

SAYING GOODBYE...

Cornell McMullin (September 28, 1916 - December 31, 2011) founded the Neurofibromatosis Clinics Association, Inc. (NFCA), with a handful of friends gathered around her dining table. She grew it to what it is today, a viable not-for-profit organization providing social services, education and camp scholarships for families with NF.

...and remembering Cornell...

"Cornell was my dear friend and will live in my heart forever. She was there for me when I needed her most and at times I think she even needed me. We understood each other because we were caregivers, teachers, mothers, and because we were both very determined to have a viable NF support group and to educate the world about NF.

Cornell's early career as both a dance and kindergarten teacher provided her with exactly the right skills needed to found and guide the NFCA for several decades. She was petite and strong and had the energy and compassion to work tirelessly on behalf of people who had NF and for their families. Cornell charmed physicians, politicians, celebrities, and friends old and new with her knowledge, her humor, and her positive attitude despite having endured many personal hardships including the early deaths of her husband and son to NF. Cornell never gave up and recruited others so that we could all benefit from the support group that we have today.

Cornell's visions for us far exceed what we have been able to accomplish. She would be touched and pleased if all of us would continue her work by networking, by celebrating the joys of living, and by giving those with NF hope and a brighter future. I have no doubt that Cornell will still be looking out for all of us from heaven and that everyone in heaven will be educated about neurofibromatosis."

Carol Bookmiller



"People in Pittsburgh do not realize what a force Cornell was. You know, the lady who started the Acoustic Neuroma Association did it the same way - 5 ladies around her kitchen table. I have always remembered what she said at a seminar we attended. The question of everyone was, "How would you like to be remembered?" She replied, "That I left footprints in the sand!" Cornell left a big footprint!"

Marie Drew

"Cornell was a woman of great conviction and dedication. The NFCA would not have existed or thrived without her. Through her vision, the NFCA has been able to help a multitude of families in the region. She will be missed, but with everyone's help we can continue her good work."

Cheryl Bender

“My granddaughter was diagnosed with NF in the spring of 94. I had never heard of the disorder and had nowhere to turn. A person working in my husband’s office had been to a walk in South Park and brought a brochure to work explaining what the walk was benefiting: Neurofibromatosis.

There was the contact name: Cornell McMullin. I immediately called her and there started my 18 year relationship with the founder of the NFCA. She was the voice that guided many families, including our family, on where we could seek help. She was our own unpaid social worker. She was always the first voice that families would go to for advice, where to find treatment and just having this wonderful person to talk to. She told everyone where they could get medical information and find medical doctors who specialized in the field of NF. She would even go to the hospitals to visit families that were being treated, even though she had never met these families personally. She made arrangements with the University of Pittsburgh medical school to have medical students speak with her and other NF parents to hear firsthand how and what families were dealing with. Her life was 24x7 NF. For those of us who knew Cornell, we have a great void in our lives. She was the tiny little lady that changed the lives of many. God rest her soul.”

Lorna Irvin

“Cornell was like a second mother and a mentor to Ann (Kramer). Her dedication / can-do attitude inspired others to help grow awareness of NF”

Jeff Kramer

I will certainly always remember Cornell with great fondness. I admired her vision and tenacity as well as her kindness. She was determined to have social work services for NF families in this region and made it happen. She was the inspiration and force behind the NFCA organization which has a unique partnership with Children's Hospital and UPMC to offer direct family service to NF patients coming in for medical treatment. Cornell indeed has been the wind beneath our wings”

Sinikka Davis

“Cornell’s and my relationship began when her son, David, worked for me at US Steel. Funny thing, 27 years later I cannot remember exactly how we connected. Since Cornell was outgoing and had a way of meeting people and subtly “gathering them into her fold”, I can only think she looked up a phone number, began educating me on NF and invited me, and any co-workers I could rustle up, to a walk at South Park. She gently raised her influential rope to lasso me, to sear me with the NFCA brand and to free me to fulfill a role as an ambassador for neurofibromatosis and the NFCA. Over the years, I have met some of the strongest and finest people who fight for what Cornell always called this “orphan disease”, who look for NF recognition, support, treatment and ultimately a cure. This I attribute to this wonderful lady who was relentless in her determination to make a difference. And...she did! A cute quirk of Cornell’s: she would NEVER divulge her age.”

