



Mark Your Calendar

August

Pace Setter 5K Run/Walk
Ocean City, NJ
August 13, 2005

Camp Oasis – CCFA Camps
Camp Nock-a-mixon
Kintnersville, PA
August 18-23, 2005

Heel to Heal 5K Walk/Run
City Island, Harrisburg, PA
August 20, 2005

September

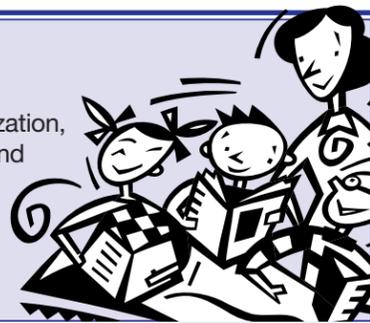
**Power Speedway
Speed the Cure**
Dover International Speedway,
Dover, DE
September 18, 2005

Sippin' by the River
Festival Pier at Penn's Landing
Philadelphia, PA
September 25, 2005

**October
"You've Gotta Have Guts"
Run/Walk**
Martin Luther King Drive
(formerly West River Drive)
Philadelphia, PA
October 1, 2005

Our Mission

CCFA, a voluntary, non-profit national organization, seeks to cure and prevent Crohn's disease and ulcerative colitis through research, and to improve the quality of life of children and adults affected by these digestive diseases through education and support.



CCFA Celebrates 11 Years of Sippin'!

Enjoy "Sippin' by the River," at this year's 11th annual event on September 25, on Festival Pier at Penn's Landing. Festivities include live music, a wide assortment of world-famous wines and beers, cooking demonstrations and fine cuisine from area restaurants. The event also features both a German beer and a Colonial Philadelphia pavilion.

Sippin' by the River also offers attendees a more intimate experience by providing an air-conditioned VIP tent. In addition to fine food, beer and wine, the VIP tent features tutored tastings by wine and beer connoisseurs. For more information about purchasing individual tickets or corporate tables in the VIP tent, call the CCFA office at 215-396-9100.

Tickets for this year's event are \$25 per person if purchased in advance, or \$30 at the gate. Purchase tickets online at www.sippinbytheriver.com, beginning August 1, or by phone at 215-396-9100.



Congratulations to Jamie Ginn of Upper Township, NJ. She competed in the Miss New Jersey pageant June 18 and won first runner-up! Way to go Jamie!

Special thanks to Edmunds Direct Mail for donating their services for all Chapter mailings.

Crohn's & Colitis Foundation of America
Philadelphia/Delaware Valley Chapter
367 E. Street Road, Trevese, PA 19053

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A Letter From Camp...

Though former youth ambassador, Catherine Marchetta's term is up, she still takes an active role in CCFA. When told some kids might be apprehensive about coming to Camp Oasis, previously Camp Guts and Glory, she wrote a letter describing her experiences and why she believes, "CCFA camp changed her life."

My name is Catherine Marchetta. I am 17 years old and live in Princeton, New Jersey. I attend Princeton High School and am currently a junior. Like you, I also have ulcerative colitis and I take at least 17 pills each day to stay healthy.

Last year I was the youth ambassador for the Philadelphia/Delaware Valley Chapter of CCFA. It was a ton of fun, and I really enjoyed meeting so many new people who suffered from IBD or dedicated individuals who were just as determined and adamant about finding a cure as I am.

I was diagnosed in August of 2001. That year was really tough for me emotionally and psychologically. The most significant reason why I made it through the year successfully was because my family and close friends stuck by me and supported me through those challenging months. However, I still longed to talk to other kids my age who were also diagnosed with IBD. Although my support system at home was really strong, nobody within it knew what it was like to be a teenager fighting against IBD.

Summer came around and my mom told me about CCFA camp. When she described how it was a camp solely for kids with IBD, I was a bit worried and nervous about what the experience would be like. I feared they wouldn't like me and I wouldn't fit in????? I WAS COMPLETELY WRONG!! I realized they were merely normal, harmless kids ... JUST like you and me.

I was informed that you're considering the idea of attending CCFA camp this year. THAT IS SOOOOOO EXCITING to hear! I absolutely LOVE camp! I have gone to Camp for the past 3 summers, and I have never reconsidered or second-guessed my decision to return each year.

CCFA camp has definitely changed my life. I really don't know how I could be living so optimistically if it were not for the support system I developed with the kids and counselors at CCFA. It has definitely been one of the MOST rewarding experiences I have ever been privileged to participate in! I really hope you will come join me at camp this summer. I have so many friends that would LOVE to meet you and get to know you better! Please come!!! I promise you will have an AMAZING time! I will always be here to listen. You can contact me through the CCFA office at 215-396-9100.

