



Summer 2011

# THE CHILDREN'S IBD CENTER AT MOUNT SINAI NEWSLETTER



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**Future Lecture & IBDkids Chat group:** October 11th and December 13th 2011

## The Annual Wilson Fundraiser Was an Astounding Success!

By Keith Breglio, M.D.

**F**or the fourth year in a row, George and Antoinette Wilson orchestrated a beautiful and successful fundraiser for the Children's IBD Center on Sunday, March 13<sup>th</sup>. With 140 attendees, this year's fundraiser was the largest yet. In previous years, the fundraiser was held at George and Antoinette's restaurant, Ancona Pizzeria in Valley Stream, New York, but because the number of attendees has grown significantly, this year's fundraiser was held at the beautiful Garden City Country Club on Long Island. The day included musical entertainment by a wonderful D.J., delicious food, and even an amazing dance performance by George and Antoinette's daughter, who has been a patient at the Children's IBD Center since 2008. Through their hard work and dedication, the Wilsons were able to organize wonderful raffle prizes in the form of gift baskets and packages including movie tickets, jewelry, bath and spa products, children's toys, and more. Silently auctioned items including art work, autographed sports memorabilia, and an iPod touch drew a large number of excited bidders. Along with this, there were local vendors from Long Island selling beautiful crafts and clothing.

Everyone in attendance had an amazing time, and the afternoon was a tremendous success. The event raised more

than \$6,000 for the Children's IBD Center at Mount Sinai Hospital. We are thankful to the Wilsons for all of their hard work and dedication in putting together a successful event!



Dr. Keith Benkov speaks to the crowd at the Wilson Fundraiser.

## Narrative Medicine Workshops at The IBD Center

By Caitlin Chase, Laurie Gunst  
The Narrative Medicine Workshop for adolescents is a program that works to allow teens to explore their voices and personal narratives, facilitate a community of trust and empathy, and enable teens to connect with peers who share similar experiences with illness. We have been working with Columbia University's Narrative Medicine program and were pleased to have the opportunity to facilitate a workshop for adolescents as well as a workshop for parents at the

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Children’s IBD Center this past Spring. We begin each workshop with a detailed reading of a short work of literature. Members of the workshop explored a multitude of genres, including poetry, memoirs, and short stories. Following the reading, we have the participants respond to a related “writing prompt” or question. We close each workshop session with the opportunity to share and discuss the day’s literary work and our responses with the group.

The participants in the workshops gained a lot from the experience. One teen, when asked if the workshop changed his thinking about his illness, replied “Yes, because now I hear what other kids my age have to say and I know I am not alone.” Another teen remarked, “[the workshop] has challenged me about my acceptance and who I shared it with. I now know that who I share my story with is up to me.”

At our second workshop, one mother remarked that, although she tried very hard to pick up a book and stay with it, she was so tired so much of the time that she just couldn’t keep from falling asleep after only a few pages. In addition, her native language was Spanish, so we began to search for and find texts—poems, sections from fictional works—in both Spanish and English for us to talk and write about in our workshops. It became one of our greatest joys, at the outset of our sessions, to hear her read these selections in Spanish before we then read them in English. Meanwhile, we were remembering what she’d said, about finding it so hard to concentrate on a whole book, and thinking about what we could do to make that possible.

We found a Spanish translation of the novel *The Secret Life of Bees*, by Sue Monk Kidd, and gave it to her at our next workshop. Two meetings later, she brought in her much-thumbed, dog-eared copy to show us. “Look how much I’ve read!” she exclaimed. “I’m almost halfway through, and I **love** this story!” We were so happy!

“Do you still fall asleep when you read?” we asked, with a wide smile. “Oh, yes,” she said. “But I just wake up and keep reading.”

Of all the gifts that our group

members gave us, this was the best. And it made us realize one of the things about teaching this workshop—and almost any narrative medicine group—that we treasure the most. The three parents who came together for our Mount Sinai workshop were so very diverse: Jewish, Hispanic, and African American. In almost any other setting, they might never have even met, much less been encouraged by the narrative medicine framework, to trust one another enough to share their stories and their lives.

