



THE CHILDREN'S IBD CENTER AT MOUNT SINAI

SUMMER 2006

Friends of Pediatric IBD- An Update

By Rita Serock, Parent Advisor,
Friends Program

In October 24, 2004, the Friends of Pediatric Inflammatory Bowel Disease group was formed as an advisory group to assist in expanding the goals of the Children's IBD Center of Mount Sinai. Its charge was to work directly with Dr. Benkov and other key staff in achieving the following objectives:

- * Developing a corps of trained parent volunteers who would be available to converse with other parents experiencing the challenges of managing a child diagnosed with IBD.
- * Help coordinate educational, social and fundraising events.
- * Assist in identifying a database consultant to advance the development of an efficient database system for the center to work with.
- * Participate in and help direct research projects.

During the past year and a half the Friends group has made major strides. We have a core group of trained volunteers already communicating with parents of new patients as they begin to navigate the process of caring for a child with IBD. We have attempted to con-

Continued on the next page...

Summer is Back!!!!

The Doctors & Friends are Running! For IBD Awareness

By Jason Martin

Running the New York City Marathon to raise money and increase awareness about IBD is exactly what these Mount Sinai doctors are doing. As of now, some are rigorously preparing themselves for the 26.2 mile race around the Big Apple.

Dr. Keith Benkov is going to be organizing and leading a team in the Marathon with the goal of making the public more knowledgeable about IBD in children and to raise funds for the Children's IBD Center at Mount Sinai.

All of us at Mount Sinai Medical Center and in the IBD community salute these runners for their commitment to the struggle against IBD. If anyone is interested in supporting or running in this event please contact the Center.

**The ING Nov. 5, 2006
New York City Marathon**



"This is me feeling
vevy sick. I am
turning red in my
face."

Sasson, age 6

A self-portrait,
made with colored markers,
of a 6 year old child living with IBD

Update for Pediatric IBD continued...

tinually bring new people into this group by means of surveying parents via the mail and phone calling. Our objective is to continue to fine tune the support an experienced group of parents can bring to those newly introduced to the challenge of IBD. We are always open to individuals wanting to support the Friends group in this quest.

The group has been quite active on the fundraising front. Our efforts initially focused on articulating the needs of the Center, identifying potential sources of funds and the writing of grants to solicit those funds, targeting various foundations and pharmaceutical companies. Individuals have also played a very important role in raising funds for the Center. Daniel Glass ran the NYC marathon this past October. Daniel's sponsors consisted of family members, friends and corporations. To date, Daniel has raised almost \$15,000 for the IBD Center. Another member, Allison Rosson, donated the proceeds from a bowl she created and sold. These are just a couple of highlights of our successful fundraising efforts. One of our primary goals was to fund the salary of the Center's social worker, Ms. Bambi Fisher, for a day each week dedicated to pediatric IBD patients and families. The importance of a readily available social worker at the Center is invaluable. Looking to the future, the Friends group would like to be able to fund a fellowship which would focus on specific training in Pediatric IBD. Such a fellowship would cost about \$70,000 for a two year fellowship. We have started raising money in support of this goal. If anyone has interest in joining the group, or any suggestions for fundraising education or support efforts, please contact Bambi Fisher, LCSW at 212-241-9113.

The Friends of Pediatric IBD is an ever-evolving group. It is early in its development and has great expectations to support the work of the fine doctors and staff associated with The Children's IBD Center at Mount Sinai. We thank everyone who contributed to turning our dreams into reality.

Educational Resources for IBD

By Clare Ceballos, RN, PNP

In February of this year the Kravis Children's hospital at Mount Sinai opened The Zone. The Zone is a therapeutic play space for hospitalized children and their families. Situated on the first floor of the children's pavilion on Fifth Avenue, The Zone features different spaces including a reading area, an art center, a game room and a TV studio. The Family Resource Center, located in The Zone, is a library stocked with books and educational resources to help families learn about specific diseases, acute and chronic illnesses and coping when a child is sick either in or out of the hospital. The Family Resource Center is staffed by a medical librarian, Dana Wyles, BSN, MLS, and is open for selected hours from 9am to 7pm Monday to Friday.

One of the goals of The Children's IBD Center at Mount Sinai is to educate families about inflammatory bowel disease. Our website www.IBDKids.com features information and educational material both for those new to the disease and for families seeking more in-depth reviews. If you would like to learn more about searching the internet for resources then Dana can help you. The Family Resource Center is open to both hospitalized and non-hospitalized families. Dana can arrange a time to meet with you and provide tutorials in using the internet. Call The Family Resource Center at 212-241-8583 for more information.

Got Calories?

One of Two Installments

By Ellen Schranz, MS, RD, CDN

"It's okay to eat fast food...go for the French fries, slather on the mayo and butter/margarine...be sure to load up on fried chicken and drizzle extra oil."

Is that a dietitian speaking?

Fat is the best source of calories. Protein and carbohydrate each have 4 calories per gram while fat has a whopping 9 calories per gram. So if you are in search of calories, fat holds the answer. No wonder the general population's waistline is



Ellen Schranz, M.S.R.D

growing at a staggering rate. Increased intake of fast foods and fatty foods, combined with less activity is in good measure responsible for an obesity epidemic.

epidemic.

But, for those have trouble keeping the weight on, for example our IBD Children...look for calorically-dense foods. Examples of these foods are: chicken nuggets, macaroni and cheese, ice cream shakes, grilled cheese, burgers, most Chinese food. To increase calories, add oil, butter, margarine, mayonnaise, cream, cheese, cream cheese. So think fat for calories and eat up for pounds.

⇒ Continued on the next newsletter.

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

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.