Your NEW FRIEND,
Catherine



Catherine Marchetta, former youth ambassador, offers encouraging words about CCFA Camp Oasis.

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IN THE SPOTLIGHT

A Victorious Battle



Andrew Barbin, 39, has had his share of challenges. A PGA golf professional and co-owner of two golf courses, he works hard to balance family (four boys ages 18 mos. to 11 yrs.) and the responsibilities

that come with running a business. But five years ago, Andy faced his toughest challenge yet – he was diagnosed with ulcerative colitis.

“My life changed instantly. I had a tough time with it the first few months, then I went into remission for two years,” says Andy. “But it came back with a vengeance.”

Andy could no longer handle simple everyday tasks. It was a battle to make it from one day to the next, with the pain, inconvenience and indignities that accompany this disease.

“The Crohn’s & Colitis Foundation changed my life. I went to a consultation meeting with others who had the same problems, and they convinced me to have my colon removed. It was a huge step to take,” admits Andy. Four years later, Marge Oteri, Vice President of Supportive Services, or as Andy calls her, his “angel,” guided him to surgery in December 2003.

“Now I’m back to being as good as I can be. I’m managing my son’s baseball team, playing competitive golf again...I can do anything,” Andy proclaims.

Using his contacts in the golf business, Andy founded the Victory Pass – a book that offers discounts at

golf courses in Delaware, Pennsylvania, New Jersey and Maryland. Andy began contacting courses in December 2004 and had things in motion by January. He signed up 68 courses that agreed to participate, including eight private courses. “I wanted to use my expertise to do something to help CCFA – they saved my life,” said Andy.

“Now I’m back to being as good as I can be ... I can do anything.”

When asked how he came up with the name “Victory Pass,” Andy said, “I had victory through my surgery and, hopefully, through the money raised by the book, other people will find victory as well.”

The books cost \$49.95 each, or two for \$80 and can be purchased at www.victorygolfpass.com. A portion of the sale of each book goes to charity, with the primary beneficiary being CCFA Camp Oasis. Andy presented CCFA with a \$10,000 check for Camp at the recent Bill Campbell Golf Tournament and plans to send another check at the end of the year.



Andy Barbin (third from right) presents a \$10,000 check to Chapter Chairman Richard Frankel, President Valerie Swarbrick and Golf Chairman Arnie Winick.

Upcoming Walks/Runs

The Harrisburg “Heel to Heal” 5K Run/Walk takes place on Saturday, August 20. Registration begins at 7:30 a.m., at the Carousel Pavilion on City Island, with the event starting at 8:30 a.m. The entry fee is \$20 for advance sign up and \$25 the day of the event.



The 12th annual Ocean City Pace Setter 5K Run/Walk is on Saturday, August 13. Registration begins at 7:30 a.m., at the Sport & Civic Center Building at 5th and the Boardwalk, with the event starting at 8:30 a.m. The entry fee is \$15 for advance sign up and \$20 the day of the event. The event is sponsored by Edmunds & Associates.

The 14th annual “You’ve Gotta Have Guts” 5K Run/Walk returns this year to Martin Luther King Drive (formerly West River Drive) on Saturday, October 1. The entry fee is \$15 for advance registration, or \$20 the day of the event. Registration begins at 9 a.m. at the entrance to Martin Luther King Drive (Philadelphia Art Museum area), with the race commencing at 10 a.m.

For more information or to register for any of the run/walks, please visit www.ccfa.org/chapters/philadelphia or contact the CCFA office at 215-396-9100.

Camp Oasis

CCFA is dedicated to showing children how to have a good time in an atmosphere where they can feel comfortable. Kids between the ages of 10-17 with IBD are given the chance to have a “true” summer camp experience – a week of games, sports, friends and fun. Most importantly, they are able to forget about their illness and let someone else do the worrying.

With a full staff of gastroenterologists and a nursing team on 24-hour call, the kids are free to enjoy themselves and the company of others like them.

Previously known as CCFA Camp Guts and Glory, CCFA Camp Oasis runs from August 18-23, at Camp Nock-a-mixon in Bucks County, Pa.

This year, Andrew Barbin, a competitive golfer and ulcerative colitis patient, featured on page two, will donate his expertise and advice by teaching a golf clinic at Camp Oasis.



“I want to show children how much fun golf can be and that they can overcome their disease. Teaching them to be competitive at whatever they do, whether it is business or sports, will hopefully inspire them to be competitive enough to beat their illness,” says Andy.