We are not only grateful to them, but also to the department of Pediatric Gastroenterology at Mount Sinai, whose wonderfully generous and supportive staff made this experience happen.

In helping children coping with illness and their parents to share their stories and meet others just like them with similar experiences, these workshops have had a profound impact on their participants. Overall, the program looks to have been an astounding success!

## P.S. 42 Students Present the IBD Center with a Check

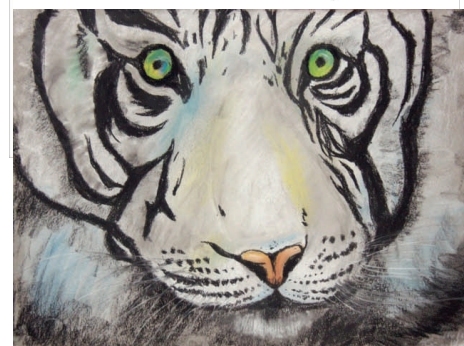


**D**r. Nanci Pittman accepts a check from P.S. 42 student, Olivia. The funds, for \$850, were collected from a student penny harvest. The IBD Center applauds their success!

## IBD Kids Show Artistic Talent

**M**any of the children at IBD Kids like to express their creativity and talent through art. Below is a poem by Michael, age 8 and art work by Alexa, age 13.

Mothers Day morning, I couldn't lift my head.  
All I wanted to do was lay in my bed.  
We went to Mount Sinai because  
Dr. Breglio said  
I needed a blood transfusion.  
After mom told me that, it left me with such  
Confusion.  
The blood went drip, drip, drip into my arm.  
Not knowing who's blood it was I was very  
Alarmed.  
It could of been A-Rod's for all I knew but it  
didn't  
Matter because it made me feel as good as  
new.  
My numbers went up so quickly I was in  
shock  
I felt so strong, as strong as a rock.  
As time goes on I'm going to beat this  
Crohn's Disease  
No matter how much... It Challenges Me!



# Meet the Challenge, Run with Team IBDKids

By Tom Fitzsimmons

**T**his November a group of people dedicated to improving the lives of kids with IBD are going to feel a rush of success as they cross the finish line having put their own courage and endurance to the test. These people are the marathon runners of Team IBDkids. They are not super-human but they are committed, and you can be one of them this year.

Summer is a good time to start training for the ING New York City Marathon, one of the world's great road races, which will take place on November 6. Team IBDkids is looking for a few determined runners to challenge themselves and help children with IBD by raising funds to support the programs and research at the Children's IBD Center.

This is the sixth year in a row that Team IBDkids has run the marathon. Is 2011 your year to meet the challenge? The ING New York City Marathon draws more than 100,000 applicants each year. Team IBDkids is able to guarantee entry for a limited number of runner-fundraisers. Kids with IBD know about endurance, now is your chance to help them with your toughness and commitment.

For information on applying to run with Team IBDkids this November go to [www.ibdkids.org/run-with-team-ibdkids](http://www.ibdkids.org/run-with-team-ibdkids) or contact the Center's Project Coordinator: Tom Fitzsimmons [thomas.fitzsimmons@mssm.edu](mailto:thomas.fitzsimmons@mssm.edu) (212) 241-6727

## Become a Non-Running Teammate

Not all of us are capable of running a 26.2 mile marathon. No worries, you can still join Team IBDkids by setting up your own fundraising page on the team's website. Our "non-running" teammates have played a crucial role

in the success of Team IBDkids in years past by using their own personal fundraising pages to connect with their friends, families and colleagues, raising awareness and bringing in donations.

Here is how you can create your own page to support our 2011 ING New York City Marathon effort. On the home page of [ibdkids.org](http://ibdkids.org), click the Team IBDkids logo on the left side of the screen (this will take you to [www.active.com/donate/TeamIBDKids2011](http://www.active.com/donate/TeamIBDKids2011)). At the top of the Team IBDkids 2011 page, just beneath the logo, click the link to "Become a Fundraiser."

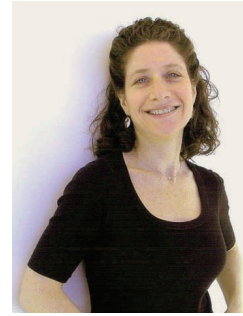
You will be prompted to create a username and password and to enter some basic information. Then you log in with your new password and customize your web address and your web page by entering your own message, uploading pictures, and setting a goal. Click "save & finish" in the bottom right corner and you're done – you have joined the team.



