

To the Members of the NFCA Community:

Hello. Please allow me to introduce myself. My name is Wanda Harper. On July 27, 2013, I was honored to accept the presidency of the Neurofibromatosis Clinics Association.

Quite frankly, 12 years ago, I was unaware that NF even existed. Then a child afflicted with NF was born into my family circle. In the time since, I have seen the struggles, challenges and – yes – triumphs that those battling NF experience every day.

Over the years, I have been blessed to meet individuals who inspire me by their strength, resilience, dedication and grace under pressure. As president, I will strive to continue the NFCA's goal of aiding these families through the medical, financial and social mazes that can be so overwhelming.

We are stronger together than we could ever be alone. I want to look for more opportunities to bring the NFCA community together – provide more services, share experiences and knowledge.



Wanda with Gateway Financial's Sam Zacharias, Former Steeler Andy Russell, and Brendan Allen



Wanda and Dalton Psomas

To that end, please feel free to contact me should you have any comments, suggestions, or questions. My email address is NFCAWanda@yahoo.com. I look forward to hearing from you about how the NFCA could better help you and your families.

I also look forward to meeting the members of the community. To those I haven't already met, please stop and introduce yourself at the next NFCA gathering. To those I have, I'd love to see and talk with you again!

Sincerely,
Wanda Harper

REMEMBERING AMY

Amy Bookmiller passed away in April of this year. Having been diagnosed with NF1 as a toddler, her mother Carol was participative with Cornell McMullin, founder of the NFCA, from the inception of the organization. Amy "grew up" with the NFCA and was a HUGE personality, visible at most NFCA events and promoting knowledge of NF in her community. She and her mom would solicit prizes for the golf outing and attend to enjoy camaraderie with the golfers at dinner after the outing.

Amy crocheted Polamalu hats and last year one was auctioned at the golf event. Carol sent many prizes again this year and this "thank you" for all the caring for Amy:

Thank you for attending this year's NFCA golf outing. You have no idea how much your support of this event means to the individuals and families that are affected by neurofibromatosis. Last year, as you may remember, my daughter, Amy, donated one of her crochet creations - a Troy Polamalu hat. She spent many hours working on her hats, an activity she could still complete with extremely poor vision and limited use of her hands, both handicaps caused by NF and brain tumors. Amy loved the limelight and was thrilled that golfers were bidding on her creation, the latest version of a Polamalu hat. By the time the bidding reached \$70, Amy was waving her hat in the air and her self-esteem soared. She was so overjoyed that she was able to contribute to a cause she strongly believed in -- helping those affected by NF. A few weeks after the golf outing last year, Amy was diagnosed with terminal brain cancer, a complication of NF, and passed away in April. Before she died, she shared the story of the auction hundreds of times always bursting with pride and with a big smile on her face. Thank you for that \$70 bid; it was truly priceless. Not only did you contribute to a worthwhile cause, you made a young lady

who battled NF her entire life feel very important and gave her a place in this world. Your attendance at this golf outing means more than you could ever imagine. We will never forget the contribution that you have made for those children who have to live their lives with NF. Thank you for everything.

- Carol Bookmiller

A SPECIAL SUMMER 2012

A Summer Experience by Nina Casella

Traveling across the country to live on an Indian reservation is life changing. The sights I saw and the people I met will never leave my memory. The thought of waking up and going out to help people who are less fortunate than me is very pleasing. I lived on an Indian Reservation in Browning, Montana by the name of "Blackfeet Indian Reservation", and there was a total of about 70 volunteers who were there with me. The reservation is an extreme difference to what most of us are used too. A majority of the houses there are small and sadly falling apart, and a majority of everything else there is not that great of quality either.

Every morning, at around 7:30 AM, we would all get up and get ready for our busy day. For the first two days I went to work on the playground with my team. Since the children played barefoot most of the time, we cleaned up the broken glass and garbage for the children's safety. The following day when we switched groups, my group went to the towns' only hardware store. We bought several feet of wood and screws to build a new picnic table for the newly cleaned playground. After several hours of measuring, cutting, and drilling wood, the beautiful table was complete.