For information about sponsoring a child, call 215-396-9100.

LADIES AND GENTLEMAN, START YOUR ENGINES!

It’s that time of year again, when CCFA members can put the pedal to the metal and experience the thrill of being a NASCAR driver for a day. On September 18, Dover International Speedway hosts the second annual CCFA Power Speedway Speed the Cure Event. Participants have the choice of driving 10 laps around the track in a racecar by themselves, or being driven four laps at top speed.

To secure your place to drive the 10 laps, you must raise a minimum of \$1,500, which entitles you to a drive package, including: an official CCFA Power Speedway #67 Speed the Cure racing jacket, T-shirt, cap and a professional photograph of you and your racecar.

CCFA members interested in riding four laps must raise a minimum of \$500, which entitles you to a ride

package, including: an official CCFA Power Speedway #67 Speed the Cure racing T-shirt and a professional photograph of you and your racecar.

There is a \$25 registration fee due by September 9, to participate in the event. To register, please visit www.ccfa.org/chapters/greatevents/PowerSpeedway05. See you at the checkered flag!



Bacteria for Breakfast May be Just What the Doctor Ordered

by Kelly Dowhower Karpa, PhD, RPh.

Probiotics are live microorganisms, typically “healthy” bacteria, that provide us with benefits when we ingest them. The most commonly used probiotics are lactobacillus and bifidobacteria.

These friendly bacteria are advantageous to us in a variety of ways. Probiotics: (a) increase acidity in the colon, inhibiting growth of disease-causing bacteria, (b) secrete toxins that kill harmful bacteria, (c) stimulate mucus production, making it difficult for harmful bacteria to adhere to the gastrointestinal wall, (d) compete with harmful bacteria for space and nutrients within the gastrointestinal tract, (e) produce anti-inflammatory chemicals, (f) activate scavenger immune cells, and (g) increase protective antibody production.

It may come as a surprise for patients with inflammatory bowel disease (IBD) that abnormal gastrointestinal bacteria, known as normal flora, are increasingly being implicated in Crohn’s disease and ulcerative colitis. Perturbations in normal flora may be either the underlying cause or a contributing factor to IBD symptoms. In fact, from both animal and human studies, we know that gastrointestinal inflammation only occurs if gut bacteria are present.

Bacterial Theories of IBD

In 2002, two gastroenterologists at Harvard Medical School suggested what they considered to be the four most likely theories explaining

inflammatory bowel disease. Each theory involves gut bacteria.

Theory one: IBD is an appropriate response to a persistent gastrointestinal infection. Although many different microbes have been suggested, one candidate is *Mycobacterium avium* paratuberculosis. This organism is slow growing and difficult to detect, but in one study it was found in tissue biopsies from 100% of patients with Crohn’s disease and was absent from 100% of non-Crohn’s tissue specimens. Although these results are encouraging, further study is needed to determine the potential importance of this organism in IBD.

“Normal flora are increasingly being implicated in Crohn’s disease and ulcerative colitis.”

Theory two: Subtle alterations in gastrointestinal bacteria may cause IBD. Experts tell us that there are 400-500 different bacterial species living in our gastrointestinal tracts. But truth be told, we have no idea what most of these bacteria are supposed to be doing there. Scientists haven’t identified all the different species yet, so we certainly don’t know the idiosyncrasies caused when there are “too many” of one species and “too few” of another.

However, we do know some things. We know from a recent study

that patients with Crohn’s disease possess only 50% of the bacterial diversity found in healthy gastrointestinal tracts, with Crohn’s patients lacking some “healthy” bacterial species. Other studies have confirmed the finding that patients with IBD lack “healthy” lactobacilli and bifidobacteria, while additional studies have implicated too many “unhealthy” bacteria as a cause of IBD.

How could slight alterations in normal gut flora cause damaging effects? We know that metabolic by-products (i.e. butyrate) produced by many species of “healthy” bacteria have anti-inflammatory actions. On the other hand, some “harmful” bacteria actually interfere with butyric acid synthesis. Lack of anti-inflammatory chemicals produced by healthy bacteria could cause or contribute to inflammation in the gut.

Theory three: IBD will result if the mucosal lining of the gut is defective and is continuously stimulated by bacteria. This theory works on the premise that gut bacteria perpetuate inflammation if there is already an underlying defect. This theory is an extension of what is known as “leaky gut syndrome”. A “leaky gut” can be caused by many things including drugs, viruses, foods, and bacteria. Basically this theory asserts that if there is already a “leaky gut”, continuous stimulation of the gastrointestinal mucosal lining, by normal gut flora, will perpetuate inflammation.

