



THE CHILDREN'S IBD CENTER AT MOUNT SINAI

WINTER 2006/2007

News From Team IBD

By Kathy H. Thal, PNP

On November 5, 2006 Dr. Benkov and a team of 25 runners set out to run the NYC Marathon with a dual mission; to raise funds for research at The Children's IBD Center and awareness of Inflammatory Bowel Disease in children. Our team was diverse and each runner brought with them a unique and interesting story. Approximately half the runners were running a Marathon for the first time.

The week started off with Dr. Benkov and some runners appearing on WBLI on Long Island first thing Sunday morning. On Thursday, Dr. Benkov along with members of the IBD Center and six runners appeared on The CBS Morning Show. From there, it was on to Marathon Day.

The runners were off at the starting line, while a group of IBD Center staff, children and their families organized by Susan Naveran donned

their "Team IBD" t-shirts and met in front of 1st Ave and in front of Mount Sinai to cheer for the runners.

Amongst the runners were fathers, mothers, uncles, brothers, friends and doctors of children with IBD. There were Mount Sinai employees and their spouses, researchers and runners with IBD themselves. When we set out to recruit runners for "Team IBD" our mission was to find runners who equally shared our passion for the cause - helping children with IBD. So, we asked the question "Do you have any connection to IBD or to The Mount Sinai Hospital?"

Many of the responses and stories from our runners were extremely inspirational and we wanted to share them with our families: "I was diagnosed with Crohn's when I was 14. I have had many surgeries and know the pain these children are living with. I have since ridden as a member of an Equestrian team, had triplets, and run 4 marathons"

"I have UC diagnosed 4 years ago. I wanted to do something to make a



Bill and Jack Rudin, longstanding sponsors of the ING New York City Marathon; Greta Weitz, 9 time winner of the New York City marathon; Keith Benkov and Daniel Glass, 2 runners in Team IBD, running to raise awareness and funds for pediatric IBD.

difference"

"Our daughter has colitis - I ran the DC Marathon years back - now, I have incredible inspiration to run the NYC Marathon to raise awareness for IBD"

"I am 33 years old, live in Canada and have UC. I found out about your team from an American lady I met while running. I believe a child she knows with Crohn's disease

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Cheers for Volunteers

By Clare Ceballos, RN, PNP

Our unseasonably warm weather makes it hard to call this the winter newsletter! This season we wanted to highlight the work of volunteers. Liz Wachstein describes her summers volunteering at a camp for children with IBD. This past November Team IBD came together to run in the New York City Marathon to raise awareness and funds for pediatric IBD. Finally our Family Friends Program was recognized as a winner for the work the volunteers do with families newly diagnosed with IBD. Please join us for the next Children's IBD Center Lecture, "New Medications in IBD" by Nanci Pittman, M.D. at The Zone, 1184 Fifth Avenue, on February 6th 2007 at 5pm. We look forward to seeing you there.

Start the New Year Fresh, Be A Volunteer

By Liz Wachstein

Camp Oasis for me is the one thing that I look forward to every year regardless of my busy schedule. As hard to imagine as it maybe, I think that I might actually look forward to camp more than the campers! It is the one place where I can escape for just 5 days at the end of every summer and finally just be me without having to explain to others what I have (Crohn's) and why I am the way I am. Everyone there is just like me. Although a lot of people may be sicker and some are even less sick which is great because I have never felt better than I do right now, everyone has either Crohn's or Ulcerative Colitis.

I can only imagine how different my childhood would have been if I had been able to go to Camp Oasis. Instead, I went to your typical sports-oriented sleep-a-way camp for 3

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Team IBD continued...

was treated at Mount Sinai. I never knew such a place existed and I will be honored to be part of your team. The 2 year anniversary of my disease will fall on Marathon day, November 5th. At this time, I am potentially heading towards surgery. It's easy to get down about this disease and how life altering it may be. I think about all the children with ulcerative colitis and Crohn's disease and how tough it must be to be dealing with it through your adolescence. I became a mother 6 months ago and am aware that my child could be at risk of developing this disease so I know that research in this field is key. Oh, one other detail you ought to know, I will also be running the Chicago Marathon two weeks prior to the NYC Marathon. So, on Nov. 5th, this worthy cause is going to see me through those tough last few miles"

And our final inspirational story- A father of one of our IBD Children who set out late in his Marathon training and was skeptical of his ability but extremely motivated met with a woman who promised a "significant contribution" with the request that he meet with her to pick up the check, which he did. In their short interaction, she strongly encouraged him to not run the Marathon because he was a "Mesa morph". She said that he did not have to worry about the donation because she would make it anyway and as a matter of fact, she so believed that he should not run that if he didn't, she would double the pledge. Of course, that was a hard offer to refuse but this father was determined to accomplish what he had set out to do-run for his son and for all children with IBD. So he politely thanked her for the generous contribution and concern and said that he felt compelled to run. Upon leaving, he quickly e-mailed Dr. Benkov and said "What is a Mesa morph?" Despite all the adversity, he ran his first Marathon and finished in excellent time.

Thank you to all the dedicated runners and families who supported The Children's IBD Center for this extremely successful event.

Be A Volunteer continued...

summers followed by three additional summers at a wonderful arts camp in Maine. At both camps I knew and was constantly reminded of how different I was from all the other campers and in particular my friends. I was always leaving meals early to either take medicine or use the bathroom and it was very difficult for my friends to understand, I mean how could they, there was no way! One of the many fantastic things about Camp Oasis is that at every meal and even evening activity (for those who take meds 4 times a day) the meds are brought to the campers and counselors! Another wonderful and probably the most important aspect of camp, is that we are like one big family. I can only imagine how much easier it would have been for me if I had had this remarkable place where everyone is there to help and support one another, where counselors help campers, campers help campers, and counselors help counselors.

Through inspirational and often troubling stories of dealing with IBD, we find strength in one another and the means to carry on. Whenever I am feeling sick or depressed I know that without a doubt I can call anyone from camp and they will be there to talk to me. I also love being an example to my campers of someone who can grow up being very sick and turn out pretty darn well, feeling for the most part healthy and very happy.

This is why I can't wait until camp rolls around each year!



Liz Wachstein

Family Friends Program Wins National Award

By Clare Ceballos, RN, PNP

The Children's IBD Center **Family Friends** Program won the Excellence in Patient Education Award at the Association for Pediatric Gastroenterology and Nutrition Nurses annual meeting, in Orlando, Florida in October. The Family Friends Program trains volunteer parents and young adults to counsel families of children who have been newly diagnosed with IBD or who are undergoing a new therapy or surgery. If you are interested in a referral to, or in volunteering for the program, please contact the Center social worker, Bambi Fisher at bambi.fisher@mssm.edu or call (212) 241-9113

IBD Kids Chat

Please join us for our next IBD Kids Chat group, 2/6/07 at **The Zone**, 1184 5th Ave, 5:00-6:00pm

We want to hear from you:

To contact us or to receive updated information about Center events, please contact us by:

E-MAIL: ChildrenIBD@mssm.edu

PHONE: 212-241-5415

WEB SITE: www.IBDKids.com

Address:

Children's IBD Center at Mount Sinai
5 East 98th Street
New York, NY 10029

Resources for Families:

www.IBDKids.com

www.CCFA.org

www.medlineplus.gov

Some suggestions from patients:

www.Crohnszone.com

www.dragonpack.com

www.healingwell.com

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The Children's IBD Center at Mount Sinai is funded solely through philanthropy. Please contact us if you are interested in making a contribution to support our Center or in learning about other ways that you can help.