As the week was coming to an end, I worked at two more places. I went to one of the elementary schools to play and bond with the Indian children. The children were shy at first, but after a while they were full of life. Many of the children did not have the opportunity of being cared for by loving, responsible parents and often came to the school because their parents were either sobering up or abusing drugs. I noticed that besides not being fed properly, a lot of the children had at least 3 silver teeth, because they lacked daily dental hygiene. Though they had to live this life it did not affect their personality in any way.

On very last day of work, a few groups went to the Senior Citizen Center to paint it. After finishing the paint job, we were able to enjoy a hot meal and spend time with some of the elderly.

The experience I had on this trip taught me many valuable lessons. I learned not to take small items that I own for granted because I realized that it is such a privilege to own them. It upsets me to know that there are some many families out there who don't have the money to afford warm clothes or food for their home, and I hope to continue traveling to different locations to help those families as best as I can.

****Nina has begun studies at Pitt Johnstown.
Congratulations, Nina!****

****If you have an experience to share, please send
the information to info@nfpittsburgh.org****

INDEPENDENT FUNDRAISERS: THANKYOU . . .

Probola Family

They did it again! Linda and Anthony Probola, along with Anthony's sister Jenn, ran their 3rd fundraiser in the fall for the benefit of the NFCA raising \$3100!! The family held the first event in 2009 and are already planning the next. **THANKYOU FORYOURTIME, ENERGY AND CONTRIBUTION TO THE NFCA.**

SCHOLARSHIP NEWS

We are so proud of our 2013 Academic Scholarship recipients. We look forward to following their collegiate progress!

Academic Scholarships Granted 2013:

Elizabeth Brown, California University of Pennsylvania
Nina Casella, University of Pittsburgh, Johnstown
Amanda Kilian, Robert Morris University
Kara Kramer, CCAC Boyce
Melissa Neal, Edinboro University
Megan Weise, Edinboro University

**APPLY FOR THE 2014 SCHOLARSHIPS
BY APRIL 1, 2014**

SUPPORT GROUP MEETINGS

**Come, order a sandwich and join us for an
informal sharing of our NF stories:**

Support group meetings occur several times a year at Panera locations.

Inquiries: Sinikka Davis, 412-795-3029 or
nfsocialworker@nfpittsburgh.org

CAMP NEWS

Two campers enjoyed a week at Camp NewFriends this summer. If your child has an interest in enjoying a week of summer fun and meeting New Friends in 2014, **Contact Sinikka Davis in March 2014 at 412-795-3029 or nfsocialworker@nfpittsburgh.org**

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, 412-795-3029 or nfsocialworker@nfpittsburgh.org.

You are cordially invited to a fundraiser at....

five BELOW

The best place to get hot stuff, cool prices and raise money for
Neurofibromatosis Clinics Association!!!!

five BELOW

carries school supplies, software, books, electronics, sporting goods, games, t-shirts, jewelry, bath and body, candy, snacks and beverages, room décor, storage, plus much more. And everything is priced at \$5 or less!!

Get cool Christmas gifts AND contribute to the fight against NF!!!

Shop any day between:

Sunday, December 1, 2013 and Saturday, December 7, 2013!

Store hours:

Sunday: 9 a.m. – 7 p.m.; Monday – Saturday: 9 a.m. – 9 p.m.

Locations:

Pleasant Hills, Southland Four Seasons, 587 Clairton Blvd., Pleasant Hills, PA 15236

McMurray, Donaldson Crossroads, 3959 Washington Road, McMurray, PA 15317

Pittsburgh, Settlers Ridge, 1010 Settlers Ridge Center Drive, Pittsburgh, PA 15205

Pittsburgh, Waterworks, 950/952 Freeport Road, Pittsburgh, PA 15238

Pittsburgh, North Hills Village, 4801 McKnight Road, Pittsburgh, PA 15237

Monroeville, Miracle Mile, 4088 William Penn Highway, Monroeville, PA 15146

Tarentum, Pittsburgh Mills, 1020 Village Center Drive, Tarentum, PA 15084

10% of your purchase dollars
will be donated back to NFCA!!

Please don't forget to bring this flyer with you between
12/1/2013 – 12/7/2013 so that the NFCA gets credit for your purchases!

