



Fall 2020

THE CHILDREN'S IBD CENTER AT MOUNT SINAI NEWSLETTER



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A parent shares her experience

A Crohn's Success Story

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Team IBDKids Runs the ING NYC Marathon to Raise Funds & Awareness of Pediatric IBD

Team IBDKids was supported by an enthusiastic cheering squad outside the hospital on Fifth Avenue

Center Staff Volunteer at CCFA Camp Oasis

Several members of the Mount Sinai medical staff volunteer at the CCFA summer camp for children with IBD

SAVE THE DATES:

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

Dec. 14th—Becoming a Successful Adult with IBD

A panel of young adults share their stories of success with IBD and answer your questions

Feb. 8th

April 12th

Coming to Mount Sinai for IBD Tuesdays, A Parent's Reflections

Last week, my ten-year-old son, Noah, and I headed into NYC for our scheduled appointment with Noah's Gastroenterologist, Dr. Benkov. It was three-and-a-half years since Noah had been diagnosed with ulcerative colitis, and like many children with IBD, Noah has been through the ringer: hospitalizations, prednisone, transfusions, you name it. Today, however, was expected to be a "routine" visit, as Noah was energetic and asymptomatic.

Several weeks earlier, Dr. Benkov had suggested that I bring

Noah to Mount Sinai, on a Tuesday, so we could combine his check-up with activities offered weekly, at the IBD Center. Now that the day had arrived, I was in the mind-set of an overly-scheduled person. I thought, 'schlepping into NYC from Fairfield, CT is a bit of an imposition'; After all, I rationalized, why bother... I'm his MOTHER, and I can see that he's well! I caught myself indulging in self-pity, and consciously switched to gratitude: What a luxury to have this be my biggest problem of the day! What a joy to see my son looking and

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Chelsea Stock, Broadway Star, tells her Story of Success

My war began 12 years ago, at the age of 13, when I was first diagnosed with Crohn's disease. At first I was told I had mononucleosis, but with no improvement in my symptoms, and a weight loss that left me at what I weighed when I was 10 years old, a referral to a pediatric gastroenterologist resulted in the diagnosis. I had pain, ulcers in my mouth, involvement of most of my GI system, discomfort, and embarrassment. However, I have used my inner determination, and my strength, to eventually succeed in beating this disease back.

As a child I was very active, always busy with dance classes, rehearsals for dance and musical theater performances, soccer practice, and more. My dream was to make it to the Broadway stage. My family and I knew something was wrong when I suddenly lost my



spunk and energy. Everything seemed to come crashing down when I was forced to quit soccer, along with the musical I was in at the time.

After what seemed to me at the time to be a million different tests, the doctors at the Packard Children's

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IBD Tuesdays

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feeling healthy!

After Noah's doctor's appointment, which was affirmative and up-lifting, Noah and I hit the local pizza place, and then returned to the IBD Center for the lecture/activity. While I went to the lecture, Noah went to a support group/art activity for children, led by Bambi Fisher, LCSW. Before he and I split for our respective events, Noah whispered in my ear, "I hope it's not like school". Later, when we met up, he told me happily that the first thing said was, "This is not like school." From that moment, Noah was on board.

On the car ride home, both of us agreed that combining the doctor's appointment with the IBD center activities was a really good idea. Noah had fun with the other children, while I learned new, useful information on IBD. My only regret was that Noah's approaching bedtime didn't allow my attendance at the parent support meeting, offered every Tuesday, after the lecture.

All and all, I highly recommend participating in the IBD Center's Tuesday evening activities. We found it to be very worthwhile!

Chelsea Stock

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Hospital at Stanford finally diagnosed me with Crohn's disease. Initial treatment was large doses of oral medications, including prednisone. I was taking a total of 16 pills a day.

Every struggle seemed huge, but there was never any doubt in my mind that I would get past every obstacle. I had the embarrassment in junior high school of huge cheeks from prednisone and delayed puberty. In high school, it was the embarrassing uncontrollable stomach noises. I battled tremendous daily fatigue. Where others could work long hours on homework, I could not. However, through all of these struggles and all of the internal questioning as to why I had to go through this, I continued to focus on what I wanted to accomplish. I

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Team IBDKids Runs the Marathon cheered on by Supporters at Mount Sinai

A dedicated team of 34 runners made up Team IBDKids in the ING New York City Marathon this year, to raise funds and awareness of pediatric inflammatory bowel disease. As the runners were making their way along the 26.2 mile route, the IBD Center Staff and volunteers, led by Allison Rosson, prepared a brunch for Center families on the roof of the pediatrics building at Mount Sinai Hospital on Fifth Avenue. Children made banners to support all of the Team

IBDKids runners and went down to the street to cheer them on as they ran past. A wonderful day was had by all.

