



Fall 2011

THE CHILDREN'S IBD CENTER AT MOUNT SINAI NEWSLETTER



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The Center launches another format to educate families

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Save The Dates:

Video Conference—

November 28th 2011 7:00-7:45pm, Erica Ilton, RD, 'The Specific Carbohydrate Diet in IBD'

Lecture & IBDKids

Chat group: December 13th 2011 6:00-7:00pm, Mount Sinai Hospital, Annenberg Building, 17th Floor. Keith Breglio, MD presents 'Advances in IBD'

Video Conferences—A New Way to Learn

By Clare Ceballos, NP

The Children's IBD Center is now able to offer regular video conferences. Learning about all aspects of inflammatory bowel disease leads to better understanding of the condition and its treatment. This in turn often results in improved outcomes.

A generous donation from a patient, who raised money for his Bar Mitzvah project, allowed the Center to start this innovative program.

Every month, an evening video conference is offered. To date, Keith Benkov, MD, the IBD Center Director, has lectured on 'IBD in the News', 'Safety Concerns with Biologic Agents' and a general 'Ask the Doctor' session. Erica Ilton, RD, CDN, the Center dietician, has lectured on 'Fat Soluble Vitamins' and a general 'Ask the Nutritionist' session.

Regular on-site lectures are offered by the Center staff bi-monthly. For families who are unable to come into the hospital to attend these lectures, the video conferences are an alternative.

Information on video conferences is sent via email and twitter to families who have signed up for electronic notification. The conferences are also posted on our website, www.IBDkids.org.

Future plans include having psycho-social conferences and having a KidsCHAT session. If you have any suggestions, let us know!

Health Maintenance in IBD


By Clare Ceballos, NP

Staying well when you have inflammatory bowel disease involves managing the disease, as well as paying special attention to your general wellbeing.

To help families stay on track, the Center has developed a 'Wellness Checklist'. The checklist focuses on five different areas: Nutritional Health; Emotional Health; Educational Health; and Health Maintenance. Each area lists suggestions to help families optimize the patient's wellbeing.

We will be piloting the Wellness checklist in the next few months. Since family feedback is very important to us, we welcome your thoughts and suggestions on this new initiative to maximize your child's overall wellbeing.

The Children's IBD Center at Mount Sinai WELLNESS CHECKLIST



To achieve and maintain wellness with IBD it is important to take care of all areas of your health. Below is a checklist to make sure that you are doing everything you can to help yourself.

- Nutritional Health**
 - ✓ Talk to Erica Ilton, the IBD Center Nutritionist
 - You can make an individual appointment or see her during the monthly open session (first Tuesday afternoon of each month)
 - Tune into an IBD Center video chat hosted by the nutritionist
- Emotional Health**
 - ✓ Talk to Bambi Fisher, the IBD Center Social Worker
 - You can meet her Tuesday afternoons at the Center or contact her via telephone or e-mail
 - Tune into an IBD Center video chat hosted by the social worker
- Educational Health**
 - ✓ Learn about IBD
 - Attend the IBD Center bi-monthly Lecture Series
 - Tune into an IBD Center video chat hosted by one of the doctors
 - Check out the Center website www.IBDkids.org
- Developmental Health**
 - ✓ Patients should understand IBD as appropriate for their age and gradually start to take care of themselves independently to ensure a safe transition from pediatric to adult care
 - Talk to any of the IBD Center providers about preparations for independent care
- Maintenance of Health**
 - ✓ Keeping yourself in good general health
 - Ask your pediatrician for a copy of your immunization and growth record
 - Keep immunizations (including an annual flu shot) up to date, but ask us about the MMR and varicella vaccine first

CCFA Camp Oasis

By Clare Ceballos, NP



Each year, the Crohn's and Colitis Foundation runs a summer camp at the end of August for children and teens with Crohn's disease and ulcerative colitis. This year, over 160 campers from New York and New England states attended Camp Oasis, which is held in Elizaville, New York.

The camp relies on volunteers working as counselors, activity specialists and a medical team. This year's medical team included Keith Benkov, MD, Clare Ceballos, NP and Bambi Fisher, LCSW, the Medical Director, Clinical Coordinator and Social Worker for The Children's IBD Center.