Importantly, not all bacteria evoke

inflammation. In fact, some “healthy” bacterial species such as lactobacilli and bifidobacteria actually reduce inflammation.

Theory four: IBD occurs due to a lack of oral tolerance. This is a fancy way of saying that patients with IBD may have developed an allergy to their own normal gut flora.

Our immune systems need to tolerate the foods we eat and the bacteria that live inside of us, otherwise we begin mounting inappropriate immune responses against harmless substances. This theory draws from the hygiene hypothesis, which basically says that in underdeveloped countries, our immune systems turn on certain genes to protect us from harmful invaders. However, in sanitized conditions of the western world, these same genes tend to be liabilities, reacting against harmless foods (i.e. causing food allergies) and even non-disease causing bacteria.

Fixing the Imbalances

If gut bacteria contribute to IBD, then it stands to reason that eliminating or altering these bacteria might remedy inflammatory problems. For scores of patients, this has been true. And one can either modify gut bacteria by taking antibiotics or through the more natural means of ingesting probiotics.

Benefits of probiotics in humans with IBD were first noted in 1989, when two physicians independently published their own successes.

The first was a physician who successfully treated his own ulcerative colitis with probiotics. The second involved both IBD and irritable bowel syndrome (IBS) patients who were either “cured” or experienced significantly reduced symptoms following probiotic therapy.

During the past 15 years, numerous studies have confirmed that probiotics can be beneficial treatments for Crohn’s disease, ulcerative colitis, and pouchitis.

Though amazingly safe and often quite effective, probiotics frequently get a bad rap, probably because the industry is so unregulated. In the United States, probiotics are available without a prescription and are largely considered “alternative medicines.” This makes some prescribers reluctant to recommend them, and it often prevents insurance companies from paying for them.

Frankly, a healthy dose of apprehension is probably warranted since many of the thousands of available products have no data to back up their claims and may not be worth the price of the bottle they are packaged in.

“Several probiotic products have been shown to be extremely effective and tend to stand out from the rest.”

In my opinion, for treatment of IBD, a probiotic product:

- should contain a minimum of three different strains of bacteria (usually some combination of lactobacilli and bifidobacteria)
- should guarantee a minimum of 10 billion bacteria per dose through the manufacturer’s expiration date (realizing that in order to meet that claim, the products have to contain substantially more bacteria than that at the time of manufacturing), and should be kept refrigerated at all times.

Additionally, in order to get the most benefits from probiotic therapy, I typically instruct patients to take probiotics on an empty stomach with non-chlorinated water or milk. In our family, we like to take them one hour before breakfast.

Although there are no guarantees that probiotics will help every patient, we know from both anecdotal stories and clinical trial data that good, quality probiotics have helped many people with IBD. In fact, probiotics or “bacteria for breakfast” might be what your doctor orders.

Dr. Karpa is author of the book Bacteria for Breakfast: Probiotics for Good Health, a book that summarizes in layman’s terms all the clinical trials that have used probiotics to treat, prevent, or cure illness. She is an assistant professor at Penn State University College of Medicine and owner of An Apple A Day Health Solutions, LLC, a consulting practice where she counsels patients about probiotic therapy.

THIRD-PARTY EVENTS

Special thanks to the following members who put together fundraising events of their own and donated the money to CCFA!

- Basketball event in Collegeville – The Courides family
- Cherry Hill Fashion Show – The Mangel family

- Bowl-a-thon at Wynnewood Lanes – Gail & LillyAnn Singer
- Historic Cumberland County Tour – Laura Barness
- Flag Football Tournament – Susquehanna University – Amanda Weinstein

CLINICAL TRIALS

There are currently several clinical trials in Delaware, South Jersey and Pennsylvania. If you would like to participate in the treatment advancement of Crohn’s

and ulcerative colitis, visit www.cdfa.org and click on “clinical trials.”



Renaissance Ball

Renaissance Ball Raises a Record \$420,000 for CCFA

The sun setting over Penn's Landing provided the perfect backdrop on May 7, for the 30th Annual CCFA Renaissance Ball. The Hyatt Regency hosted 500 members and supporters who gathered to raise money for research, education and support programs for people coping with Crohn's disease and ulcerative colitis. Chairpersons **Susan and David Lipson** along with Ad Journal Chairs **Margo and Dan Polett** organized this elegant event, which raised close to \$420,000.

