



# CROHN'S & COLITIS FOUNDATION OF AMERICA

GREATER NEW YORK CHAPTER

## Chapter Newsletter

August, 2011

### Ali's Running Her First Marathon to Raise Crucial Funds for CCFA



In 2009, Ali Feller ran her first half-marathon from Napa to Sonoma with CCFA's Team Challenge program. Since then, she has run six half-marathons and was recently chosen by JackRabbit Sports from 350 applicants to train for a full marathon while raising funds for the charity of her choice. Since both Ali and her brother have Crohn's disease, choosing CCFA was a no-brainer. Ali was diagnosed when she was only 7 years old, and her Crohn's flare ups have affected her life at the most inopportune times: starting college, studying abroad in Australia, and beginning her first job in Manhattan. But she hasn't let her disease stop her from getting her dream job as Deputy Editor in Chief of Dance Spirit Magazine and now, from running a marathon.

Ali will be running the Hamptons Marathon on September 24th, and she feels fortunate to have the opportunity to be a spokesperson for the Crohn's and Colitis Foundation and she says, "help other 20 years olds, who are just starting their lives, know that they are not alone in dealing with this disease."

When she was first diagnosed, her parents turned to CCFA for advice. They knew nothing about the disease, and CCFA, along with her doctors, gave them the knowledge they needed to help her. By the time her older brother was diagnosed, they already had support in place through CCFA.

After running her first half-marathon with Team Challenge, Ali was hooked. She says that during her Team Challenge trainings she bonded with other people with IBD, and for the first time, began to feel more comfortable talking about her disease with others.

**You can donate to Ali's run at <http://runfortherabbit.com/runners/ali/>**

**Team New York is now recruiting for Las Vegas 2011!**

**Sign up for an info session at <http://www.ccteamchallenge.org>**

**Team NYC:**

contact Megan Haran at 212-679-1570, ext. 3  
[mharan@ccfa.org](mailto:mharan@ccfa.org)

**Team Brooklyn:**

contact Stacey Clark at 212-679-1570, ext. 7136  
[sclark@ccfa.org](mailto:sclark@ccfa.org)

Ali ran her second half-marathon with Team Challenge in December 2009 in Las Vegas. She says, "the best way to see the city is by foot!" She loved the people-watching while she was running: "There were women wearing wedding dresses who had just gotten married, cheering us on!"



## Message from the Executive Director:



### DID YOU KNOW?

One of CCFA's top three priority projects right now is the Pediatric Network Initiative. This study will enroll over 1,500 pediatric IBD patients at the time of their diagnosis, across 50 study centers nationwide. The goal of the study is to collect genetic, clinical and immunological data at the time of diagnosis, continue to monitor these children over the course of time, and eventually create a model that will aid clinicians in deciding which course of treatment will be the best for every newly diagnosed child, minimizing their symptoms and risk of surgery. This is *the largest collaborative pediatric study ever*, and our researchers are excited to see the outcomes.

The Pediatric Network Initiative is a step in the right direction, not only for children with IBD, but for all IBD patients and the treatment of their disease.

Please feel free to contact me at anytime if you have questions about the Foundation's work. I would love to meet you and tell you more!

*Rhondell*

## Foundation News:

### CCFA Partners Gives Patients a Chance to Share

CCFA is looking for 10,000 or more IBD patients to share how IBD has impacted their lives through CCFA Partners



<http://ccfapartners.org>, our newly-launched groundbreaking online research and education program. **By completing a short, confidential survey about their current quality of life and providing occasional updates on their health, participants can shape researchers' understanding of IBD.** This will ultimately help us to reach the goal of more rapid research progress, better treatments, and the cures we need.

### CCFA and DDNC Testify at FDA Hearing

At the end of July, Dr. Sandra Kim, University of North Carolina School of Medicine and Co-chair of CCFA's Pediatric Affairs Committee, and Nick Uzl, patient and alumni of the CCFA's National Youth Leadership Council, testified at an FDA Advisory Committee meeting about the FDA approval of Remicade for use on pediatric Ulcerative Colitis patients. **Dr. Kim emphasized the importance of facilitating additional treatment options for pediatric UC patients, while also discussing the risks and benefits of this treatment. The Advisory Committee voted to recommend to the FDA that the indication for Remicade be expanded to include the treatment of pediatric Ulcerative Colitis.**

### Department of Defense (DOD) Peer Reviewed Medical Research Program

In June, Congress approved IBD as an eligible disease for research grants from the Department of Defense (DOD). **Since then, it has been reported that the DOD has received over 80 letters of intent from IBD researchers around the country, more than any prior year!**

# CCFA Greater New York Chapter Upcoming Events:

## **Patient Education and Support**

For more information contact Sergio Seijas: 212-679-1570, ext. 1 [sseijas@ccfa.org](mailto:sseijas@ccfa.org)

### **First Tuesdays Open Support Group**

September 6, 2011: 6:30-8:00 PM

386 Park Avenue South, 14th Floor, New York, NY 10016

### **Patient Education Symposium**

September 18, 2011

The Lighthouse International: 111 East 59th Street, New York, NY 10022

Register at: <http://online.ccfa.org/pes11>

### **Third Wednesdays Women's Support Group**

September 21, 2011: 6:30-8:00 PM

386 Park Avenue South, 14th Floor, New York, NY 10016

### **Pediatric IBD Day**

October 16th, 2011

Dave and Busters: 234 West 42nd Street, New York, NY 10036

August 14, 2011: Guitars for Guts: A Benefit Concert featuring The Alphabets and ROADS Williamsburg Music Hall