Making Banners for Team IBDKids



Mount Sinai IBD Center Staff Volunteer at CCFA Camp Oasis

The Crohn's and Colitis Foundation Summer Camp Oasis had another wonderful year. The camp in Elizaville, New York, runs for six days at the end of August each year. This year a hundred campers with IBD attended the camp. The young adult counselors all have IBD themselves and act as great role models for the campers. Key to any successful camp are the medical staff. Five members of The Mount Sinai Hospital community volunteered their time at camp this year. Photographed from left are: Alexis Sherman, RN, Danya Rosen, MD, Clare Ceballos, NP, Juli Tomaino, MD and Keith Benkov, MD.



Chelsea Stock

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accepted that Crohn's was something I was going to have to deal with, but I was confident I wouldn't let it hold me back.

Although Crohn's disease has always been a big part of my life, I never wanted it to define me. I'll admit I wasn't big on going to support groups or talking to anyone because I didn't want to dwell on the fact that I had this disease. But, whether I like it or not, it is something I will have to deal with as long as we are still searching for a cure.

The lowest point after my initial diagnosis came in the summer after my junior year of high school. I had become very anemic and I was going in to the hospital for a colonoscopy and other diagnostics because the medications were not controlling my Crohn's. While being prepared for the colonoscopy, my vital signs were such that instead of a colonoscopy, I was admitted to the hospital for a series of blood transfusions. I was in the hospital for a week while they tried to figure out what was wrong. After the transfusions, they decided to try Remicade. For me, Remicade worked and I remain on it. I was discharged at the end of the week, and was able to perform that following weekend in the musical I was in at the time.

Following high school I went to The Boston Conservatory to major in musical theater. The Boston Conservatory is one of the top schools in the country for musical theater, and I was absolutely stoked. Nervous as I was to travel so far from home, especially with this disease, I knew I was strong enough to conquer anything. I earned my BFA while I was there. I found a new doctor in Boston, and continued to get Remicade. The Conservatory is a very rigorous program, and had I not been healthy or been able to work so hard, I might not have made it. I worked every day as hard as I could, handling the ups and downs of Crohn's as they came.

During my senior year of college, a New York theater agent contacted one of my professors, telling her Disney Theatrical was still

looking for an Ariel for the new production of *The Little Mermaid*, on Broadway. My professor gave him my name and the agent got me an appointment. I went in to audition during my Christmas break and made it down to the final few actors being considered for Ariel. I eventually was cast in the original Broadway show as Ariel's sister, Andrina, and the understudy for Ariel. I was excited, and ridiculously nervous!

During the run of the show, I rounded up my sister and a few friends to train for the ING Miami half marathon. We were part of the



CCFA team raising money for Crohn's and Colitis. I took off a weekend from the show, we flew to Miami, and I actually finished the full 13.1 miles, running the entire way. For everything that I had been through with the disease, and everything I had been able to accomplish in spite of the disease, I was so happy to be able to contribute, and encourage others to contribute, to the fight.

After *The Little Mermaid* had been open for about a year and a half, the actress playing Ariel was hired to do another show. The company did a nationwide search for the next Ariel. In the end, after searching the entire country, I was hired to play Ariel. So, I played the lead role in *The Little Mermaid* until

it closed. To be able to give pleasure to kids and their families every night was such an honor. I had always made a point to come out the stage door after the show, and greet anyone who was there, and it was so much fun to see the enthusiasm and appreciation for the cast's performance from the people waiting at the stage door.

I feel incredibly fortunate to have achieved my childhood dream on the Broadway stage. Of course, I am not sitting back and settled now, as there are always more dreams to pursue. And there are always hurdles with my disease. But with the help and understanding of so many doctors, nurses, health care specialists, family, friends, I have been able to persevere and I really believe I am able to do anything. I was very lucky to star in a Broadway show, but luck is when preparation meets opportunity. I was in the right place at the right time, but it took a lot of work to get me prepared to take advantage of the opportunity.

I am very happy to be volunteering at Mount Sinai. I would like to spend time with patients and families. I've been through a lot, and I know how personal and embarrassing the details of IBD can be. When I was a teenager, going through the beginnings of this disease, I would have loved to talk to someone who had been through the experience. I am extremely grateful to have had my parents and my sister who were so extremely supportive, but none of them had been through it either. My parents would also have loved a young adult reference for advice. I am here for kids or parents. You can get my information from the office. Please contact me if you just want to chat, or vent, or ask my advice. I am all ears.

Please don't give up! Don't ever say, "I can't," because you can. Just to live with Crohn's or Colitis, makes you stronger. If we understand what we have to deal with, but take action to find the right medicine and right diet, we can move forward. It is always a battle, but I believe that the real fight sometimes is finding the power to think positively and in continuing to strive for your dreams!

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 to discuss your ideas and help support our work.

Please join us for our next lecture:

Tuesday, December 14th

5:30-6:00pm—Meet other families & Center Staff

6:00-7:00pm—Becoming a Successful Adult with IBD

Join us as a panel of young adults with IBD share their stories & answer your questions

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

PHONE: 212-241-5415

WEB SITE: 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

www.CCFA.org

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
- IBDChat, 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



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