## Nutritionist Erica Ilton, Joins the IBD Center

**O**n June 7, The Children's IBD Center's new Nutritionist, Erica Ilton, held her first open session at the practice. Erica, a senior nutritionist at Joy Bauer

Nutrition for seven years, and currently in private practice in New York City, is bringing her expertise to the Center, and contributing to the multi-disciplinary care available.



Erica Ilton, RD, CDN

Erica's areas of expertise include gastrointestinal disorders such as Crohn's and colitis, irritable bowel syndrome, celiac disease, gastroesophageal reflux disease as well as weight management, cardiovascular disease, metabolic syndrome, fatty liver, polycystic ovary syndrome, food allergies, osteoporosis, and dietary supplement guidance. She graduated from Brown University, studied nutrition education at Teachers College-Columbia University, and interned in clinical dietetics at White Plains Hospital.

In addition to her work as a nutrition counselor, Erica writes about health and nutrition for major U.S. publications. She was also Director of Nutrition Research for *Food Cures*, by Joy Bauer, and editor of the fourth edition of *The Complete Idiot's Guide to Total Nutrition*. Prior to joining Joy Bauer Nutrition in 2003, Erica was the senior nutritionist at Reebok Sports Club/NY, and a contributing producer for the "Leonard Lopate Show" on WNYC New York Public Radio, and NPR's "Talk of the Nation: Science Friday."

Every Tuesday afternoon at our practice is IBDday and the full care-giving team of the Children's IBD Center is available on those afternoons. Erica will join us on the first Tuesday of each month, and will be available for group question and answer sessions. She has also begun to conduct online group video chats on nutrition. Individual nutrition sessions with Erica are available by appointment; she can be contacted directly at 347-809-6789, or by emailing her at [Erica.ilton@mounsinai.org](mailto:Erica.ilton@mounsinai.org). The Center is happy to have Erica sharing her expertise with us.

**Can You** think of creative ways to support The Children's IBD Center? Targeted grant money, donations to our existing programs and your ideas and participation all help. Please contact us at [childrenIBD@mssm.edu](mailto:childrenIBD@mssm.edu) to discuss your ideas and help support our work.

We want your feedback regarding our programs and suggestions for improvements to better meet your needs. In the coming weeks, we will be sending a survey to families followed at The IBD Center via electronic mail. Please complete the survey, which takes about 10 minutes to fill out. It will help us to better serve the families who come to the Center. Thank you from The Children's IBD Center Staff.

### **We want to hear from you:**

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

**E-MAIL:** [ChildrenIBD@mssm.edu](mailto:ChildrenIBD@mssm.edu) **Please email us so we may add you to our contact list and keep you updated on Center activities!**

**PHONE:** 212-241-5415

**WEB SITE:** [www.IBDKids.org](http://www.IBDKids.org)

The Children's IBD Center at Mount Sinai is funded in large part 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.

### **Resources for Families:**

[www.IBDKids.org](http://www.IBDKids.org)

[www.CCFA.org](http://www.CCFA.org)

[www.medlineplus.gov](http://www.medlineplus.gov)

The Children's IBD Center at Mount Sinai offers the following services for families:

- **Regular lectures where you can learn more about the disease and meet other families and Center staff**
- **IBDChat, an interactive group for kids with IBD and their siblings**
- **IBD Parent Chat, a support group for parents by parents**
- **IBD Tuesdays, where you can see our Social Worker, Child Life Worker, Psychologist, Nurse Practitioner and Dietician in the Faculty Practice**
- **A website of resources for families at [www.IBDKids.org](http://www.IBDKids.org)**



The Children's IBD Center at Mount Sinai

### **The Department of Pediatric Gastroenterology**

One Gustave L. Levy Place  
Box 1656  
New York, NY 10029

Tel: (212) 241-5415  
Fax: (212) 831-7974

[ChildrenIBD@mssm.edu](mailto:ChildrenIBD@mssm.edu)