go and see how truly amazing it really is, Thank you so much NFCA for the scholarship.

### Megan Weise



## Ann Kramer Memorial Golf Scramble

### Location, location, location!

Another NFCA fundraiser settled in different scenery when the Annual Golf Scramble moved to Hickory Heights Golf Course in Bridgeville. Friday, August 1, was a glorious day to whirl the cart around the course and "scramble" for FUN and the PRIZES of the day. Though an outsider might wonder if this is not an entire holi-day as golfers start with breakfast, munch at the turn and finish off with a dinner meal and an over abundance of door prizes: one per golfer!! Where else can you dine all day, have a day of camaraderie, and be assured to take home a prize estimated to be worth \$15 to \$50 for a mere \$100 entry fee?

Thanks to Chairperson, Bill Kramer, and all who made this possible: volunteers, participants, prize donors and generous sponsors. Hey, let's play it again, Sam!

What a great way to honor and celebrate the life of Ann Kramer who made a significant impact on the profile of the NFCA.

### JOIN US NEXT YEAR: HICKORY HEIGHTS GOLF COURSE, JULY 10, 2009

## Bowling and LaserTag Party at FunFest

On Saturday, March 1, NF friends ONCE AGAIN lit up Harmarville with the frivolity of bowling and laser tag. And...pizza, pizza, pizza. Stayed tuned for information on the 2009 event...sure to be held as it is surely a winner AND a way to chase winter chills away!

## Is Good Search your search engine?

CHOOSE TO USE and \$ add up for the NFCA. Simply Log on to [www.goodsearch.com](http://www.goodsearch.com) and see how to make GoodSearch your internet home page. Or just use it for your searches. But please identify the NFCA as the organization you "search for" and the pennies will add up to dollars.

## Run4NF – Pittsburgh Marathon

Dear friends and families touched by Neurofibromatosis: Did you know that every day 115 babies are born in this world with Neurofibromatosis. Yet we do not have cures or many treatments for NF. There are many hopes of cures across the U.S.

### How can we make a difference?

We need to be seen and heard. We need to continue to fundraise to insure government funding and private research to continue.

In May 2009, NF Inc., Run4NF.org and your local NF Support Group want to come together and walk a half marathon during May, which is National NF Awareness Month. We want to be seen and heard.

We will walk together in our NF tees. The more there is the better we will be heard. There is no skills needed except the passion to be a part of the future of NF.

### So how do you get involved?

First and quickly~Register for a half marathon(or marathon or relay). A complete list is available at [www.run4nf.org](http://www.run4nf.org) (along with direct links to register)

Pittsburgh will host a half marathon and a relay along with their full marathon. The direct link to register for an event is <http://www.pittsburghmarathon.com/>

Then you set up your personal fundraising page or a group page at [www.firstgiving.com/run4nf](http://www.firstgiving.com/run4nf)

There is not \$ commitment to be involved, but if you raise over \$500 your registration will be reimbursed.

### It is never too early to begin your fundraising.

Lastly, you email [debbi@run4nf.org](mailto:debbi@run4nf.org) so that your welcome packet can be sent to you. All emails will be answered in a timely manner and all questions welcome. For more info go to [www.run4nf.org](http://www.run4nf.org)

**Debbi Hanlon, [debbi@run4nf.org](mailto:debbi@run4nf.org)**