Contact Liz Sylvan at 212-679-1570, ext. 7137 or [sylvan@ccfa.org](mailto:sylvan@ccfa.org)

August 16, 2011: Team Challenge Brooklyn Info Session, 6:30 PM

T & R Endurance Sports: 7924 3rd Avenue (at 80th Street), Brooklyn, NY 11209

Contact Stacey Clark: 212-679-1570, Ext. 7136 or [sclark@ccfa.org](mailto:sclark@ccfa.org)

August 17, 2011: Take Steps Brooklyn Kick-off Party at the Brooklyn Cylcones (see page 4)

MCU Stadium, Brooklyn

Contact Danielle Thibault at 212-679-1570, Ext. 4 or [dthibault@ccfa.org](mailto:dthibault@ccfa.org)

August 17, 2011: Team Challenge Brooklyn Info Session, 7:00 PM

Le Barricou: 533 Grand Street at Union Avenue, Brooklyn, NY 11211

Contact Stacey Clark: 212-679-1570, Ext. 7136 or [sclark@ccfa.org](mailto:sclark@ccfa.org)

August 17, 2011: Team Challenge Manhattan Info Session, 6:30 PM

Sidebar; 120 East 15th Street; NYC10002

Contact Megan Haran: 212-679-1570, Ext. 3 or [mharan@ccfa.org](mailto:mharan@ccfa.org)

August 18, 2011: CCFA Theater Club presents, "Baby It's You," 8:00 PM

\$350 for two tickets

Contact Ed Muñoz at 212-679-1570, ext. 2 or [emunoz@ccfa.org](mailto:emunoz@ccfa.org)

August 23, 2011: Team Challenge Manhattan Info Session, 6:30 PM

Butterfield 8; 5 East 38th Street, NYC 10016

Contact Megan Haran: 212-679-1570, Ext. 3 or [mharan@ccfa.org](mailto:mharan@ccfa.org)

August 25, 2011: Team Challenge Brooklyn Info Session, 7:00 PM

Union Hall: 702 Union St. (at 5th Ave.) Brooklyn

Contact Stacey Clark: 212-679-1570, Ext. 7136 or [sclark@ccfa.org](mailto:sclark@ccfa.org)

September 15, 2011: CCFA Theater Club presents, "Anything Goes," 8:00 PM

\$350 for two tickets

Contact Ed Muñoz at 212-679-1570, ext. 2 or [emunoz@ccfa.org](mailto:emunoz@ccfa.org)

October 20, 2011: Bet Your A\$\$ Off:

Young Professionals Casino NightL Crimson

Contact Ed Muñoz at 212-679-1570, ext. 2 or [emunoz@ccfa.org](mailto:emunoz@ccfa.org)

October 30, 2011: Take Steps Brooklyn

Prospect Park

Contact Danielle Thibault at 212-679-1570, Ext. 4 or [dthibault@ccfa.org](mailto:dthibault@ccfa.org)

**Crohn's & Colitis**  
**BROOKLYN WALK**  
**FREE Kick-off Party!**

Learn more about the upcoming  
 Take Steps Walk for Crohn's & Colitis Walk

**WEDNESDAY, AUGUST 17, 2011**  
**MCU STADIUM, Coney Island**  
**Brooklyn Cyclones Pre-game**

Take the field during the National  
 Anthem and attendee with the most guests  
**THROWS THE FIRST PITCH!**  
*RSVP required*

**TAKE STEPS**  
 FOR CROHN'S & COLITIS

Crohn's & Colitis Foundation of America  
[www.cctakesteps.org/brooklyn](http://www.cctakesteps.org/brooklyn)  
 Danielle, Walk Manager, 212-679-1570 x4

## Take Steps Brooklyn October 30, 2011 Prospect Park!

Register for the 1st ever Brooklyn walk

Raise critical funds for the Crohn's and  
 Colitis Foundation!

To register, contact Danielle Thibault:  
 212-679-1570 ext. 7133

[dthibault@ccfa.org](mailto:dthibault@ccfa.org)

<http://cctakesteps.org/brooklyn>



## Join us for our annual Patient Education Symposium!

September 18, 2011, 8:30 AM to 3:30 PM

The Lighthouse International Conference Center  
 111 East 59<sup>th</sup> Street, New York, NY 10022-1202

Learn about the latest advances in IBD treatment with lectures and breakout sessions:

**Keynote: Know Your Rights : Health Insurance in the Age of Reform, Jennifer C. Jaff, Esq.**

*How to be an Empowered Patient: Navigating the Relationship with your Doctor, Dr. Peter Rubin, MD*

*IBD and Nutrition, Dr. Arthur Heller, MD*

*What to expect Post-Operatively, Dr. Rebecca Levine, MD*

*Surgery: New Advances, Dr. Joel Bauer, MD*

*IBD & Cancer: Facts & Fiction, Dr. James Marion, MD*

*New Advances in the Medical Treatment of IBD, Dr. Ellen J. Scherl, MD*

*Stress and Coping with Chronic Disease, Laura C. Reigada, Ph.D*

*Living Fully with an Ostomy, Alexis Sherman, RN, BNS, WOCN*

*Managing Illness in the Workplace, Joanne Bobes, MA, LMSW*

**To register go to <http://online.ccfa.org/PES11> or**

**contact Sergio Seijas at 212-679-1570, ext. 1 or [sseijas@ccfa.org](mailto:sseijas@ccfa.org)**

Symposium made possible in part with grants from the Arnold P. Gold Foundation; HSBC, USA, inc.; and UCB.