



THE CHILDREN'S IBD CENTER AT MOUNT SINAI

FALL 2006

Health Information on the Web: Fact or Fancy?

By Dana F. Wyles, BSN, MLS

More and more consumers are using the World Wide Web to search for health information for themselves and family members.

**"Good information is your best medicine."
-Dr. Michael DeBakey**

This explosion of online material has transformed the way people learn about wellness and disease. But how does the consumer sort through the hundreds of health-related sites to find the most authoritative and accurate ones?

All sites are not created equal, and appearance on the Web is no guarantee of quality. Ask yourself these questions before you rely on any health-related site:

- What is the purpose of the site? A medical site ending in .com may be trying to sell you something (medication, for instance). Sites whose URLs end in .gov can probably be relied on for accurate information.

Continued on the next page...

The Children's IBD Center at Mount Sinai begins its fourth year...

We hope that everyone enjoyed their summer and the transition back to school and work schedules are going well. The Center staff has had a busy summer preparing for the coming year. Many of us volunteered at the CCFA Camp Oasis in August caring for over 100 campers and young adult counselors, all with IBD. Dr. Benkov and team IBD

are preparing to run in the New York City Marathon in November to raise awareness and funds for pediatric IBD. We have planned lectures for the Center including: 12/5/06 'The Role of Bacteria in IBD'; 2/6/07 'New Medications in IBD'; and 5/1/07 'Alternative Treatment for IBD'. We hope to see you there.



Children's IBD Center staff volunteering at CCFA Camp Oasis (from left to right) Kathy Hoffstadter-Thal, CPNP, Research Coordinator, Bambi Fisher, LCSW, Social Worker, Clare Ceballos, BC-PNP, Clinical Coordinator Pediatric GI at Mount Sinai & Health Director Camp Oasis and Keith Benkov, MD, Chief Pediatric GI at Mount Sinai & Medical Director Camp Oasis.

Generous Donations

By Jason Martin, IBD Center Volunteer

Mike & Ally is a designer and manufacturer of a collection of luxury

home accessories. The New York City-based business sells to various retailers around the country, as well as internationally to such well-known stores as Bloomingdale's, Neiman Marcus, Harrods (London) and Lane Crawford (Hong Kong).

The owners, Allison & Bill Rosson, have created a special "Papillion" (French for "butterfly")



Centerpiece Bowl. Each bowl is custom made by a group of talented artisans in the Mike & Ally studio.

100% of the proceeds from the sale of the bowl will be donated to The Children's IBD Center at Mount Sinai. The 12" Butterfly Bowl is enameled in Tuscan earth colors and embellished with 18K gold-plated butterflies and flowers and further enhanced with Austrian crystals. The Rosson's generous donation to the Center was prompted by the diagnosis of ulcerative colitis in their 15-year-old son last year. "We are pleased to be able to contribute to the Center's great work. We wanted to create something that was both fanciful and cheerful", said Allison. For more information please contact Mike & Ally at 212-563-5433 or at allison@mikeandally.com.

Health Information on the Web...

- Who is responsible for the site's content? What are the author's credentials? Quality sites always have a "contact us" section.
 - Do the medical facts and figures have references to back up their statements?
 - Is the information up-to-date? When was the site last updated? Are there a lot of broken links? A high-quality site is updated regularly.
- Does the site ask you to register? What will they do with your information? Is there a privacy statement?

A shortcut to good information is available at MedlinePlus (www.medlineplus.gov), a gateway site sponsored by the National Library of Medicine with authoritative articles on every health topic imaginable, many in Spanish. Other top medical sites may be found on the Medical Library Association's home page under "Top Ten Most Useful Websites."

In the meantime, please feel free to contact the Family Resource Center with any questions about consumer health information.
Family Resource Center
1184 Fifth Avenue, First floor
(212) 241-7636

The Debate About the Etiology of Crohn's Disease

By Keith J Benkov, MD

The etiology of Crohn's disease has been the subject of intense research and debate for many years. A considerable amount of investigation has pointed to irregularities in the regulation of the immune system. This system consists of cells and organs that form a defense to prevent various invading organisms from gaining entry into the body as well as policing other threats. There is some debate whether it is a defective immune system or specific bacteria that trigger the inflammation associated with Crohn's disease.

Billions of routine bacteria live

uneventfully in everyone's intestinal tract. Recent work with the NOD2 gene suggests that patients with Crohn's disease have a defect in how they respond to the surface proteins of these bacteria. Because of these defects, the proteins are thought to penetrate the lining of the GI tract and stimulate the immune system to have an exaggerated response causing inflammation. While not clearly documented, many clinicians have very successfully used non-specific antibiotics to help control Crohn's inflammation. A new approach has been to administer a drug that stimulates the white blood cells lining the GI tract to try to prevent the bacteria from penetrating the lining and causing their usual effect.

A long running debate has centered over the type of bacteria or viruses that might provoke Crohn's disease. There is anecdotal evidence that suggests that many cases of inflammatory bowel disease seem to start with an acute infection, at times with documented organisms, though never a universal organism for all cases. Many investigators and clinicians believe that the development of Crohn's disease is not dependent on an organism, but the interaction with the normal bacterial flora of the GI tract. Clinical trials using probiotics which are normal bacterial flora have proved ineffective in changing the course of Crohn's.

This is an interesting and complex topic and we hope that you will join us to hear more about it at The Children's IBD Center lecture on December 5th, to be held in The Zone, 1184 5th Ave, from 5-6pm.

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

Got Calories?

By Ellen Schranz, MS, RD, CDN

Need extra calories? Finding it difficult to eat enough to meet your energy needs?

Try a supplement drink. These come prepared like Boost, Ensure, PediaSure, Nutren/Nutren Jr., Resource and Carnation Instant Breakfast. Most are lactose free and come in a variety of flavors. Or,

make your own special shake. Mix 1 cup milk plus 2 scoops ice cream, add fruit or flavoring and blend. Many people add Carnation Instant Breakfast packets for flavor, extra calories and more protein.



Ellen Schranz, M.S.R.D.

If milk is a problem...try alternative beverages, e.g., lactaid/enriched soy beverage with a milk free or soy based frozen dessert. These beverages can provide approximately 250-400+ calories and added protein. An alternative to these "milky" type products is a "juicy" type supplement, e.g., Enlive, Resource or Carnation Instant Breakfast clear fruit drinks. These drinks provide more calories than juice and added protein (not usually found in regular juice) and approximately 250-300 calories per serving. Sip these beverages to supplement meals and snacks and help improve your weight and nutritional status.

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.