Joyce Trew

“I’m laughing about you asking about the date of birth for your memorial and Cornell never telling her age. She bragged about her age from the time she arrived here (six years ago moving from Pittsburgh to Lansdowne). Her grandmother lived 'til she was 103, and she was certain she could beat that. But after her 94th, she never was sure how old she was and didn't bring it up.”

Jack O’Neil, son-in-law

Perhaps Cornell was not hiding her age, but simply implying it was not important. As Lorna said “Cornell’s life was 24x7 NF”

INDEPENDENT FUNDRAISERS:

THANK YOU . . .

Linda & Tim Orban

who, for family and friends, hold a Farmfest at their home each year to raise money for deserving charities and organizations that have personal connections to these families and friends. They provide a day of food and outdoor entertainment with the opportunity to participate in raffles and donations.

Per Linda: "In August of 2011, Tim & I held Farmfest for the benefit of the NFCA which is important to my sister, Barbara Cornetti, and her daughter, MaryKate who has NF1. She is a cheery, bright and optimistic young lady who bravely welcomed everyone to FarmFest and talked about what she is experiencing. It made the event especially meaningful to all who attended and opened their hearts to the NFCA.

We are proud to have raised \$790.00 in honor of MaryKate to benefit the Anne Kramer Education Fund." WELL DONE!

Edie & Glen Krofcheck and Son-Shine PreSchool

who once again held the Turkey Trot to honor sons Curtis Esquibel and Miles Krofcheck and benefit the NFCA.

Mom, Edie, organizes this event with the pre school Miles attended a few years ago. The students let their energy loose and solicit family and friends to donate on their behalf. Donations in the amount of \$240.00 will be added to the NFCA "bank for giving" as a result of their fine work. THANKYOU, TINY "TROTTERS"!

Deb Paolo

who had the NFCA share as beneficiary of monies from a fundraiser being held in conjunction with a Corvette Car Show on May 15, 2011, at Day Chevrolet in Monroeville, Pennsylvania.

The popularity of this car event drew people from the tri-state area. What an excellent opportunity to raise awareness of NF. The fees and Basket Raffle brought the donation to the NFCA to \$375.00. THANKS DEB!

UPCOMING EVENTS

18th Annual Walk for NF

NFCA's 'Walk In the Wild' at the Pittsburgh Zoo & PPG Aquarium
Saturday, April 21, 2012, 9AM
See enclosed.

2nd Annual Bowling Over NF

Paradise Island Bowl on Neville Island
Sunday, July 8, 2012, 1 - 4PM
Contact Wanda Harper @ (412)833-5809 or lfacs1@verizon.net

2012 Ann Kramer Memorial Golf Scramble

Hickory Heights Golf Course
Bridgeville
August 3, 2012

Support Group Meetings-

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

May 4 Friday, 6:00 - 8:00 PM, Cranberry Paneras
20111 Route 19
Cranberry Township, PA 16066

May 11 Saturday, 6:00 - 8:00 PM, Monroeville Miracle Mile Paneras
4172 William Penn Highway
Monroeville, PA15146

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

CAMP NEWS

Camp Scholarships are still available but HURRY

Camp New Friends, located in Massanetta Springs, VA, July 15-21

Contact Sinikka Davis 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.

FUN-RAISING

Funfest in Harmarville

on March 3, 2012, was again a fun and festive time.

- Bowling with shoes included (up to six people on a lane)
- One game of laser tag per person
- Two slices of Pizza per person
- Unlimited Pitchers of Pop
- Fifteen game tokens per youth





FUN-RAISING
Funfest in Harmarville

NFCA FUNDRAISERS:

The 17th Annual Walk for NF saw a record crowd walking through the Pittsburgh Zoo & PPG Aquarium!

Please join us and our Master of Ceremonies, Andy Russell, for number 18! See the enclosed for further details.

The 1st Annual Bowling Over NF initiated by board member Wanda Harper, was held at Paradise Island Bowl on Neville Island and was a STRIKE!

Please join us for number 2 on Sunday, July 8, 2012. Includes prizes, 3 hours of bowling, shoe rental, unlimited chips, pretzels, pizza, wings, soft drinks & FUN! Adults \$20, Youth (12 & under) \$10. Contact Wanda Harper @ (412) 833-5809 or lfacs1@verizon.net.