NBC-10 news anchor **Dawn Timmeney** served as emcee for the evening, introducing the honorees. The following individuals were honored for their exemplary dedication in helping find a cure for Crohn's disease and ulcerative colitis:

Woman of the Year
Lu Ann Cahn

Man of the Year
Richard Frankel

Physician of the Year
Dr. Anthony Infantolino

Humanitarians of the Year
Anne and Matt Hamilton

The evening included heartfelt speeches and videos, produced by **Lu Ann Cahn** and her husband, **Phil Houser**, about each of the honorees and their involvement in CCFA.

CCFA would like to congratulate all of our honorees and sincerely thank our chairpersons for their hard work.



Congratulations to this year's honorees – (l to r) Matt and Anne Hamilton, Richard Frankel, Anthony Infantolino, M.D., and Lu Ann Cahn.



Woman of the Year, Lu Ann Cahn, and event emcee Dawn Timmeney, (NBC-10 news) pose for the camera.



Ad Journal Chairs, Dan and Margo Polett (left) and Ball Chairs, David and Susan Lipson (right) helped make this year's event a success!

Education & Support NETWORK

EDUCATION GROUPS

Education Groups regularly hold informational meetings led by physicians and other healthcare professionals. Each education group has its own gastroenterologist(s) and lay leader(s) who guide the group's activities. We invite you to call the coordinator and confirm the date of the next meeting.

SOUTHEASTERN PA

Abington

Abington Hospital
Call: Howard Tevelson (215) 844-6075

Langhorne

St. Mary Medical Center
Call: Lynn Gelman (215) 752-7089

Lansdale

Central Montgomery Hospital
Call: Nancy Schmidt (215) 343-0548

Philadelphia

Graduate Hospital.
Call: Ellen Cohen (215) 546-5842

Philadelphia

Jeanes Hospital
Call: Lynn Kazoroski (215) 342-7190 or
Howard Tevelson (215) 844-6075

West Chester

Chester County Hospital
Call: Ginger Gray (610) 430-1698

NORTHEASTERN PA

Pocono Pines

Clymer Library
Call: Joyce Castillo (570) 646-6332

Scranton

Community Medical Center
Call: Marie Huggler (570) 457-2231

CENTRAL PA

Carlisle

Carlisle Regional Medical Center
Call: Carol Garling (717) 776-7130

Lancaster

Lancaster General Hospital
Call: Bob Brockley (717) 625-4653

Susquehanna

Evangelical Community Hospital
Call: Sharon Murphy (570) 522-2994

NEW JERSEY

Atlantic City

Atlantic City Medical Center
Call: Donna Lombard (609) 602-6167

Cherry Hill

J.F. Kennedy Memorial Hospital
Call: Sherri Katz-Gordon (856) 424-0459

Hamilton

Robert Wood Johnson Medical Center
Call: Bill Giovannetti (609) 587-7215

DELAWARE

Wilmington

Christiana Hospital
Call: Cheryl Wheeler (302) 764-5717

SUPPORT GROUPS

Support Groups provide support and coping skills to enable patients and their families to live successfully with IBD. Meetings are coordinated by trained volunteers.

ILEO-ANAL GROUP

Philadelphia, Presbyterian Medical Center
Call: Marge Oteri (215) 698-2251

OSTOMY SUPPORT GROUP

Philadelphia, Thomas Jefferson Hospital
Call: Judy Axler (215) 561-4780 or
Lyn Kirshenbaum (215) 629-1648

PARENT AND CHILDREN SUPPORT GROUP

Philadelphia, Children's Hospital of Philadelphia
Call: Fran Martin (215) 782-1250

SUPPORT GROUP LEADERS NEEDED!

If we don't have a support group in your area, then give us a call. Maybe you could become a trained support group leader.

"Heel to Heal" People and Dog Walk



Arden Rhodside, daughter of Suzanne Rhodside, Development Director for CCFA, takes a ride on Tugg at the "Heel to Heal" People and Dog walk on Saturday, June 4 in Norristown, Pa. Tugg won the largest dog contest, one of many contests included in the day's festivities. More than 40 dogs and their owners raised \$15,000 for CCFA.

Special thanks goes to the following sponsors: Gertrude Hawk, Canine Country, Disability Benefits Law Center, Bryn Mawr Medical Specialists Endoscopy Center,

Commerce Bank, ProPlan, J.J. White Inc., Einstein Bagels, ViaVeneto Italian Ice, ISG Office Concepts, Inc., Porretti Contractors, All About Dogs, A Loving Touch, Community Medical Center, The Finkelstein Family, Gastrointestinal Associates, Inc., Hillmont Gastroenterology, Mail Line Gastroenterology, Pepperidge Farm, Inc., Philadelphia Gastroenterology Consultants, Quest Diagnostics, The Resort at Split Rock, Target and the Vaccaro Family.