Camp Oasis Medical Staff

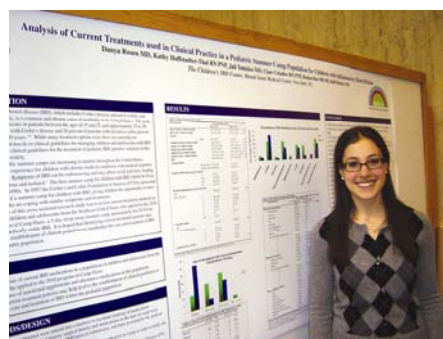
2011 marked the 10th anniversary of the New York Camp. In a special ceremony, three individuals were honored for their service to camp and for volunteering all ten years. Those honored were Keith Benkov, MD, the chief of

Pediatric Gastroenterology at Mount Sinai Medical Center and the co-Medical Director at camp; Alexis Sherman, RN, a nurse clinician at Mount Sinai Medical Center and the head counselor for the G1 girl's cabin; and Marcy Nanus, the camp's program director. Dr. Benkov was presented with a beautiful collage of photographs from the last ten years as a tribute to his dedication to Camp Oasis. The picture is on display at the New York office so come see it at your next appointment!

Danya Rosen, MD, a third year resident in Pediatrics at Mount Sinai Medical Center, volunteered at camp last year. As a result of her camp experience, Danya worked with the research staff at The Children's IBD Center and completed a project looking at trends in treatment for pediatric IBD. Her research was presented at Pediatric Research Day at Mount Sinai Medical Center and was accepted for national presentation at the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. Danya presented her poster at the national meeting in Orlando, Florida in October 2011.

Danya has been selected into the fellowship training program at Mount Sinai and will start her three year training as a Pediatric Gastroenterologist in July 2012.

If you would like more information about attending Camp Oasis next summer as a camper (7-16 yrs), leader in training (17-18 yrs), or camp counselor (19 yrs or older), ask any of the IBD Center staff.



Danya Rosen, MD with her research poster at Pediatric Research Day

Coping with Anxiety and Inflammatory Bowel Disease

By H. Cynthia Lin and Laura Reigada, Ph.D.

Inflammatory Bowel Disease encompasses Crohn's disease and ulcerative colitis. For many patients, managing a chronic illness such as IBD can have a profound effect on their quality of life and psychological well-being. Given the unpredictable and chronic nature of IBD, it is not surprising that children and adolescents with IBD may be more vulnerable to anxiety disorders. Some patients report that stress may have precipitated a flare-up. It is possible that there may be a cyclical relationship between stress and IBD symptoms. In other words, stress can exacerbate symptoms of IBD, and managing IBD symptoms can increase one's anxiety levels.

We conducted a study to examine the potential benefit of a psychological intervention for adolescents with IBD and co-occurring anxiety. Out of 116 families with an adolescent (aged 11-17) diagnosed with IBD, 40 adolescents (34%) were experiencing elevated anxiety symptoms. Research staff was able to connect with 21 families, and 10 agreed to be interviewed to assess for anxiety symptoms. A total of eight families participated in a 12-week psychological treatment program aimed at reducing anxiety, physical symptoms, and disease-specific concerns for adolescents with IBD. The program provided education regarding IBD symptom-management, healthy lifestyles (i.e. diet, physical exercise, sleep hygiene), and medication adherence. Following the program, results were very promising as adolescents displayed less anxiety symptoms, disease-specific concerns and pain. Furthermore, adolescents showed improvements in health-related

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quality of life and medication adherence. Findings provide preliminary evidence that psychological treatment may be helpful in reducing co-occurring anxiety and physical symptoms.

Currently, we are conducting a trial in which we are testing two different psychotherapeutic approaches for youth with IBD. If your child is between the ages of 8 and 17, and has a diagnosis of Crohn's disease or ulcerative colitis, you and your child may be eligible to participate in our therapeutic treatment program. The aim of the program is to make your child feel better, to control emotional symptoms, and to improve health outcomes. The 13-week program is at no-cost to participants. If you are interested in participating or learning more about this program, please contact Cynthia Lin at 718-951-9000 (ext. 6651) or Dr. Laura Reigada at 718-951-5000 (ext. 6021) or via email lrgada@brooklyn.cuny.edu.

