



Winter 2010/2011

# THE CHILDREN'S IBD CENTER AT MOUNT SINAI NEWSLETTER



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Latest Offering in the  
Center Lecture Series

A panel of young adults  
with IBD share their stories  
**Reflections on Parenting a  
Child with IBD**

A father with UC  
remembers how his parents  
helped him as a teenager  
**Center Clinical Coordinator  
Clare Ceballos wins the  
2010 New York Times**

**Tribute to Nurses Award**  
Clare wins award for  
community service

**New Opportunities for IBD  
Kids Chat participants**  
Children and teens can now  
work with Kid Zone TV  
productions to broadcast  
shows to hospitalized  
patients

### SAVE THE DATE:

Parent Lectures & IBDChat  
will be offered on the  
following days, 6:00-7:00pm

**April 12**—Advancing  
Understanding: Current

Research at The Children's  
IBD Center

Future Lecture & IBDKids  
Chat group:

October 11th 2011

December 13th 2011

## Becoming Successful Adults with IBD

By Kathy Hoffstadter-Thal, NP

**O**n Tuesday, December 14<sup>th</sup> 2010, the Children's IBD Center had a special presentation in place of our usual bimonthly lecture series. On this day, four young adults with IBD presented their journey with IBD to staff and families of children with IBD. The panel was diverse and each of the four presented their personal stories and perspectives in dealing with IBD.

**William, a financial analyst with Crohn's disease**, now a parent with a two children of his own, discussed that as a parent, he now appreciates what his parents did for him. He stressed that when safe and feasible, parents should allow teens and young adults to have the opportunity to test their boundaries. Teens and young adults with IBD should not live in a bubble. William wanted to be like everyone else and embraced wrestling in high school. "If someone told me that I couldn't do something, I made sure to do it. For example, my boss told me that I should not become a financial analyst because it was too stressful, so I became a financial analyst."

**Chelsea, an actress with Crohn's disease**, spoke of how she has always been independent, wanting to do everything that everyone else was doing. Her parents were supportive. Chelsea has always been open about her Crohn's disease but has focused her energy on her passion of acting,

*(Continued on page 3)*

## Lecture Series & Kids Chat moves to the Zone

By Clare Ceballos, NP

**T**he bi-monthly lecture series and the Kids CHAT and Parents CHAT groups are moving to a new location. Starting in February 2011, our bi-monthly educational and support groups will be held in The Zone. The Zone is a therapeutic creative arts and play space located off the lobby of The Kravitz Children's Hospital at Mount Sinai, on Fifth Avenue.

One of the many advantages of using The Zone, is the opportunity to participate in KidsZone TV programming. KidZone TV is a state of the art, interactive production and internal broadcast studio within the children's hospital. KidZone TV produces live programming at least twice a day, seven days a week, for pediatric patients and families throughout the medical center on a dedicated channel. Hospitalized children, who are confined to their rooms, are able twice daily to tune in and participate in KidZone TV programming. Live entertainment includes musicians, actors, choirs, magicians, and science programs. Popular interactive games that promote learning, socialization and creativity are Bingo, Name That Tune, Text Twist, and other KidZone Trivia shows. Children have the opportunity to participate within the studio as camera operators, storywriters, or hosts of the show, while others have the opportunity to view the program and participate by calling in and answering a question, creating a story or winning prizes.

At the most recent lecture

*(Continued on page 3)*

# I Have UC, but UC Doesn't Have Me—Advice for Parents of Teens with IBD

By Brett, A successful businessman living with ulcerative colitis.

**T**he diagnosis came as a shock and I was too young to truly understand the concept of a chronic illness. Up until that point in my life, when something was wrong I fixed it and jumped back into my routine. What I know today is that Ulcerative Colitis is an ongoing part of my life. I have learned over the last 20 years that living with a chronic illness is part of what makes me who I am. Today I am very accepting of my condition, bordering on proud. So how did I get to this point and how can parents of teens with IBD help their kids get here sooner?

I was diagnosed when I was 16 years old. I was a typical teenaged boy who liked girls and sports and wasn't old enough to know what else I liked. These two pursuits were constantly hampered by frequent and urgent trips to the bathroom, if I was lucky enough to make it to the bathroom. To a 16 year old, any inconvenience is a big deal. And for any teenager, IBD is just about as inconvenient as it gets.