(pre-tax) Purchase Amount:

\$

To be completed by Five Below Associate

Register: 1 2 3 4 (circle one)

Associate Name: _____



At **five BELOW**, whatever you got will buy a lot!

The event is sponsored by five Below, with proceeds benefiting NFCA.
Visit us at www.fivebelow.com and www.nfpittsburgh.org.



NFCA FUN and FUNDRAISING

The 19th Annual Walk for NF

For the 19th year (*amazing, isn't it?!*), many of our supporters – both inside and outside the NF community – enjoyed the opportunity to “Walk in the Wild” on April 27, 2013, at the Pittsburgh Zoo & PPG Aquarium.

The day was ROARingly spectacular - complete with musical entertainment provided by Franco LeDonne, face painting, food, raffle and - of course- the delights of the zoo! Many of us took the opportunity to introduce ourselves to the most adorable Red Panda! Along with having a great time, the focus of the Walk is to raise much needed funds to support our different programs (*scholarships, camp, tutoring...*). So, let's make next year's Walk (#20!!) the biggest and best yet!! Anyone who can guide us to new sponsors or works for companies that match donations, please contact Joyce Trew (info@nfpittsburgh.org) and you can help make this a BEAR of a success.



20th Annual Walk for NF
May 3, 2014

NFCA FUN and FUNDRAISING

The Annual Cosmic Bowling

The Harmarville FunFest was held March 3, 2013. We were so excited to see more and more of our NF community come out for fun, food and games. The FunFest provides a wonderful opportunity to connect with old friends and meet new ones! Look for your postcard in February for the details of the 2014 event.

The 3rd Annual Bowling Over NF

The 3rd Annual Bowling Over NF was held at Paradise Island Bowl on Neville Island on July 28, 2013.

A strikingly good time was had by all! We were thrilled with the number of bowlers (*and observers*) who participated! With so many door and raffle prizes, practically all who attended went home with some memento! Thank you to Wanda Harper's team for helping to make this a success! Stay tuned to www.nfpittsburgh.org for details of The 4th Annual Bowling Over NF to be held July 2014. Where else can your family get all the chips, pretzels, pizza, wings and soda they can consume, bowl and have an awesome time with such fun people?!

The 2013 Ann Kramer Memorial Golf Scramble

was a success at HICKORY HEIGHTS GOLF COURSE, August 3, 2013. It was a perfect golf-weather day! There were lows and highs, whoops and sighs...but mostly plenty of fun for a great group which truly "golfs for the cause"! We invite anyone who can swing a club to join this fun filled day, 1st Friday in August, annually. Thanks to board members Jeff and Bill Kramer and Joe Johns for repeating this fundraiser.

NF Clinic Children's Hospital of Pittsburgh update:

Reminder that the NF Clinic appointment line is 412-692-5520. Always ask to be put into the NF clinic schedule to see Dr. Amy Goldstein or Dr. Kathy Gardner. NF clinic has added an experienced nurse practitioner to the team, Beth Heuer CRNP.

Children's Hospital of Pittsburgh of UPMC is now in Bloomfield. Adults with NF can be seen by Dr. Kathy Gardner at the Kaufmann Building 3471 Fifth Ave Suite 810 in Oakland by calling 412-692-4920.

Get Involved!!!!

As a Pennsylvania non-profit organization, the NFCA is dependent on the kindness, strength and resolve of our community. If you have some ideas on how you can help, ideas on other fundraising events, or perhaps you have some items that you would like to donate for future raffles, please email Wanda Harper at NFCAWanda@yahoo.com. Together, we can do anything!

MOVING?

Put THE NFCA on your "Moving List"

The US Post Office will forward mail for one year. In order for you to continue to receive newsletters and event updates from the NFCA, please send change of address to NFCA, PO Box 14185, Pittsburgh, PA 15239 or info@nfpittsburgh.org.

United Way

Many thanks to all who give generously through the United Way. For those who are interested in participating, specify NFCA UW Contributor Choice **#885410**.

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CHOOSE TO USE and \$ add up for the NFCA. Simply Log on to 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.

Please Mail to NFCA, P.O. BOX 14185, PGH., PA 15239