The 2011 Ann Kramer Memorial Golf Scramble

was a hole-in-one at HICKORY HEIGHTS GOLF COURSE on August 5, 2011. Along with enjoying a tremendously beautiful day in the sun, the golfers honored Bill Kramer, Sr. Bill was a Scramble regular who passed away earlier in the year. We will miss him dearly. Thanks to board member Jeff Kramer and his brother, Bill, for organizing this fundraiser each year.

Please tee-off with us on Friday, August 3, 2012 for this year's fun-filled event!

Oktoberfest

at the Hofbrauhaus was the location of the fall 2011 gathering of the NF community.

Located in South Side Works and fashioned after the Munich, Germany food and music hall, it embraces family gatherings and promotes Oktoberfest every day of the year. It was a good setting for our families to relax and share time with each other.

SCHOLARSHIP NEWS

Academic Scholarships Granted 2011:

Elizabeth Brown, California University of Pennsylvania
Amanda Kilian, Robert Morris University
Melissa Neal, Penn State Behrand
Alex Sassone, Butler County Community College
Jordan Sirianni, University of Pittsburgh
Megan Weise, Edinboro University

APPLY FOR THE 2012 SCHOLARSHIPS BY APRIL 1

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, Dr. Kathy Gardner or Dr. Christina Patterson.

Children's Hospital of Pittsburgh of UPMC is now in Lawrenceville. 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.

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**.

Is Good Search your search engine?

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.

NFCA

Neurofibromatosis Clinics Association

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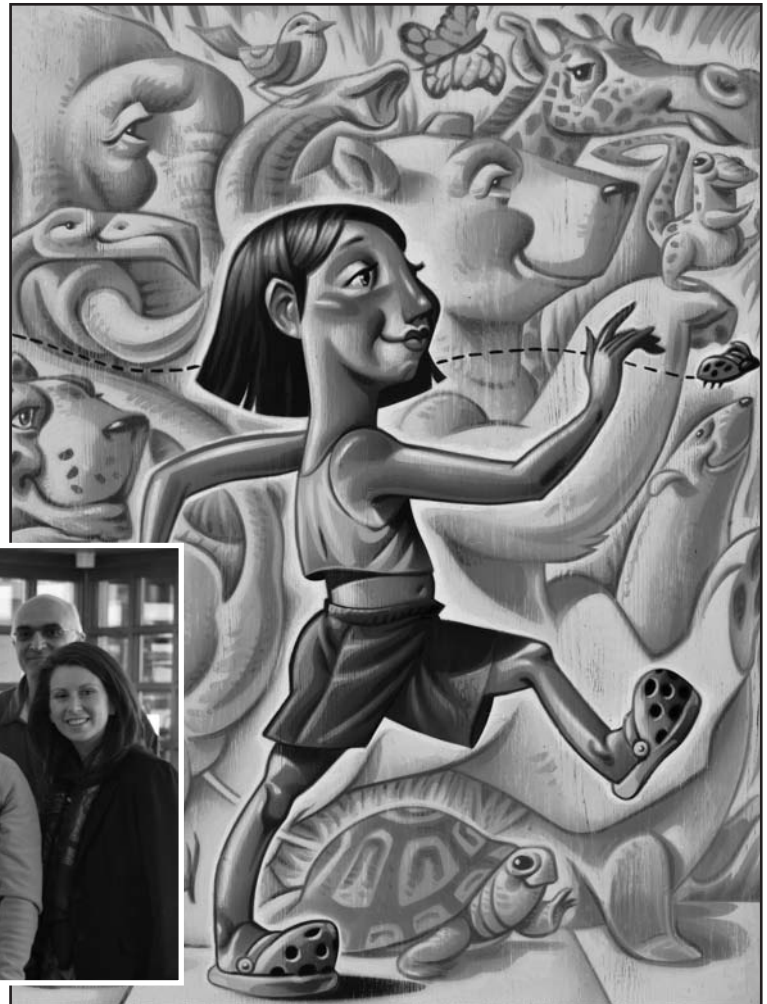
Growing awareness. Seeking hope.

P.O. Box 14185
Pittsburgh, PA 15239
phone: 412.795.3029

www.nfpittsburgh.org

18th Annual Walk for NF

APRIL 21, 9AM



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FORM INSIDE

Walk in the Wild