Looking back, a few things helped me get through this. The first was an amazing support group of family and friends. I was simply lucky. My family is great and I had friends that were incredibly understanding for teenagers. If I were the parent of a teen with IBD, I would pay close attention to my kid's friends. You can't necessarily control who your teenager chooses to hang out with (nor do I think you should), but you certainly can influence your kid's choices.

Secondly, I had a good sense of humor about my condition. I made fun of myself and was way out in front of any jokes that my friends

were thinking up. Again, this is not something you can necessarily control as a parent, but you may be able to steer it in the right direction.

Finally, and most importantly, I felt "normal". And this is the part I think a parent has the most control over. Statistically speaking, nearly 1 in 2 Americans is living with a chronic illness. So does that mean half are normal and half aren't? Good luck explaining that to your teenager. Your teen doesn't yet understand the concept of "normal", but this is the most important thing in their life. Treating your teenaged child as if (s)he's extremely delicate and requires special attention breeds a feeling of "abnormality" that teens despise. Parents need to let go a little bit so that a teenager with IBD can have the chance to be a "normal" teen. Letting go will likely lead to moments of embarrassment and pain that probably could have been prevented. I am making the argument that these moments may be worth the upside in the long run. I'd ask all parents of teens with IBD to give this some consideration.

It must be extremely difficult to be a parent of a teen with IBD. I don't claim to know what it's like. I only offer the above thoughts as a former teen with IBD who has grown into a very happy adult life. When you're running to the bathroom with great urgency 10-20 times a day at the age of 16, all of the sudden life takes on a whole new perspective. Today, I am 35 years old with a beautiful wife and a 2-year old son. Things that used to be a big deal aren't such a big deal anymore, and the things that really matter leapfrog the daily minutia. The joys of my life are magnified and pop from the shadows of regular pain, fatigue and inconveniences. Chronic illnesses are terrible...of course. But they can either be viewed as permanent "abnormality" or adjusted lifestyles with both good and bad side effects. I urge the parents of IBD patients to consider that their kids will one day have an amazing perspective on life that others may not have. That and that alone is what should make them feel "abnormal". Hang in there.

# Clare Ceballos, NP, Wins the New York Times 2010 Nursing Community Award

By Kathy Hoffstadter-Thal, NP

**O**n December 5<sup>th</sup>, 2010 Clare Ceballos, the Nurse Practitioner and Clinical Coordinator of the Children's IBD Center proudly represented Mount Sinai in the New York Times magazine as the winner of the 2010 Community Award for Nursing. Clare was the first Mount Sinai nurse to ever win this prestigious award, making Mount Sinai and the Children's IBD Center extremely proud.

Anyone who has had the good fortune to work with Clare knows that she is well deserving of this award. Clare's leadership skills at the center have contributed to the development of our lecture series, children's CHAT group, IBDKids.org website, Center newsletter and many Center activities that have revolved around children and families at the IBD Center getting to know one another.

Clare not only gives of her time to volunteer at Camp Oasis, the CCFA camp for IBD, but she also volunteers her time and expertise to help children with life threatening illnesses at Camp Sunshine.

The Children's IBD Center commends Clare for her exemplary performance as a nurse and honors her for her outstanding achievement and relentless dedication to children.



Clare Ceballos with Carol Porter, RN, Keith Benkov, MD & Carol Torchen, RN

## Becoming Successful Adults with IBD, *Continued from page 1*

not her disease. She admits that as a teen, there were times that she skipped her medications especially the prednisone since it made her look different. But then she ended up in the hospital so –yes, she wished she had listened to the doctors and her parents and stuck to the pills.

**Adam, a PhD student with Crohn's disease**, said that when he was first diagnosed his parents gave him the space he needed but checked in on him in a non-threatening way. They gave him the space he needed to adjust to his diagnosis. Adam shared that he and his friends with CD and UC always felt that their parents related to them as though they were sicker than they were. "My mom's anxiety made me more anxious." His advice to parents of teens with IBD is to be realistic and not exaggerate the child's illness which may result in a self fulfilling prophecy. "Now that I am older, my mom says that she thinks my illness affected her more than it affected me."