Do You Know Your A, D, E and K's?

By Erica Ilton, RD

The topic of vitamins inevitably comes up in my private practice and monthly IBDday open sessions.

That's why I decided to devote my first newsletter article to a few that can be an issue in IBD—the fat-soluble vitamins A, D, E, and K.

Fat-soluble vitamin deficiencies can occur in IBD (and more specifically, in Crohn's) because they're absorbed with dietary fat, which can be malabsorbed when disease activity is high. The good news is, you can store these vitamins in various body tissues, and draw on reserves when you aren't able to take in or absorb enough from your diet. This makes it all the more important to consume sufficient quantities when you're feeling well.

Vitamin A

Vitamin A comes in two forms. Preformed vitamin A, or

retinol, is found in foods of animal origin, such as liver and whole milk. Beta-carotene can be converted into retinol in your body, and is found in plant foods – especially orange/yellow and dark green veggies like carrots, cantaloupe, spinach, and kale.

Vitamin A is essential for the immune and reproductive systems, and for maintenance of eye, skin and skeletal health. Too much preformed vitamin A can be toxic, so more is not always better (excess beta carotene just turns your skin orangey).

I generally do not recommend separate preformed vitamin A supplements, nor do I feel beta carotene pills are necessary. I'd rather you eat a rainbow of fruits and vegetables, and take a daily "insurance policy" multivitamin that contains no more than 2,500 IU's of vitamin A, with at least 60% as beta-carotene.

Vitamin D

I call D the "It" vitamin, because it's been in the news almost every day for the past several years. Vitamin D partners with calcium to keep your bones strong and healthy, and research indicates that deficiencies may increase the risk of various diseases, including Crohn's and colitis.

Milk and many milk substitutes are fortified with D, and salmon, sardines, and other fatty fish are naturally rich in this vitamin. Another natural source of vitamin D is the sun, but too much exposure is not a good idea. Most multivitamins contain 400 IU's of vitamin D, which many experts believe is insufficient. I generally recommend a daily dose of at least 1,000 IU's, but ask your doctor to run blood tests before you add more D to your day.

Vitamin E

Vitamin E got a lot of press years ago, but has since receded from the headlines. Studies linking vitamin E to everything from prostate cancer to PMS have a mixed track record, but no one refutes E's role as a stellar fat-soluble antioxidant. In that capacity, vitamin E protects the body's cell membranes, as well as certain

dietary fats (such as the superstar omega-3's) from oxidative damage.

Vitamin E is found in fatty foods like vegetable oils, avocados, and almond butter. Because high-fat foods can be problematic for some people with IBD, a basic multivitamin that contains 100% of the Daily Value (DV) should cover your bases.

Vitamin K

Compared to vitamins A, D, and E, vitamin K keeps a pretty low profile. Nonetheless, it plays a crucial role when it comes to proper blood clotting and skeletal health. Leafy greens, such as spinach, kale, and collards, are chock-full of K, and your body synthesizes small amounts in your colon. If K-rich veggies are not your thing, most multivitamins contain 100% of the DV. One note of caution: people taking oral anticoagulants have to monitor their dietary intake of vitamin K, and should only take supplements under a doctor's supervision.

Now you know your A, D, E, and K's!

Erica Ilton, RD, CDN is a nutritionist with expertise in counseling children with gastrointestinal disorders, including IBD. She has been working with the IBD Center since June 2011. Erica is available for group discussion with families on the first Tuesday of every month during the Center's Tuesday IBDday session, at 5 East 98th Street, 10th Floor, from 1:00-2:00pm. Erica also gives regular interactive video conferences on topics of interest to families of children with IBD. Announcements for upcoming video conferences are sent via e-mail to all families who provide us an email address and posted on our website www.IBDkids.org. There is no cost for either of these programs.

Erica is also available for private nutrition consultation and counseling. To schedule an appointment with Erica email her at Erica.Ilton@mountsinai.org or call 347-809-6789.

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.



You can now follow us on Twitter **@KidsIBD** to stay up to date on IBD-related information and all of the announcements, activities and events at the Center

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 **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

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 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



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