**Brian, an outdoor enthusiast/entrepreneur with Crohn's disease**, shared that when he was first diagnosed people asked him how he was going to continue to do all of his activities. But despite his Crohn's disease, he continues to go camping, rock climbing, skiing, hiking, kayaking and has even tried sky diving. Follow your passion and live a normal life is his advice. "I have climbed a 300 hundred foot sandstone. If you want to do something, there is a way."

We thank our panel members for their candid

presentation and the parents for the thought provoking questions and comments.

Two of our terrific *IBD Center Young Adult Volunteers* are trained and eager to be contacted by parents or patients to talk by phone or by email and share their experiences and thoughts. Whether newly diagnosed, starting a new treatment, going to camp or college for the first time, or just wanting to chat about what has worked for them in coping with IBD, Chelsea and Adam are happy to offer their time. Chelsea can be reached at [chelsea.stock@gmail.com](mailto:chelsea.stock@gmail.com) and Adam is at [adamfrankel1@gmail.com](mailto:adamfrankel1@gmail.com).

## Lecture Series & Kids Chat moves to the Zone, *Continued from page 1*

and Chat group evening, ten children participated in a live broadcast on KidZone TV of Pictionary. While hospitalized children called in to guess what was being drawn, the IBDKids Chat group took turns drawing pictures and also helped with camera and sound production. This provided a great opportunity for the participants to help hospitalized children and their families by creating an interactive show, but also was an opportunity for kids with IBD to meet others who also have the same disease.

After the program had finished and the parent lecture had concluded, parents had the opportunity to participate in their own Parent Chat group, or to mingle with one another and informally discuss the challenges of

parenting children with IBD. The kids had an opportunity to interact with each other and participate in Zone activities, including arts and crafts, air hockey and pool, under the supervision of Yuki Takahashi, Child Life Specialist.

Our next lecture and Chat groups will be held on April 12th. We hope that you will join us.

## Narrative Medicine—An Exciting New Program Available Through the IBD Center

By Clare Ceballos, NP

**H**ave you ever read a sentence in a story or heard a line in a song or poem that describes exactly what you're feeling? Have you ever tried writing your thoughts down to try to understand them better? Or maybe you've wished that you had an opportunity to express your experiences and feelings on paper?

The Children's IBD Center is offering a Narrative Medicine Workshop, run by facilitators from Columbia University's Narrative Medicine Program.

Narrative Medicine workshops are based on "close reading" of a text—a story, a poem, or picture—that we read or look at together. Words or phrases will resonate in a particular way for each of us, and as we listen to each other, the text itself takes on new layers of meaning. This is what we mean by "close reading," and it leads naturally into the second part of the workshop, "reflective writing," in which we take four or five minutes to connect our own experience to the text.

Workshops are being offered for both parents and 12-17 year olds. For more information, contact Tom Fitzsimmons, The IBD Center Special Program Coordinator, at [thomas.fitzsimmons@mssm.edu](mailto:thomas.fitzsimmons@mssm.edu) or 212-241-6727.

## CCFA Summer Camp August 16-21, 2011



**T**he CCFA runs a co-ed residential summer camp for children living with Crohn's disease and ulcerative colitis. They are currently accepting applications for campers in grades 3-10; for the leaders in training program for grades 11-12; and for volunteers over age 18.

If you are interested in this fantastic experience contact the CCFA at [www.cffa.org/camps](http://www.cffa.org/camps).

**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.

Please join us for our next lecture:  
**Tuesday, April 12th**  
**5:30-6:00pm—Meet other families & Center Staff**  
**6:00-7:00pm—Lecture & IBDKids Chat activity**  
**7:00-8:00pm—Parent Chat**

### **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 & Center staff
- IBDCChat, an interactive group for kids with IBD & their siblings
- IBD Parent Chat, A support group for parents by parents
- Tuesday Talks, open discussions on topics of interest to families with IBD, held on Tuesday afternoons in the Faculty Practice
- A website of resources for families [www.IBDKids.org](http://www.IBDKids.org)



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